
**IN THE COURT OF APPEALS, DIVISION I,
OF THE STATE OF WASHINGTON**

No. 62711-2-I

**In the Matter of the
GUARDIANSHIP OF SANDRA LAMB**

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**GUARDIANS' RESPONSE TO
DRW'S MOTION TO APPEAR AS AMICUS CURIAE
IN SUPPORT OF DSHS
and
GUARDIANS' RESPONSE TO
DRW'S AMICUS CURIAE BRIEF**

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I. INTRODUCTION.

DRW's appearance in this case is the Guardians' best argument for the necessity of Guardian advocacy of the best interests of Sandy and Rebecca. On one hand DRW argues it is uniquely suited to protect their best interests, DRW's Amicus Curiae Brief in Support of [DSHS's] Response and Cross-Appeal, at Pages 18-20 (DRW Brief, 18-20) and on the other hand says that Sandy and Rebecca retain rights they can never exercise to DRW's detriment, DRW Brief, 13-14 (arguing Sandy and Rebecca retain political rights of expression and guardian cannot exercise those rights). The Guardians rely on the Declarations filed in the case, which set forth the undisputed facts. CP 130-45; 192-95; 196-202.

The Guardians must advocate against DRW's absolutist integration view. It may be best for DRW and other developmentally disabled individuals to promote that viewpoint to the world, but DRW does not represent the best interests of Sandy and Rebecca by doing so. The "disability community", in DRW's view, is the mainstream community, not the minority of severely disabled who live at Fircrest.

DRW insults the Guardians for their hard work, but receiving guardian fees for guardianship services does not constitute a conflict of interest. The Guardians' exercise of Sandy's and Rebecca's rights against

violation of their best interests of Sandy is informed by public policy, law and by the facts. The Guardians protect the best interests by exercise the right to petition to all branches of government.

II. RESPONSE TO MOTION TO APPEAR.

DRW's appearance here is a clear violation of federal policy and jeopardizes federal funding. Under federal law, in order to receive federal funding, the State shall have in effect a system to "protect and advocate the rights of individuals with developmental disabilities". 42 U.S.C. § 15043(a)(1). Opposition to rights can never be protection and advocacy of those rights. This legislative session, DRW opposed equal rights for residents of ICF/MR. Sandy and Rebecca are both residents of ICF/MR. Rights of residents under federal regulations are recognized as conditions of federal matching funds, not substantive individual rights. See, e.g., 42 C.F.R. § 483.400 et seq. Similarly, Chapter 70.129 RCW ("Long-Term Care Resident Rights") omits rights for residents of Intermediate Care Facilities for the Mentally Retarded (ICF/MR), though recognizes rights for other long term care arrangements. DRW lobbied against adding ICF/MR residents to the statute. The long-standing right to hearing on transfers of residents from one facility to another -- based on the best interests standard -- was stripped from them in 2004 by administrative regulation. Chapter 388-837 WAC. *But see* RCW 72.33.220 (repealed);

RCW 71A.10.902 (re-enacted).

This failure of DRW to protect and advocate rights for Sandy and Rebecca -- and in fact oppose those rights -- is not an isolated event. It is an ongoing pattern. They have advocated time and time again against residents of residential habilitation centers, which include ICF/MR. Before the Legislature, they insist ICFs/MR should be closed and residents should be forcibly moved into private care. DRW not only fails to protect and advocate their rights, but actively opposes their rights and best interests, which violates federal law and jeopardizes federal funding.

DRW is charged to protect and advocate the “right to appropriate treatment, services, and habilitation for such disabilities, consistent with [the policies in] section 15001(c) of this title.” 42 U.S.C. § 15009(a)(1). Section 15001(c) includes, in relevant part, the following rights:

First, services shall be provided in an “individualized manner”, 42 U.S.C. § 15001(c)(2). DRW makes group identity rights arguments, and equates integration with freedom, autonomy, and choice. The Guardians review individual habilitation plans (IHPs) for each of these individuals, and evaluate the individual needs of Sandy and Rebecca with their best interests in mind. DRW looks at nationwide trends without regard to whether or not Sandy and Rebecca will benefit from private care.

Second, “[I]ndividuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, *including regarding choosing where the individuals live from available options*, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families”, 42 U.S.C. § 15001(c)(3) (emphasis added). DRW’s arguments concerning rights falls apart because it conveniently argues that choice and autonomy and freedom should be respected when it comes to choosing alternative residential arrangements, but those values or rights should not be respected when it comes to choosing to receive ICF/MR services. The policy of choice is discussed later in this Brief.

Third, “[S]ervices, supports, and other assistance shall be provided in a manner that demonstrates respect for individual dignity, personal preferences, and cultural differences”, 42 U.S.C. § 15001(c)(4). Once again, it is remarkable how DRW supported Fircrest downsizing in 2004 which likely resulted in 3 deaths and untold suffering. The Guardians sought and received recovery by bringing an action under the Abuse of Vulnerable Adults statute, Chapter 74.34 RCW. One wonders why DRW was supporting an effort that ultimately caused harm against Sandy and other residents who were relocated. Their absolutist integration approach engenders harm which is not in Sandy’s and Rebecca’s best interests.

Fourth, “[I]ndividuals with developmental disabilities have access to opportunities and the necessary support to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, communities, and States, and the Nation”, 42 U.S.C. § 15001(c)(8). An RHC is a community and should be fostered and supported. Institutions are Constitutionally required to be fostered and supported by the State. Wash. const. art. XIII. DRW wants to destroy that community.

RHCs (residential habilitation centers created under Article XIII) create an environment for individuals, and that environment provides a baseline of safety and security and care which serves not only the best interests of the residents but is also a standard to be applied in other environments. See 42 U.S.C. § 15009(a)(4) (right to standards of ICF/MR as baseline for other residential programs). A link or access point between those best interests and the wider world is preferable. But this presupposes a *meaningful* wider world exists for the individual. As noted by Justice Blackmun:

For many mentally retarded people, the difference between the capacity to do things for themselves within an institution and total dependence on the institution for all of their needs is as much liberty as they ever will know.

Youngberg v. Romeo, 457 U.S. 307, 102 S.Ct. 2452. 73 L.Ed.2d 28 (1980)

(Blackmun, J., concurring). This is not to say that existing access points to the wider world are closed, or that new access points are ignored. Nor is it to say that the community represented in RHCs is closed to access by others living in the wider world. What it means is that access to a wider world for certain individuals, including Sandy and Rebecca, may be meaningless to them, while retaining their baseline environment of safety, security and community is paramount. It is in this context that DRW sees not individuals, but bricks and mortar. It wishes to tear down and destroy the environment, rather than protect, nurture, and improve it and those who live within it. It is blinded by its own ideology. It failed to advocate against the recent closure of swimming pools at Fircrest School and Rainier School. This was one significant link for residents to have access to the wider community and vice versa. DRW does not care about that if its ideology is not served.

DRW is not only blind to the community represented in RHCs, it closes its eyes to legal authority on point. Though citing to *Olmstead v. LC*, 527 U.S. 581, 119 S.Ct. 2176 (1999), DRW ignores the more prescient holding of the case. The U.S. Supreme Court did not adopt an absolutist approach, but rather a more even-handed legal policy which does not require closure of ICFs/MR or any appropriate institutions. The *Olmstead* case is discussed further below.

DRW fails to protect and advocate for Sandy's and Rebecca's community. Rather, DRW seeks to destroy that community, suppress their viewpoint, and impose its own viewpoint of community on them.

Fifth, "[I]ndividuals with developmental disabilities need to have access to and use of recreational, leisure, and social opportunities in the most integrated settings, in order to enrich their participation in community life", 42 U.S.C. § 15001(c)(12). In the most recent legislative session, budget cuts of therapeutic as well as recreational use of swimming pools at Fircrest and Rainier School occurred. DRW does not advocate for continued services at ICFs/MR or for an adequate budget for ICFs/MR.

In addition, DRW appears to have a personal axe to grind with respect to the Guardians in this case. In 2004, one of the Guardians requested DRW's assistance with respect to an incapacitated person that the Guardians placed in an alternative residential arrangement. DRW (then known as WPAS) refused assistance to the incapacitated person because DRW had filed an *amicus curiae* brief in the case of *Parsons v. DSHS*, 129 Wn.App. 293, 118 P.3d 930 (2005). DRW refused to provide advocacy to an individual who needed support in the wider community because DRW took a legal position against the Guardians in another unrelated case. *2004 Letters from WPAS to Hardman*, Appendix A (App A).

Sixth, federal law also requires that the advocacy system created by the State “shall . . . be independent of any agency that provides treatment, services or habilitation to individuals with developmental disabilities”. 42 U.S.C. § 15043(a)(2)(G). DRW appears here as an instrumentality of the State with no distinct judgment from that of DSHS. Indeed, DRW claims the Guardians have a self-serving interest in guardian fees that renders any rational decisions as guardian irrational. This has no authority in law or in the facts in this case, and DRW can cite none. The facts supporting the fee request were undisputed. The allegations in the DRW Brief regarding this are not supported by facts.

The payment of compensation to a guardian does not constitute a conflict of interest because guardians are *entitled* to compensation for reasonable and necessary services. DRW merely parrots the DSHS position against guardians. Again, whenever an issue is related to the existence of RHCs, DRW defends DSHS and appears not as a friend of the court, but as a friend of DSHS.

Its longtime, conjoint effort with DSHS consistently undermines Sandy’s and Rebecca’s rights under Section 15001(c). More to the point, it demonstrates the necessity of the Guardians’ advocacy for Sandy’s and Rebecca’s best interests with legislative and executive branch officials.

Seventh, and finally, DRW is also charged under federal law with

a responsibility to “educate policymakers”, 42 U.S.C. § 15043(a)(2)(L). DRW has taken its role of education to a whole new level. It excludes any education of legislators or executive branch officials about rights of residents of RHCs. It advocates in courts (including here) that only one viewpoint should be heard -- its own.

The Guardians are given the power by state law to stand in the shoes and speak for Sandy and Rebecca and speak about their rights and best interests. DRW wants the Guardians to have less power and effectiveness so that legislators will not hear any viewpoint opposed to their own. This is troubling not only because Sandy’s and Rebecca’s rights are trampled upon, but federal funding is provided to the State, and those funds are being used to perpetuate manifest injustice here.

DRW believes legislators should get only one opinion and one point of view on an issue of controversy -- their own paternalistic one. Any viewpoint arising from Sandy’s and Rebecca’s best interests should be suppressed and legislators should not hear it. It is they -- and not the Guardians -- who come to this Court with a conflict of interest. They seek to suppress a viewpoint opposed to their own. They ask that the Guardians have less power and effectiveness so that legislators will not hear any viewpoint opposed to their own.

DRW should be making all these rights arguments on behalf of

Sandy and Rebecca. DRW should argue and educate that downsizing harmed individuals forcibly moved in 2004. DRW should argue and educate for enhancement of community at RHCs, not to tear down and destroy peoples' lives. DRW should argue for individual choice, not reflexively impose alleged nationwide trends. DRW should argue for support and services and benefits of RHC residents, including recreational rights. DRW should educate legislators about all viewpoints, not just their own. DRW should welcome guardianship advocacy of the best interests of Sandy and Rebecca, not seek to suppress them. This is odd behavior for a protection and advocacy agency. DRW has abdicated its responsibilities under federal law. Indeed, its appearance here is contrary to all these federal law policies.

In the context of RAP 10.6(b)(1), DRW appears in this case to advocate its own interest, and the interests of DSHS, and not those of Sandy and Rebecca and other residents of RHCs. Advocating its own associational interest as opposed to those of Sandy and Rebecca means its Motion is in substance a motion to intervene (assuming without agreeing it has standing to do so). Advocating for DSHS's interests against those of Sandy and Rebecca is contrary to federal law. Either way you look at it, DRW's appearance here violates federal policies.

With regard to familiarity with the issues, RAP 10.6(b)(2), DRW does not have familiarity with guardianship law and has no assistance to provide to the court on that issue. It has nothing to offer on the Medicaid or other financial issues raised. The issue of deinstitutionalization is not relevant to the issues raised on appeal. DRW has no expertise concerning the exercise of free speech rights of residents of RHCs against DSHS because it does not advocate on behalf of these residents in any event.

To the extent DRW raises specific issues, RAP 10.6(b)(3), none of the aspersions cast against the Guardians contained in the DRW Brief are supported by facts. The Guardians have not been afforded an evidentiary hearing or trial on these issues. The sum and substance of DRW's argument appears to be that its ideology of deinstitutionalization is paramount to the Constitutional rights of Sandy and Rebecca to access justice from executive and legislative branches of government through their Guardian. A Constitutional case implicates the public interest and it is a basic tenet of the adversarial system that rights should not be affected without affording those asserting rights a hearing.

If additional argument is necessary, RAP 10.6(b)(4), it should have been made before the guardianship court and not here. DRW's allegation additional argument is necessary implies that DRW has specific facts and knowledge regarding Sandy's care and Rebecca's care that would tie into

its ideological claim of absolutist integration. In fact, DRW has no set of facts to offer regarding Sandy and Rebecca in this case which support its claim, and its claim is unsupported by the undisputed facts in this case.

In conclusion, DRW's appearance in this matter epitomizes its historical failure to adequately protect and advocate the rights of Sandy and Rebecca. Accordingly, the Motion to Appear as Amicus Curiae should be denied. Because it represents its own interests here, DRW should have intervened to the extent it has standing to do so. If the Motion to Appear as Amicus Curiae is granted, DRW is supporting the interests of DSHS *against* the asserted rights and interests of Sandy and Rebecca. Regardless of its status, the Court should declare that DRW's appearance here is in direct conflict with federal law.

In any event, DRW's wholesale surrender of its role as advocate and protector of rights of residents of RHCs not only violates federal law and potentially federal funding, but demonstrates the Guardians correctly sought authority from the Court to advocate Sandy's and Rebecca's best interests against the collective efforts of DSHS and DRW to impose an absolutist ideology.

III. RESPONSE TO DRW'S BRIEF.

The Guardians incorporate the foregoing by reference as if fully set forth herein. DRW is not "uniquely situated to advocate" for Sandy and

Rebecca, DRW Brief, at 18-20. Indeed, it does not seem to be aware of how its viewpoint fails to square with legal policy, meaning public policy enunciated in court cases and statutes. Those sources of law demonstrate that DRW's absolutist approach not only might cost lives, but is incorrect. Trends towards integration originated from horrible conditions in past decades, and continued because of the efforts of moderately disabled individuals and their advocates, greatly improving the conditions and services provided in facilities like ICFs/MR.

A. Public Policy.

Legal policy -- meaning public policy enunciated in court cases and statutes -- demonstrates that DRWs absolutist approach is incorrect. Indeed, the Guardians' advocacy against violation of best interests by DSHS and DRW is necessary and appropriate.

1. The Medicaid Program (Generally)¹

Each State must administer the Medicaid program in the "best

¹ Understanding the federal requirements of the Medicaid Act "present as complex a legislative mosaic as could possibly be conceived by man", *City of New York v. Richardson*, 473 F.2d 923, 926 (2nd Cir. 1973). Indeed, "clarity is recognized as totally absent from the Medicare and Medicare statutes", *Beverly Community Hospital Assn. v. Belshe*, 132 F.3d 1259, 1266 (9th Cir. 1997) cert denied 119 S.Ct. 334 (1998). Medicaid statutes and regulations are "among the most completely impenetrable texts within human experience" constituting a "dense reading of the most tortuous kind", *Rehabilitation Ass'n of Va., Inc. v. Kozlowski*, 42 F.3d 1444, 1450 (4th Cir. 1994).

interests of the recipients.” 42 U.S.C. § 1396a(a)(19). The Act and its implementing regulations must be construed liberally in favor of the Medicaid recipient. *Cristy v. Ibarra*, 826 P.2d 361 (Colo. Ct. App. 1981).

Costs of the Medicaid program are shared by federal and state governments, with the federal government contributing more than ½ of the cost of services in Washington. A state is not obligated to participate in the Medicaid Program. If it does elect to participate, however, it must operate its program in compliance with federal statutory and regulatory requirements. 42 U.S.C. § 1396a. Washington has chosen to participate in the Medicaid Program. The program is administered at the federal level by the Center for Medicare and Medicaid Services (CMS) (formerly known as Health Care Financing Administration or HCFA). Federal regulations are codified at 42 C.F.R. Parts 430-456. Acting within federal guidelines, each state establishes a Medicaid State Plan. States also implement the Medicaid program with Constitutional provisions, legislation, and administrative regulations.

2. Intermediate Care Facilities for the Mentally Retarded.

The Medicaid Program makes “medical assistance” available. 42 U.S.C. § 1396a(a)(10). “Medical assistance” means payment of part of or all of the cost of . . . care and services . . . [including] services in an intermediate care facility for the mentally retarded. . . .” 42 U.S.C. §

1396d(a)(15). Intermediate care facilities for the mentally retarded (ICF/MR) program is an optional Medicaid service authorized by Title XIX. 42 U.S.C. § 1396. ICF/MRs provide residential, health and rehabilitative services for individuals with mental retardation. As an optional service under federal law, it must comply with all federal requirements for providing that service. Federal statutes and regulations require that individuals in ICF/MR receive active treatment including habilitation, occupational therapy, speech therapy and physical therapy. 42 U.S.C. § 1396d(d); 42 C.F.R. § 483.45.

3. Home and Community Based Waivers.

In 1981, Congress created the Home and Community-Based Waiver Program in order that individuals otherwise cared for in a nursing home or in an ICF/MR receive services in their own homes and home-like settings. 42 U.S.C. § 1396n (Section 1915(c) of the Social Security Act). “Section [1396n] permits States to offer, under a waiver of statutory requirements, an array of home and community-based services that an individual needs to avoid institutionalization.” 42 C.F.R. § 441.300.

Under a waiver, States may include as “medical assistance” the cost of home or community-based services which, if not provided, would require care to be provided in a nursing home or ICF/MR. 42 U.S.C. § 1396n(c); 42 C.F.R. § 435.217. Under the waiver, monetary respite is

available for caregivers which enables family members and others to provide care. Individuals in need of ICF/MR services are eligible for the HCBW. Room and board are not paid by Medicaid except to provide respite care and where room and board is provided by an unrelated caregiver whose presence is necessary to avoid institutionalization. 42 U.S.C. § 1396n; 42 C.F.R. § 441.310(a)(2).

The HCBW provides for an individual support plan designed to meet the individual's needs for health and rehabilitative services in a home or in a small home-like setting. The program contemplates personal privacy and basic freedom to make choices, including when to go to bed and when to wake up. Participants may to the extent able plan menus, grocery shop and cook. Ideally, individuals live in residential neighborhoods and have the opportunity to participate in a wider range of community activities than those at an ICR/MR.

Federal law sets a ceiling for funds used under the HCBW. The law requires "the average per capita expenditure estimated by the State in any fiscal year for medical assistance provided with respect to such individuals shall not exceed 100 percent of the average per capita expenditure that the State reasonable estimates would have been made in that fiscal year . . . if the waiver had not been granted" 42 U.S.C. § 1396n(c)(2)(D). Thus, federal law permits States to fund HCBW up to the

same average rate as ICF/MRs. Once all ICF/MRs are closed, this payment rate to providers will undoubtedly drop.

Congress further provided that a HCBW program shall not be granted in the State Plan unless the State provides assurances that “necessary safeguards (including adequate standards for provider participation) have been taken to protect the health and welfare of individuals provided services under the waiver” 42 U.S.C. § 1396n(c)(2)(A); 42 C.F.R. § 441.302(a). These safeguards must include “adequate standards for all types of providers that provide services under the waiver.” 42 C.F.R. § 441.302(a).

Individuals in ICF/MR do not receive SSI cash benefits. Like Sandy and Robin, residents of ICF/MR receive their cash benefits for other programs and are nevertheless eligible for ICF/MR services. Individuals under the Home and Community-Based Waiver are entitled to \$ 674 per month in SSI cash benefits, or may receive a cash benefit from other entitlement programs. HCBW residents apply their own income to room and board because Medicaid funds cannot pay for room and board, but certain home supports may be used to pay for room and board.

4. Freedom of Choice.

Under Medicaid law, individuals likely to require the level of care of a hospital, nursing facility, or ICF/MR are to be informed of choices

they have:

such individuals . . . are informed of the feasible alternatives, if available under the waiver, *at the choice of such individuals*, to the provision of inpatient hospital services, nursing facility services, or services in an intermediate care facility for the mentally retarded

42 U. S.C. § 1396n(c)(2)(C) (emphasis added). In order to participate in the HCBW program, States must provide assurance that when a recipient is determined to be likely to require the level of care in an ICF/MR, the recipient or his or her legal representative will be informed of feasible alternatives available under the waiver, and given the choice of either institutional or waiver services. *Doe v. Chiles*, 136 F.3d 709, 721, n. 21 (11th Cir. 1998).

A State Plan is in violation of 42 U.S.C. § 1396n(c)(2) if it provides no meaningful choice between waiver services and the ICF/MR services. In other words, a HCBW option is no option at all when all ICF/MRs are closed and there is no assurance that there are available supports and services which will meet individualized needs of current residents of such ICF/MRs. There are two relevant points.

One, the State does not provide meaningful choice. *Compare* “Medicaid and Long-Term Care Services for Adults”, **App. B. with** RCW 74.39A.005 (“the public interest would be served by a broad array of long-term care services that support persons who need such services at home or

in the community when practicable and that promote individual autonomy, dignity, and choice”, *and with* RCW 71A.12.020(1) (DSHS to provide eligible individuals with services “suited to the person’s needs”).

Second, the unavailability of ICF/MR programs nationwide has led to ongoing litigation over the years because of waiting lists for waiver services. Human Services Research Institute, *Status Report: Litigation Concerning Home and Community Services for People with Disabilities, May 23, 2007, App. C*. Still, an applicant for DD services who is otherwise qualified is entitled to either ICF/MR services or waiver services within 90 days. *Doe*, 136 F.3d at 723. DRW would apparently prefer an applicant go without services entirely rather than given the meaningful choice of ICF/MR services.

In summary, federal Medicaid law thus provides for a choice between ICF/MR services and home and community-based waiver services. DSHS and DRW deny this legal policy when they impose their own viewpoint on others.

5. Americans with Disabilities Act (ADA) and Olmstead.

On July 12, 1990, Congress enacted the American with Disabilities Act, 42 U.S.C. § 12101, et seq (ADA) finding “historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with

disabilities continue to be a serious and pervasive social problem.” 42 U.S.C. § 12101(a)(2). Further, “discrimination against individuals persists in . . . institutionalization . . . and access to public services.” 42 U.S.C. § 12101(a)(3). Finally, “individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, . . . segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities.” 42 U.S.C. § 12101(5). Congress identified that individuals with disabilities are a “discrete and insular minority” who face unequal treatment and relegation to a position of “political powerlessness”. 42 U.S.C. § 12101(7).

An obvious and major purpose of the ADA is to provide a mandate for the elimination of discrimination. Discrimination includes segregation, and federal regulations require that “[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 42 C.F.R. § 35.130(d).

There is no dispute that the integrationist approach has been successful and is appropriate in many cases. The question is whether or not this approach is absolute. DRW contends every developmentally disabled person must be deinstitutionalized and integrated into the community. The Guardians claim -- more reasonably -- that the

integration mandate is not absolute.

The appropriateness of the residential arrangement depends on the individual needs of the individual. Though *Olmstead* says persons with disability must be permitted the option to leave institutions, or else that can be discrimination under ADA it not permitted to leave, *Olmstead* does not require closure. *Olmstead* held:

Unjustified isolation, we hold, is properly regarded as discrimination based on disability. But we recognize, as well, the States' need to maintain a range of facilities for the care and treatment of persons with mental disabilities, and the States' obligation to administer services with an even hand.

Olmstead, 527 U.S. at 597 (emphasis added). This “reflects two evident judgments”, concluded the Court. *Id.*, at 600. They were those “who can handle and benefit from community settings” should be placed there because institutional placement “severely diminishes the everyday life activities of individuals.” *Id.* at 601. The second “judgment” should be read in the light of the first. If a person cannot enjoy a community placement, the restrictions of an institution are medically necessary, as the Court carefully pointed out next:

We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. . . .

Id., at 601-02. Accordingly,

[T]he State generally may rely on the reasonable assessments of its own professionals in determining whether an individual ‘meets the essential eligibility requirements’ for habilitation in a community-based program. *Absent such qualification, it would be inappropriate to remove a plaintiff from the more restrictive setting.*

Id., at 602 (emphasis added). The Court illustrated this conclusion with two citations: deference to “the reasonable medical judgments of public health officials”, and the reminder, “Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.” *Id.*

Olmstead does not require that Sandy and Rebecca to be “deinstitutionalized”. Instead, *Olmstead* recognizes explicitly or implicitly the following factors *limiting* the integration approach:

- (1) a State may maintain a “range of facilities” or continuum of care;
- (2) it is inappropriate under the ADA for a State to remove a person from a more restrictive setting for non-medical reasons (e.g., downsizing for budgetary reasons);
- (3) the choice to reject treatment in the wider community;
- (4) only those who handle and can benefit from services in the wider community should be placed there.

Other cases considering the question opined similarly. See

Halderman v. Pennhurst State Hospital, 612 F.2d 84, 114 (3rd Cir.1979) reversed 457 U.S. 1 (1981) (rejecting absolute integration and recognizing the need “institutionalization of patients for whom life in an institution has been found to be the least restrictive environment in which they can survive”.) (emphasis added); *Williams v. Wasserman*, 164 F. Supp. 2d 591, 636-38 (D.Md. 2001) (no violation of the ADA when state institutions retained as as viable option for those who do not benefit from other residential arrangements).

DRW’s views *Olmstead* with one eye opened and one eye closed. It sees only those portions of the opinion that supports integration, but is blind to the limits on integration that are clearly intended to protect the legal and equitable interests of persons like Sandy and Rebecca. DRW’s absolutist approach makes it unable to adequately protect and advocate for Sandy’s and Rebecca’s rights in any case of residents of institutions.

There is a right to live in the world, and there is a right to live out of it. Historically, segregation led to poor conditions and subordination. Today, adequate services and positive recognition are afforded. There is no reason to deny appropriate services so long as there is no intention to degrade or demean individuals. Ruth Colker, *Anti-Subordination Above All: A Disability Perspective*, Notre Dame L.Rev. 1415 (2007), **App. D.**

DRW has provided no evidence that Sandy and Rebecca are worse

off as residents of Fircrest School. None of the evidence they cite is specific to Sandy or Rebecca. And the “outcome” studies it relies on to show safety in the community, DRW Brief at 5-7, focus on persons who are moderately healthy and mild to moderately disabled, not individuals with more pervasive support needs.

6. Article XIII - A Constitutional Duty of Care?

Article XIII requires that institutions for the developmentally disabled “shall” be fostered and supported by the State. This provision Constitutionally establishes the provision of services at residential habilitation centers (RHCs). There is a Constitutional duty of care because the Constitutional mandate for institutional services necessarily implies those services will be provided to those who are eligible in those institutions. Hugh Spitzer, *Care for the Mentally Ill: Washington’s Constitutional Obligation*, WSPA Journal Jan/Feb 1999, and Dan Okada, *An Analysis of Article XIII of the Washington State Constitution: What Duties Does the Article Impose on Washington to Care for Its Mentally Ill* (unpublished), **App. E**.

Underfunding of either ICF/MR services or HCBW services negates meaningful choice of services in the other. A State cannot provide services solely in segregated settings; it must provide services to both ICF/MR and HCBW services. In this State, Art. XIII requires

“institutions” (but not community services) for the developmentally disabled be fostered and supported, and the ADA requires States to provide a wider community option if appropriate. The choice to receive care at Fircrest School is one with Constitutional implications; the choice to receive HCBW services is not. Unfortunately, many are under the impression that costs for services in the waiver program are less expensive, but that is not true. *Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research, Mental Retardation*, Vol. 41, No. 2, 103-122 (2003), and January 2008 Update. **App. F.**

In order to best effectuate a Constitutional duty of care, the best interests of Sandy and Rebecca must be considered, i.e., their right to receive pervasive care in a Constitutionally recognized care facility is suitable to their needs and necessary for their survival. Closure of Art. XIII institutions does not comport with the Constitutional duty to foster and support them.

In conclusion, Article XIII requires fostering and supporting institutions for the developmentally disabled. DRW’s extreme integration approach necessarily means every RHC will be closed and all residents integrated into alternative residential arrangements, rendering superfluous the Constitutional mandate.

8. Conclusion.

Medicaid, ADA, and Article XIII are harmonious. Medicaid contemplates an opportunity of choice for ICF/MR services, and the ADA, though expressing a preference for integration, does not make that mandate absolute. *Olmstead* recognizes limits on integration that DRW refuse to recognize. Finally, Art. XIII provides a Constitutional basis for providing ICF/MR services if not a Constitutional duty of care in them.

DRW claims that the Guardians seek to reject the “support” in the disability community and government for their program of absolute integration. DRW Brief, at 20. Given the historical facts outlined in the Guardians’ Declarations, one can only cringe at the prospect of what additional “support” might be provided by DRW or DSHS next since together they perpetuate an unchangeable viewpoint which does not square with legal policy and invites future litigation.

The Guardians are hopeful some day that DRW will re-evaluate its divisive position and stop tapping into federal tax dollars to promote an absolute viewpoint. The Guardians are hopeful that some day DRW will shift its resources to another battle, and join with guardian and parent groups and others who are concerned about the minority population of severely disabled, and fight for equal and adequate funding for all developmentally disabled no matter where they live.

B. Sandy and Rebecca Have Substantive “Rights”

Sandy and Rebecca have “rights”, and in particular a right to petition the government as against the interests of DSHS and DRW who violate those interests. DRW apparently agree that Sandy and Rebecca have a right to petition. However, their claim is that the Guardian may not exercise constitutional rights because it means taking them away from the Sandy and Rebecca and giving them to the Guardians. DRW Brief, at 11-14.

DRW’s argument certainly applies with respect to the nearly 95-97% of individuals with developmental disability. Congressional goals about equality of opportunity, full participation, independent living, and economic self-sufficiency as support for participation in a wider community are laudable. However, these are false goals for persons with severe disability who make up 1-3% of all developmentally disabled. CP 13. As integration has proceeded, the percentage of the populations of ICF/MRs comprised of persons with severe and profound disability has increased. As of 2000, 85% of the total population of 1,128 consisted of the severely and profoundly mentally retarded, while only 13.6% were mild and moderately mentally retarded. Charlie Lakin, David Braddock and Gary Smith, *Large State Residential Facilities: Status and Trends in Population Characteristics as of June 30, 2000*, Mental Retardation, Vol.

39, No. 4, 334-337 (August 2001). **App. G.** The threat is not to the erosion of law to protect autonomy, DRW Brief at 2. The threat is to the very survival of Sandy and Rebecca as residents with profound mental retardation who have no meaningful autonomy.

For Sandy and Rebecca, those goals of integration are false and are not as important as their safety, health, and care. We do not need to force someone to move to another place to prove they are worthy. We should not pretend Sandy and Rebecca can attain these goals in order to value them as they are as human beings and care for and nurture them.

The suggestion that Sandy and Rebecca *lose* rights by having the Guardians step into the shoes of the incapacitated person and *exercise* them is nonsense. If Sandy and Rebecca retain those rights without the assistance of a guardian, they cannot exercise them because of their severe disabilities, and the rights are merely formal. DRW's argument thus necessarily means their rights as retained will not be protected. However, if Sandy and Rebecca retain those rights, and the Guardians step into their shoes and exercise them, the right to petition is given substance and meaning. There is no other possibility.

The Guardians' argument that it is permissible to exercise the Constitutional rights of an incapacitated person is limited to the facts of this case, in part on the extent of disability, and only with respect to

residents of RHCs.²

DRW's argument needs clarity because it implicates a problem with the application of traditional "rights" theory. For example, liberal theory fails to adequately articulate the existence of "rights" of persons with severe developmental disability. The political philosophy of John Rawls, Immanuel Kant, and John Locke all contemplate participation or choice by persons in a social contract by mutual consent or for mutual advantage, which is a basis for freedom and autonomy.

The lack of capacity to make rational choices means that Sandy and Rebecca (theoretically) do not fit into traditional theories of rights or justice. Sandy and Rebecca cannot meaningfully exercise consent, choice, or rights -- the basic pre-conditions of political participation -- without the assistance of a guardian. The focus should therefore be on their care.

Rachel Patterson, *No Less Than a Person: Liberalism and Disability Policy in Washington State*, Senior Thesis, Whitman College (unpublished 2009). **App. H.**

Ironically, DRW argues for limits on the expression of their rights and not their protection. DRW argues that persons with profound and severe developmental disabilities should have rights, but not exercise

² RHCs consist of ICF/MR and/or nursing facilities (NF).

them. DRW's reliance on an empty rights formulation for those with severe disabilities demonstrates why it is necessary for the Guardians to step into the shoes of Sandy and Rebecca and provide them with assistance in exercising their right to petition.

C. The Guardians Exercise Rights of Incapacitated Persons.

DRW accuses the guardians of selfish motives by “substitut[ing] their ideas instead of the individualized needs of each ward.” DRW Brief, at 14. There is no factual basis for that statement. There is no evidence to that effect in the record. There is no legal basis for that statement. The Guardians admit that they employ the best interests standard for decision-making. The Guardians do not substitute their own judgment. Indeed, the relationship between guardian and incapacitated person is more intimate in an indescribable way than the bare legal definition. The Guardians stand in the shoes of Sandy and Rebecca with intimate knowledge and understanding, reflect on it, and act according to prevailing legal policy and the need for care, not some absolute approach like that suggested by DRW. DRW's argument is frivolous.

DRW generally contends that advocacy is “outside the scope of guardianship”, once again parroting the DSHS line. DRW Brief, at 11-14. DRW appears to be arguing that residents of severely disabled residents and their Guardians should remain silent about the place they live and the

care and treatment they receive there. This is untenable, for it would permit violations of the best interests of residents there to have ensure care and to ensure the place remains open to provide that care. DRW's position is also untenable because it weakens guardianship authority to monitor DSHS's care, potentially creating an opportunity for harm to residents to occur without guardianship oversight.

One cannot imagine why DRW wants Guardians completely silenced on issues tied to the very survival of the most severely disabled individual in the State. Indeed, this would be contrary to federal standards for ICF/MR requiring appointment of a guardian to protect residents. *Appendix J, Survey Procedures and Interpretive Guidelines for Intermediate Care Facilities for Persons with Mental Retardation.* **App.**

I. Standard W125 of Appendix J provides, in relevant part:

Individuals who need guardianship or advocacy, and do not have this need addressed, are not prepared to exercise their rights as citizens of the United States. The facility's failure to endure guardianship or advocacy for those who need it should be cited [for violation]. . . .

Id. Federal regulators specifically anticipate -- consistent with state law -- that Sandy and Rebecca cannot exercise their rights of citizens of the United States unless a guardian is appointed.

In addition, an informal working group of the Certified Professional Guardianship Board, working on assessment of a

competency-based approach to guardianship, drafted several characteristics of competency when a guardian “advocates for others”.³ Excerpt, *Sample Assessment Tool for Competency-Based Approach*, Page 3 of 5 (2008?). **App. J.** A commonly understood meaning of “advocacy”, according to the document, is to “Promote the wants, desires, and needs of another to other persons with the authority and power to grant and/or provide the objects, items and services wanted, desired, or needed.” *Id.*

Though this is merely a working definition never adopted by the CPG Board, it demonstrates a common understanding that advocacy by a Guardian includes communication to legislative and executive officials and outreach to community organizations.⁴

D. The Exercise of Sandy’s and Rebecca’s Rights Was Necessary and Appropriate Under the Circumstances.

DRW alleges that there is an appearance of self-serving and conflict of interest because the guardians collect fees. DRW Brief, at 14-18, 20. Nonsense. This betrays DRW’s lack of understanding regarding guardianship duties. The receipt of payment for guardian fees does not create an impression of violation of the fiduciary duty of loyalty.

³ However, an officer of DRW participated on the ad hoc committee.

⁴ This is not an official record of the CPG Board. Interestingly, an officer of DRW participated in the work group.

Guardians are entitled to compensation in equity based on quantum meruit or for money had and received. Typically, guardians are compensated from the estate of the incapacitated person. Those equities are mediated by inherent court supervision over the reasonableness of fees charged. There is no basis for such an allegation.⁵ Had DRW carefully read the record, it would have found that the Commissioner, in approving an advance allowance of fees, had required that the Guardians tie the particular activity engaged in with the best interest being served. DRW's feeling that somehow the Guardians have failed to do so is premature -- that issue will be reviewed by the superior court at the time of the next guardian's report.

However cast, the gist of this case is the misperception that the Guardians are promoting their own viewpoint and doing so unreasonably. A guardian's participation in decision-making on behalf of an incapacitated person provides "valuable insights", "increase[s] the accuracy of [court] proceedings", and does not undermine any

⁵ One could just as easily make the self-serving argument against DRW: by receiving salaries from federal tax dollars officers of DRW ensure and justify their institutional existence by creating conflict between the mainstream developmentally disabled and the severely developmentally disabled who reside in RHCs. This false conflict fires up its base of constituent support with donations and is seemingly more important than protecting and advocating for the latter's rights and best interests. These kinds of arguments, however, are non-productive.

Constitutional rights at stake. *Heller v. Doe*, 509 U.S. 312 (1993).

The Guardians have a reasonable basis -- the legal policies described above -- for exercising the right to petition on behalf of Sandy and Rebecca. The Guardians also have an undisputed factual basis -- set forth in the Declarations filed in this court -- for doing so. The Guardians are intimately involved with the care and protection of Sandy and Rebecca. There is no evidence on the record showing that the Guardians are substituting their personal policy preferences.

Rather, the evidence from DRW's appearance and briefing in this matter clearly demonstrates DRW has an absolutist view. Such a view is irrational. In any event, all these objections are subject to review at any time by a guardianship court. To the extent the guardianship court believes a certain activity bears no relationship to protecting Sandy and Rebecca from violation of their best interests by DSHS, DRW, or other third persons, it may instruct the Guardian to not engage in that activity.

The Guardians have a reasonable fear, based on experience, that deaths may result when the severely and profoundly developmentally disabled are dumped into the community. VOR, *Media coverage highlighting the increasing need for more effective federal and state protections in the ever-expanding community system of care for people with mental retardation*, Rev. March 2008. **App. K.** The Guardians have

reasonably articulated here a position that based on legal policy and advocate that position to the legislative branch, the executive branch, and to community organizations. On the other hand, DRW's position is absolute and extreme, all or nothing, to the point where adoption of their position may create the very conditions that may contribute to the death of those it is supposed to protect.

The evidence in the record clearly demonstrates the Guardians' advocacy was both necessary and reasonable. They have a valid and reasoned viewpoint. They do the best they can given limited resources available to Sandy and Rebecca. They are informed by lengthy experience with RHCs and the care provided there. Moreover, the Guardians have had success, but continue to face opposition from those who promote integration over care needs. State Operating Budget 2009-11, ESHB 1244, § 130(3), **App. L**, threatens closure of RHCs notwithstanding *Olmstead*.

IV. ATTORNEY FEES.

The Court should award attorney fees to the Guardians for responding to the Motion and Brief of DRW. Typically, when parties appear in a guardianship proceeding, they appear knowing some facts about the incapacitated person that assists the court in determining the best interests of the person in guardianship. DRW have offered no specific

facts regarding Sandy or Rebecca.

More importantly, though the issue of deinstitutionalization is related to Sandy and Rebecca's best interests, it is not an issue that was raised before the trial court. None of the evidence offered shows that Sandy and Rebecca are worse off by receiving ICF/MR services at Fircrest School. DRW's appearance in this guardianship case with a general agenda yet no direct relevant evidence to offer is not well taken, or else the courts will be clogged with all kinds of groups with their own agenda yet have no direct relevant evidence to the particular case at hand.

To the extent they have offered a theory of rights -- a viewpoint of absolute integration, i.e., without regard to Sandy's and Rebecca's best interests -- the application of their theory is self-serving. The Guardians' defense against DRW's extreme position by responding to DRW's Motion and Brief unnecessarily requires the Guardians to incur time for attorney fees.

To the extent Sandy Lamb's special needs trust is a source for protecting her best interests (Rebecca does not have such a trust), the trust should be reimbursed by DRW so that the funds in her trust can better be used for her special needs. A special needs trust is irrevocable and the funds are not deemed legally available to Sandy. Though special needs trusts may be used to pay for attorney fees, there is nothing in that

possibility which precludes ordering DRW to pay attorney fees to the Guardians in this matter. DRW knew when it filed papers in a guardianship case that they have no direct relevance to Sandy and Rebecca. DRW does not contend that Sandy and Rebecca should be “deinstitutionalized” by this court based on specific facts. DRW knew when it filed its Motion and Brief that Sandy and Rebecca have limited income. The Guardians and their counsel had a duty to respond to the theoretical and abstract issues raised by DRW that were never before the trial court and likely never will be. Under these circumstances, it is inequitable that Guardian and counsel be impoverished in fulfilling their duties to their incapacitated persons and clients.

DRW is a notice party in these proceedings, having appeared in this guardianship case. The Court may award attorney fees paid to the Guardians by a party appearing in a guardianship case pursuant to RCW 11.96A.150.

V. RELIEF SOUGHT.

The Guardians respectfully request that this honorable Court:

- A. Deny DRW’s Motion to Appear, or, Alternatively, find and declare that DRW’s appearance violates federal law;
- B. Award attorney fees, costs, and expenses pursuant to RCW 11.96A.150, RAP 18.1, other applicable statute, or other applicable rule in

equity or law for responding to the amicus brief;

C. For such other relief as the Court finds suitable, just, and equitable.

July 15, 2009

Respectfully submitted,

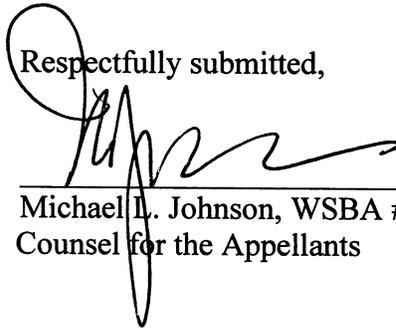
Michael L. Johnson, WSBA #28172
Counsel for the Appellants

equity or law for responding to the amicus brief;

C. For such other relief as the Court finds suitable, just, and equitable.

July 15, 2009

Respectfully submitted,

A handwritten signature in black ink, appearing to read "M. Johnson", written over a horizontal line.

Michael L. Johnson, WSBA #28172
Counsel for the Appellants

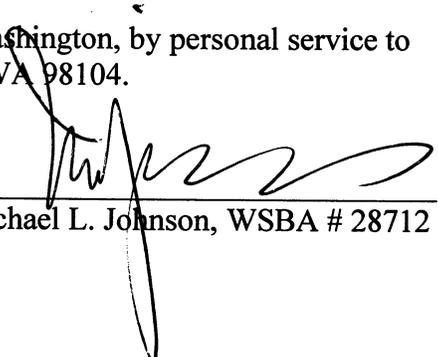
CERTIFICATE OF SERVICE

I hereby certify that on July 15, 2009, I served a copy of this Response Brief, the Declaration of Michael L. Johnson, and the Appendix on the following:

Jonathon Bashford, Assistant Attorney General, by e-mail, pursuant to agreement, and by leaving the same with a legal messenger service with instructions to deliver to 7141 Cleanwater Dr. SW, P.O. Box 40124, Olympia, WA 98504-0124, and

Emily Pura, Disability Rights Washington, by personal service to 315 - 5th Avenue So., Ste 850, Seattle, WA 98104.

July 15, 2009



Michael L. Johnson, WSBA # 28712

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STATE OF WASHINGTON
2009 JUL 15 PM 4:55

**IN THE COURT OF APPEALS
FOR THE STATE OF WASHINGTON
DIVISION I**

In the Matter of the)	No. 62711-2-I
GUARDIANSHIP OF)	
SANDRA LAMB,)	DECLARATION OF
)	MICHAEL L. JOHNSON
An Incapacitated Person)	
_____)	

The undersigned, under pain and penalty of perjury under the laws of the State of Washington, hereby states and declares as follows:

1. Appendix A contains true and correct copies of correspondence between Washington Protection & Advocacy System and James R. Hardman in 2004.
2. Appendix B is a true and correct copy of the DSHS publication "Medicaid and Long-Term Care Services for Adults" accessed on the Internet on July 15, 2009.
3. Appendix C is a true and correct copy of the Human Services Research Institute, *Status Report: Litigation Concerning Home and*

ORIGINAL

Community Services for People with Disabilities, May 23, 2007, accessed on the Internet on July 15, 2009.

4. Appendix D is a true and correct copy of Ruth Colker, *Anti-Subordination Above All: A Disability Perspective*, Notre Dame L.Rev. 1415 (2007) as accessed on the Internet on July 15, 2009.

5. Appendix E contains true copies of Hugh Spitzer, *Care for the Mentally Ill: Washington's Constitutional Obligation*, WSPA Journal Jan/Feb 1999, and Dan Okada, *An Analysis of Article XIII of the Washington State Constitution: What Duties Does the Article Impose on Washington to Care for Its Mentally Ill* (unpublished).

6. Appendix F is a true copy of the article *Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research, Mental Retardation*, Vol. 41, No. 2, 103-122 (2003), and January 2009 Update.

7. Appendix G is a true copy of the article Charlie Lakin, David Braddock and Gary Smith, *Large State Residential Facilities: Status and Trends in Population Characteristics as of June 30, 2000*, Mental Retardation, Vol. 39, No. 4, 334-337 (August 2001).

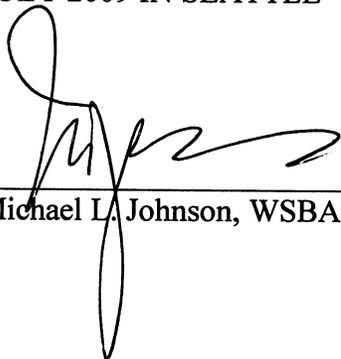
8. Appendix H is a true copy of Rachel Patterson, *No Less Than a Person: Liberalism and Disability Policy in Washington State*, Senior Thesis, Whitman College (unpublished 2009).

9. Appendix I is a true and correct copy of *Appendix J, Survey Procedures and Interpretive Guidelines for Intermediate Care Facilities for Persons with Mental Retardation*.

10. Appendix J is a true copy of Excerpt, *Sample Assessment Tool for Competency-Based Approach*, Page 3 of 5 (2008?).

11. Appendix K is a true copy of VOR, Media coverage highlighting the increasing need for more effective federal and state protections in the ever-expanding community system of care for people with mental retardation, Rev. March 2008.

DATED THIS 15th DAY OF JULY 2009 IN SEATTLE
WASHINGTON.



Michael L. Johnson, WSBA #28172

APP A



Promoting Dignity, Equality
and Self-Determination

October 1, 2004

James R. Hardman
12046 12th Avenue NE
Seattle, WA 98125-5014

via fax and mail

Dear Mr. Hardman:

Thank you for contacting Washington Protection & Advocacy System (WPAS). On September 10, 2004, you requested assistance with DDD's decision to stop paying a supplement for your ward, David Nichols. You also faxed to WPAS additional information dated September 28, 2004. You assert that the money pays for David's living expenses, and DDD asserts the money pays guardianship fees. You cited several pieces of information you feel indicate that DDD is trying to remove you as David's guardian. You have also notified CMS about this issue and requested its assistance.

You also explained that you are a party to the Fircrest lawsuit, as a member of Friends of Fircrest, and that you have petitioned the court for David Nichols to be permitted to be added to the suit.

As I explained when we spoke, I was unsure of what services, if any, WPAS could provide. I explained that WPAS has joined with the state of Washington in opposing the Fircrest suit brought by the Friends of Fircrest. For this reason, I explained that I would consult with WPAS's legal team before providing you or David with any further information or services.

Your request for assistance was reviewed by the Director of Legal Advocacy on September 21, 2004.

The merits of this case have not been investigated by this office. However, WPAS is unable to provide you with any assistance due to a conflict of interest. Pursuant to the Rules of Professional Conduct, which govern an attorney's standard of conduct, an attorney may not represent a client where a conflict of interest may or does exist or where the representation of a client may be materially limited by the lawyer's responsibilities to other clients, third persons or the lawyer's own interests. RPC 1.7. In this case, you and potentially your ward, David Nichols, for whom you are requesting representation, are plaintiffs in an ongoing lawsuit in which WPAS filed an amicus on behalf of the defendant. Moreover, David Girard, the Associate Director of Legal Advocacy at WPAS, provided a declaration to defendants opposing your receipt of guardianship fees for your work in the Fircrest lawsuit. Accordingly, we cannot provide you with representation in this matter as a result of this conflict of interest.

Washington Protection & Advocacy System
A member of the National Association of Protection & Advocacy Systems
A substantial portion of the WPAS budget is federally funded.

Facsimile
206-957-0729

Telephone (Voice)
206-324-1521
1-800-562-2702 toll free
Interpreters Available

WPAS
315 5th Avenue South, Suite 850
Seattle, WA 98104
www.wpas-rights.org

Telephone (TDD)
206-957-0728
1-800-905-0209 toll free

Electronic mail
wpas@wpas-rights.org

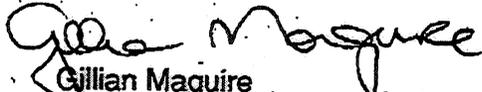
Hardman
October 1, 2004
Page 2

Please be aware that there are certain time limits or deadlines to file a complaint, a lawsuit or take legal action. If you fail to act within these time frames, you may lose your right to do so. You may wish to talk to a lawyer about this.

I am sorry that we cannot be of further assistance to you at this time. If you disagree with the Director of Legal Advocacy's decision and feel that you are entitled to direct legal assistance from this office, you may appeal the decision. I have enclosed a copy of our grievance procedures and a return envelope for your convenience. I am also enclosing a Satisfaction Survey. We ask that you complete and return it. You will receive these enclosures via U.S. Mail.

If you have any questions about this letter or if there is any information or assistance we can offer to you in the future, please feel free to contact this office at 1-800-562-2702. Thank you.

Sincerely,


Gillian Maguire
Director of Resource Advocacy

Enclosures: Grievance; and return envelope
Satisfaction Survey

CLIENT GRIEVANCE FORM

James R. Hardman, am filing this grievance with Washington Protection & Advocacy System for the following reason(s). (Please complete sentence 1, 2, or 3, whichever applies to your grievance.)

1. I was told that I am not eligible for services. Explain:

I am a petitioner in litigation ~~and~~ against D.S.H.S. where WPAS is amicus for D.S.H.S.

2. I am dissatisfied with the services that I am receiving. Explain:

I am not personally a party to the litigation. I am a nominal petitioner only as a guardian for petitioning incapacitated persons. WPAS is not a party in the litigation but is merely an amicus. The issue for which I seek WPAS assistance is not related to that litigation & David Nichols is not a

3. I am dissatisfied that my case was closed and that I have been denied further services. Explain: see #2
His joinder was denied by the court

To solve my problem, I can take the following steps:

1. File a grievance with the TEAM SUPERVISOR within 45 days of the problem;
2. File a grievance with the EXECUTIVE DIRECTOR within 15 days of the Team Supervisor's decision; and
3. File a grievance with the WPAS BOARD OF DIRECTORS GRIEVANCE COMMITTEE within 10 days of the Executive Director's decision who will issue the final decision within 30 days.

SIGNED

James R. Hardman

DATE

10/15/04

ADDRESS

12046 12th NE Seattle WA 98125

TELEPHONE

206 367 6116

Washington Protection & Advocacy System
315 5th Avenue South, Ste 850
Seattle, WA 98104



Promoting Dignity, Equality
and Self-Determination

October 25, 2004

James Hardman
12046 12th Street NE
Seattle, WA 98125

Re: WPAS Grievance for Denial of Request for Representation

Dear Mr. Hardman:

I am writing in response to the grievance that you filed with the Washington Protection and Advocacy System ("WPAS") as a result of WPAS' denial of your request for representation regarding your ward, Mr. Nichols. Specifically, you requested WPAS' assistance regarding the Division of Developmental Disabilities' decision to stop paying a supplement for Mr. Nichols for his living expenses because it pays you guardianship fees.

When WPAS originally reviewed your request for representation, it was determined that such representation could not be provided due to a conflict of interest that WPAS has with you for, at least, two reasons. First, WPAS has taken an institutional position, on behalf of its constituents, in support of closing RHCs such as Fircrest and in favor of less restrictive community placements for people with disabilities. You and your client have taken a spirited and public position against the closure of RHCs. Although reasonable persons may disagree on such issues, such a conflict directly affects any attorney-client relationship between those holding conflicting opinions on an issue so important and directly related to the provision of services to persons with disabilities. Second, a conflict exists as a result of your ward's and your roles as plaintiffs in *Parsons, et al. v. DSHS, et al.*, Superior Court of Washington for King County, Cause No. 03-2-12424-9, and the fact that WPAS appeared as amicus curiae on behalf of the defendants in that case.

One facet of any conflict of interest analysis here is the unique status of protection and advocacy agencies generally and WPAS specifically. WPAS has independent standing to act as a litigant or advocate on behalf of its constituents. Accordingly, a conflict with WPAS, in addition to a conflict with an individual WPAS client, will also trigger the conflict of interest proscriptions of the Washington Rules of Professional Conduct as WPAS itself is an affected client. As noted above, WPAS has taken legal and policy positions adverse to you and your ward.

Washington Protection & Advocacy System

*A member of the National Association of Protection & Advocacy Systems
A substantial portion of the WPAS budget is federally funded.*

Facsimile
206-957-0729

Telephone (Voice)
206-324-1521
1-800-562-2702 toll free
Interpreters Available

WPAS
315 5th Avenue South, Suite 850
Seattle, WA 98104
www.wpas-rights.org

Telephone (TDD)
206-957-0728
1-800-905-0209 toll free

Electronic mail
wpas@wpas-rights.org

James Hardman

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In your grievance you state that you are "not personally a party to the litigation." Hardman Grievance at p. 1. You further stated that you are only a "nominal petitioner" only as a guarantor for petitioning incapacitated persons. WPAS is not a party to the litigation but is merely an amicus." *Id.* Further you state that "[t]he issue for which I seek WPAS assistance is not related to that litigation and David Nichols is not a petitioner.—his joinder was denied by the Court." *Id.*

The Washington Rules of Professional Conduct (RPC) 1.7(b) state:

A lawyer shall not represent a client if the representation of that client may be materially limited by the lawyer's responsibilities to another client or to a third person, or by the lawyer's own interests, unless:

- (1) The lawyer reasonably believes that representation would not be adversely affected; and
- (2) The client consents in writing after consultation and a full disclosure of the material facts (following authorization from the other client to make such a disclosure). When representation of multiple clients in a single matter is undertaken, the consultation shall include explanation of the implications of the common representation and the advantages and risks involved.

In the instant matter, for the reasons stated below I believe that there is a conflict of interest between you and the Washington Protection and Advocacy System that cannot be reasonably overcome by your consent. The basis for the conflict is as follows:

1. **You are more than just a "nominal" party to the *Parsons* lawsuit.**

In your grievance you allege that you are just a "nominal" party to the *Parsons* lawsuit. I do not agree with this statement, as a review of the record in *Parsons* demonstrates that in fact you have been an active participant and have acted as a witness in this case. See generally Declaration of Hardman in Support of Plaintiffs Motion for Summary Judgment.

Furthermore, although you are not acting as an attorney to represent the plaintiffs in the *Parsons* litigation, it is your law firm that is one of the firms representing the plaintiffs. Your firm has a financial and other interests in the outcome of the litigation.

Clearly, your role is well more than "nominal" in the *Parsons* litigation. This is evidence of a conflict of interest between you and WPAS and its constituents.

James Hardman
Page - 3

2. The fact that WPAS is Amicus Curiae and not a party does not diminish the conflict.

The litigation in the *Parsons* case is active and pending and from the outset of the litigation you have affirmatively opposed WPAS' role as amicus curiae in that litigation. See Plaintiffs' Opposition to WPAS' Motion to appear as Amicus Curiae. This opposition is continuing as there is a pending request for the Washington State Supreme Court to review of the decision of the commissioner denying your appeal to the Supreme Court in which you directly attack WPAS' right to appear as amicus curiae in the case. See Notice of Discretionary Review to the Supreme Court 3/4/04; Motion for Discretionary Review 3/17/04 at 11-13; Statement of Grounds for Direct Review 3/17/04 at 1; Reply on Motion for Discretionary Review/Statement of Grounds for Direct Review; Answer to WPAS Amicus Motion 5/5/04 at 8-12; Motion to Modify Commissioner's Denial of Discretionary Review 6/28/04 at 2-3.

The fact that you are continuing to actively oppose WPAS' role as amicus curiae in the *Parsons* litigation is further evidence of a conflict of interest which simply cannot be overcome in this case.

3. David Nichols' situation is related to the *Parsons* litigation.

Although you stated that Mr. Nichols situation is not related to the *Parsons* litigation, you concede in your grievance that you attempted to join him as a party to the *Parsons* case, but that the Court denied your request. Obviously, you believed Mr. Nichols' situation was related to the *Parsons* litigation or under Rule 11, you could not have in good faith attempted to join him as a party. A review of the issues in Mr. Nichols case appears sufficiently related to the issues raised in *Parsons* such that if WPAS were to represent Mr. Nichols, by and through you as his guardian, there would be a conflict of interest.

4. WPAS submitted a declaration on behalf of DSHS to oppose your petition to obtain attorneys fees for work done on the *Parsons* litigation.

Further evidence of the insurmountable conflict between you and WPAS is the fact that WPAS attorney David Girard filed a declaration on behalf of DSHS in their opposition to your petition in *The Matter of Guardianship for John Fitzsimmons*, Superior Court for the State of Washington in and for King County, Cause No. 86-4-04877-8 SEA, for your alleged "proportional share" of "lobbying" costs that you expended in lobbying the legislature to stop the downsizing of Fircrest Residential Habilitation Center.

Finally, where there is a conflict of interest between two parties, as in this case, both parties, in addition to reasonably believing that the conflict will not adversely effect the representation of either party, both parties must consent in writing to waive the conflict. In this case, my client, Mark Stroh, Executive Director of the Washington Protection and

APP B



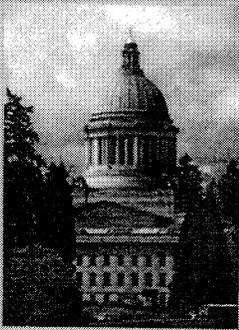
Medicaid And Long-Term Care Services for Adults

Explore:

- The process for applying and receiving Medicaid.
- Care options for people receiving Medicaid.

APP. B

A national
leader



Choice
Quality
Care

A message from the Director of...

Home and Community Services

If you have received this booklet, then you (or your loved one) are looking at options for getting help with your care. This is uncharted territory for many people and things may feel unfamiliar and confusing. It can be difficult to know what help is available and how you will pay for it.

Home and Community Services is the part of state government that helps low income seniors and adults with disabilities and their families get information, support, and services when long term care is needed.

We are proud that Washington State is recognized as a pioneer and national leader in helping all adults who need care continue to live as independently as possible at home or in a community setting.

What does this mean for you? You have many options and choices to get the care you need. You are not alone in knowing what they are and getting services set up.

Home and Community Services' financial and social workers are professionals that will help you understand your options and match your needs and preferences to quality services available in your community.

I encourage you to read through this booklet and ask your financial or social worker any questions you may have. I know you are in capable, knowledgeable hands.

Sincerely,

Bill Moss

Director, Home and Community Services

Maximizing independence, dignity, choice, and quality of life for adults with disabilities and their families.

Medicaid
And
Long-Term
Care Services
for Adults

You Have a Choice.

this booklet is for adults 18 or older who have a chronic condition, disease, or disability, need help with care, and are exploring using Medicaid to help pay for it.

This booklet will help you learn more about:

- ◇ How to apply for Medicaid.
- ◇ The income and resource eligibility limits for Medicaid.
- ◇ Estate recovery of any funds you receive.
- ◇ In-home care service options and resources if you are eligible for Medicaid.
- ◇ Residential care options if you can no longer live at home.

DSHS does not discriminate in serving or contracting with people because of race, color, national origin, gender, sexual orientation, age, religion, creed, marital status, disability, or Vietnam Era Veteran status, or the presence of any physical, mental, or sensory handicap.

Photos by Carole Huff

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Applying for Medicaid

Medicaid is a government health insurance program that pays for medical long-term care services for people who have very limited income and resources.

If you are eligible, Medicaid pays for services in your own home or in a residential care facility (adult family home, boarding home, or nursing facility).

How to Apply

If you are 18 or older, apply for Medicaid through your local Home and Community Services (HCS) office.

There are three main parts to the application process:

1. Filling out and turning in an application.
2. A financial review to determine your financial eligibility.
3. A personal care needs assessment to determine your functional eligibility.

Call or visit the HCS office to get an application form. The application form can be:

- Mailed to you.
- Picked up at the HCS office.
- Downloaded and printed off the Internet at:
http://www.dshs.wa.gov/pdf/ms/forms/14_001.pdf.

Call the nearest HCS Regional Office. They can tell you where to find the closest HCS office. Phone numbers are on the back of this booklet. This information is also available at www.adsa.dshs.wa.gov (click on "local services").

Filling Out the Application

Follow the instructions and answer all the questions on the application. If you need help filling out the application, call your local HCS office.

Information you will need to provide includes:

- A Social Security number.
- Proof of identification.
- Proof of income.



HCS is part of the Aging and Disability Services Administration (ADSA), an administration within the Department of Social and Health Services (DSHS).

HCS staff provide a variety of services and support to you.

- Documentation of resources (such as bank statements, property tax statements, life insurance).
- Immigration or alien documents.
- Proof of citizenship if you do not receive Medicare or Supplemental Security Income (SSI), or Social Security Disability Benefits.

Additional Support

If you have difficulty reading the application or have mental, physical, hearing, or sight issues that makes it difficult to understand what is happening during the application process, ask a HCS staff person for help.

HCS staff may be able to offer you Braille materials, written materials translated or on computer disk, large print materials, use of assisted listening devices, TTYs, or a qualified/certified interpreter.

If you want someone else to apply for you, you need to sign a consent form giving the other person permission to represent you during the application process. The consent form must be updated yearly.

Make sure the person is prepared to answer questions about your personal and financial situation.

Financial Review

Once you have completed your application, a HCS financial services specialist works with you to see if you are financially eligible to receive Medicaid. Depending on what works best for you, this can be an in-person, mail, or telephone interview.

When you talk to the financial services specialist, you can explain in more detail the answers on your application form.

See the next section "Income and Resource Eligibility Limits" for more information about the income and resource eligibility limits and any resource transfers the financial services specialist will be reviewing with you.

HCS employees can explain Medicaid rules but are not able to give you personal, financial, or legal advice. You may want to talk with an attorney who understands Medicaid rules if you need help with a decision.



Medicaid rules can be found at:
<http://www.dshs.wa.gov/manuals/eaz/sections/ltcindex.shtml>

Staff at your local Senior Information and Assistance Office can help you locate legal assistance. See page 17 for how to contact them.

Income and resource eligibility limits

You must meet various income and resource requirements to be eligible for Medicaid. Income and resource limits are set by law and change each year.

Income

Medicaid income limits vary depending on the services you need, your living situation, and your marital status. The HCS office will have current information.

Resources

You must declare all resources you have when applying for Medicaid. Resources include money, assets, or property you have such as cash, bank accounts, stocks and bonds, retirement plans, trusts, annuities, life insurance policies, sales contracts, vehicles and land. If you are married, resources of both spouses will be used to determine your eligibility for Medicaid.

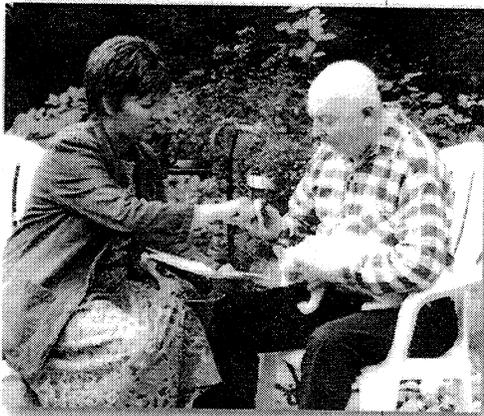
Certain "exempt" resources are not counted toward the resource limits. Exempt resources can include your home, household goods and personal effects, some real estate sales contracts, a car, life insurance with a face value not more than \$1,500, burial plots, and most prepaid burial plans.

Transferring resources

Under state and federal law, the HCS financial services specialist must review any transfer of resources that took place 60 months before the date you apply for Medicaid.

If resources were transferred within that timeframe and you did not receive fair market value for them, you may not be eligible to receive long-term care Medicaid services for a period of time.

You must declare all resources you have when applying for Medicaid.



Federal law states that certain gifts or transfers made to qualify for Medicaid are subject to penalties. State law also contains penalties for the person who receives resources transferred for less than fair market value.

You will receive a letter letting you know if you have been approved for Medicaid coverage.

What to Expect When Your Application is Approved

You will receive a letter letting you know you have been approved for Medicaid coverage.

The letter will tell you how much of your income you may keep for your personal needs, spousal support, home maintenance allowance, medical insurance premiums, necessary medical expenses not covered by Medicaid, and how much you must pay your provider towards your cost of care (participation). See the next section, Your income once you receive Medicaid, for more information about what these things are.

Contact the person who sent you the letter if you have any questions about what is in the approval letter.

You will receive a Medicaid Identification Card or a Provider One Services Card. It pays for:

- Medical services covered under Medicaid such as lab work or doctor visits.
- Prescription drugs if you are **not** receiving Medicare. Medicare Part D pays for most of your prescription drugs if you are receiving Medicare.

The social worker will help you develop an individualized care plan. He or she then coordinates setting up needed services.

You will receive a Client Rights and Responsibility form (DSHS 14-113) that outlines your rights and responsibilities when receiving Medicaid. A copy of it can also be viewed at www1.dshs.wa.gov/pdf/ms/forms/14_113.PDF.

Your financial and functional eligibility to receive Medicaid benefits will be reviewed at least once a year.

If you are not approved

There are many low-cost resources and programs that you might want to explore. Contact your local Senior Information and Assistance office. See page 17 for more information.

Your eligibility to receive Medicaid benefits will be reviewed at least once a year.

Your Income Once You Receive Medicaid

Once you begin receiving Medicaid, you may have to contribute some of your income towards the cost of your care. This is called your participation. Your participation amount depends on the services you receive, your marital status, and your income. You must pay these participation costs if they are required.

Part of your available income may go towards a spousal allowance. A spousal allowance is used to bring your spouse's income up to established federal government standards. Receiving a spousal allowance depends on the program, your needed services, and your living situation. Part of your available income may also go to support dependent relatives.

If you live at home, part of your available income can be kept for home maintenance such as rent, utilities, and taxes and personal needs. If you live in a residential care facility, you keep some of your income for your personal needs.

If you will be staying in a nursing facility a short time, you may be able to keep additional income to help maintain your home for your return. This is known as a "Housing Maintenance Exemption". Your doctor must verify that you will likely return home.

Recovery of Funds From Your Estate

By law, Washington State may recover (be paid back) payments DSHS made for all Medicaid and long-term care services you received prior to your death. Payment is taken from the your estate (assets you owned or had an interest in at the time of death). This is called Estate Recovery.

Washington State will recover the cost of all Medicaid-funded services (federal and state-funded programs) and long-term care services from age 55, including:

- Doctor visits
- Hospital stays
- Prescription drugs



Resident Personal Funds Held by a Facility

If a residential care facility holds any personal funds of a resident who dies, the money must be given within 45 days to:

- The individual or probate jurisdiction administering the resident's estate.
- or -
- The Office of Financial Recovery. This office may release funds to pay for burial costs.

- Medical equipment
- All other medical services
- Nursing home services
- Waiver services (COPEs, Medically Needy Residential and In Home Services), New Freedom
- Medicaid personal care services
- Adult day health
- Private duty nursing
- Managed care premiums
- Medicare premiums for individuals also receiving Medicaid
- Medicare Savings Program services for individuals also receiving Medicaid

Washington State will also recover the cost of state-only funded long-term care services received at any age, including:

- Chore
- Adult family home services
- DDD state-funded long-term care services
- Adult residential care services
- Related hospital services and prescription drug costs

Estate recovery only applies to assets you owned or had an interest in at the time of death. The state will not begin recovery efforts until after your death, during the life of a surviving spouse, domestic partner, or while a surviving child is under age 21, blind, or disabled. Hardship provisions to protect dependent heirs may apply.

Certain lands belonging to American Indians or Alaska Natives may be exempt from Estate Recovery.

Various exemptions have existed over the years. DSHS will apply whatever estate recovery law existed on the date that benefits were received.

Liens Against Property

DSHS may file a lien or make a claim against any property to repay the costs of long-term care and medical services received if:

- The property is part of your estate and you have died.
- You are permanently living in a nursing home or other medical facility.

Before filing a lien against real property as part of estate recovery, DSHS will give notice and an opportunity for a hearing to your estate's personal representative or any other established titled owner of the property.

If you are permanently living in a nursing home or other medical facility and receive Medicaid, DSHS may recover costs from your estate or the sale of your property. If you return home, the lien is released. A lien is not filed against your home if your:

- Spouse, domestic partner, or a minor, blind, or disabled child lives in the home.
- Sibling has an equity interest in the home, currently lives there, and has lived there for at least one year immediately before you moved to the facility.

For more information on estate recovery, consult an attorney with experience in Medicaid law. You can also contact Coordinated Legal Education, Advice, and Referral (CLEAR) toll-free at 1-888-201-1014.

CLEAR is a project of the Northwest Justice Project – a non-profit statewide organization that provides free civil legal services to low-income Washington State residents. They have a web site in English and Spanish at www.nwjustice.org.



There are many services, programs, and resources available to help you continue to live at home.



It is your choice who your caregiver(s) will be.

Care Options for People Receiving Medicaid

A HCS social worker, sometimes referred to as a case manager, will review your care options with you after your care assessment (see page 4).

The following pages are a summary of some of the care options you may discuss. Your social worker will have more information and answer any questions you may have about these options, your eligibility for them, and talk through with you what you think will work best.

Services and Programs That Help You Stay at Home

Many people can continue to live at home if they have help with things like preparing meals, personal care, or housekeeping. There are many services, programs, and resources available to help you in these areas.

Often, family and friends are already helping you and will continue to do so. Your social worker will work with you and develop a care plan to fill in gaps where more help is needed.

Help with Personal Care

Needing help with personal care means you need assistance with things such as bathing, dressing, or toileting. Programs such as Medicaid Personal Care (MPC) or Community Options Program Entry System (COPEs) pay for personal care services.

A caregiver can be hired to help you with personal care if you meet the eligibility requirements. Depending on your income, DSHS will pay for all or part of these caregiver services (see page 6 for more information). DSHS also pays for basic caregiver training for any qualified caregiver(s) hired.

It is your choice who your caregiver(s) will be. You have several options for finding a caregiver. You can find a caregiver yourself, called an Individual Provider (IP), or find one through a home care agency. You can also use a combination of both. Your social worker can help you with this process.

Individual Provider (IP)

With an IP, you decide who comes to your house and provides your care. You may have more flexibility when setting the person's work schedule.

You are the IP's employer. This means you choose, hire, and supervise the caregiver. You may also want to find a backup caregiver when your regular IP has time off. To find an IP, you can:

- Choose a friend or family member (with some exceptions).
- Use the Home Care Referral Registry (see below).
- Look for someone in your community.

DSHS will do a background check on anyone you select.

Home Care Agencies

Your other option is to choose a licensed and contracted home care agency to provide a caregiver. A home care agency recruits, does background checks through DSHS, hires, and supervises their workers. A home care agency provides you with a backup caregiver if you need one.

The home care agency supervisor will work with you to find caregivers that best meet your needs. However, you have less control over who is chosen and you may not have the same caregiver coming into your home each time.

Washington State Home Care Referral Registry

The Washington State Home Care Referral Registry is a FREE referral service that matches you with prescreened IPs in your area. You can use the Home Care Referral Registry to find an IP or backup caregiver when your regular IP has time off from work.

There are Home Care Referral Registry Centers throughout Washington. Center staff will help you find IPs through the Referral Registry. Center staff are a great resource and can give you a variety of informational materials, suggestions, and advice to help you successfully hire and keep quality providers.

To find the Home Care Referral Registry Center nearest you, call 1-800-970-5456. You can also visit their website at www.hcqa.wa.gov for more information.



For a list of prescreened IP's in your area, visit www.hcqa.wa.gov.

There are several in-home care options available if you need help with health care.



Help with Health Care Needs

In the past, many people moved to a nursing home if care was needed from a licensed health care professional such as a registered nurse. Today, there are several in-home care options that may be available if you need help with health care tasks.

Self-Directed Care

If you live in your home and receive Medicaid, you can direct and supervise an IP to help you with health care tasks that you can't do because of your disability. This would include things an IP would not usually be able to do including administering medications, bowel programs, bladder catheterization, and wound care.

Nurse Delegation

In this program, a registered nurse (RN) evaluates your health care needs and trains and supervises a nursing assistant to provide health care tasks that you can't do for yourself. There are rules about what types of care can and cannot be delegated.

The nursing assistant must be registered with the state, receive training, and be approved by the delegating nurse before doing any delegated tasks. Nurse delegation is available in your home or a residential care facility.

Nursing Services

The Nursing Services program provides nursing expertise to help determine the kinds of care and services you may need. This health-related assessment and consultation service can be a phone call, consultation, or home visit with you and the RN.

Home Health Care

A home health care agency also provides skilled nursing care or a home health aide for a short period of time. Home health care must be authorized by a doctor and is often covered by Medicare. Your social worker can work with you on this.

Hospice

Hospice care involves a team of professionals and volunteers who provide medical, psychological, and spiritual care for people near the end of life and their families. Hospice care is most often provided at home but is also available in other care settings, including a hospital. A doctor's referral is needed.

Other Services That Can Help

The following are additional services that may be available.

Adult Day Services

Adult day services are daytime programs offering services in a group setting outside the home. Adult Day Care programs include help with personal care, social and therapeutic activities, education, routine health monitoring, a nutritious meal and snacks, coordination of transportation, first aid, and emergency care.

Adult Day Health programs provide all of these services plus nursing, rehabilitative therapies, and other skilled professional care.

Environmental Modifications

Modifications, such as ramps, a grab-bar in the shower or near a toilet, or widening doorways for a wheelchair, may be added to your home to help you adapt to your changing needs safely.

Home Delivered Meals

A nutritious meal is delivered to your home once a day.

Individualized Training

Training is provided if you or your caregiver(s) need further information/skills to effectively carry out your care plan.

Medical Equipment

Necessary medical equipment is purchased that isn't covered by Medicaid or Medicare.

Personal Emergency Response System (PERS)

An electronic device is provided that allows you to get help in an emergency. The system is connected to your phone or you may also wear a portable "help" button. When activated, staff at a response center will call 911 and/or take whatever action has been set-up ahead of time.

Transportation

Limited transportation is provided to help you get to needed services and activities.



Additional Programs

The following programs are limited to certain geographic areas throughout the state. Talk with your social worker to learn more about these programs.

New Freedom Consumer Directed Services

New Freedom is a program that pays for personal care services in your home and is designed for people who want more choice and control of what services they receive.

With New Freedom, a consultant helps to decide what services you need and helps you get them. The consultant will check with you periodically to make sure these services continue to meet your needs.

New Freedom is currently available for people living in King County.

Washington Medicaid Integration Partnership (WMIP)

WMIP is a managed care program available to adults 21 and older who are eligible for Medicaid.

WMIP is currently offered in Snohomish County. To learn more about WMIP, visit <http://fortress.wa.gov/dshs/maa/mip/> or call Molina Healthcare of Washington at 1-800-869-7165.

Program of All-Inclusive Care for the Elderly (PACE)

PACE provides an integrated, multidisciplinary, team approach to health care and social services for adults 55 and older at a local PACE center. Tailored to meet your individual needs, the PACE center is the focal point for coordinating and providing most services.

PACE is currently available in parts of King County. To learn more about the King County PACE program, visit www.providence.org/Long_Term_Care/Elderplace or call Providence ElderPlace at 206-320-5325.



Residential Housing and Care Options

There are many options where you can live and get care if you can no longer stay at home. Most people are familiar with nursing homes. People are not as familiar with other live-in care options that have become available in the last several years.

Assisted living is often used to describe any live-in care facility that is not a nursing home. Since there is no universal definition of what assisted living includes, it is important to understand what services and housing options are offered.

The following is some helpful information about possible residential care housing options for people receiving Medicaid. The facility must be licensed by Washington State and accept Medicaid payment for residents.

Adult Family Homes and Boarding Homes

An adult family home (AFH) is licensed to provide housing and care services for up to six people in a house located in a residential neighborhood. The AFH may be run by a family with children, a single person, couple, friends, or business partners. The AFH may also hire other employees. Some AFHs allow pets. In some homes, multiple languages may be spoken.

A boarding home (BH) is licensed to provide housing and care for seven or more people in a home or facility located in a residential neighborhood. Housing options range from a room with access to shared living space to your own apartment. BHs vary in size and ownership from a family operated 7-bed facility to a 150-bed facility operated by a large national corporation.

All AFHs and BHs provide housing and meals (room and board), varying levels of help with personal care, and assume general responsibility for your safety and care. What additional services are offered is different for each home and may include:

- Intermittent nursing care (a nurse available on a part-time basis).
- Assistance with or administering of medications.
- Specialized care to people living with developmental disabilities, dementia, or mental illness.



There are many options where you can live and get care if you can no longer stay at home.

Your social worker will have a listing and knowledge of what homes are available in your local area. A listing of adult family homes and boarding homes can also be found on the internet at www.adsa.dshs.wa.gov.

Choosing Care in an Adult Family Home or Boarding Home (DSHS 22-707) is a free booklet from DSHS that talks about how to find and choose the right home for you. The booklet includes a checklist of things to ask and look for that can help you make your decision. See page 16 for ordering information or read it on the internet at www.adsa.dshs.wa.gov (click on Publications).

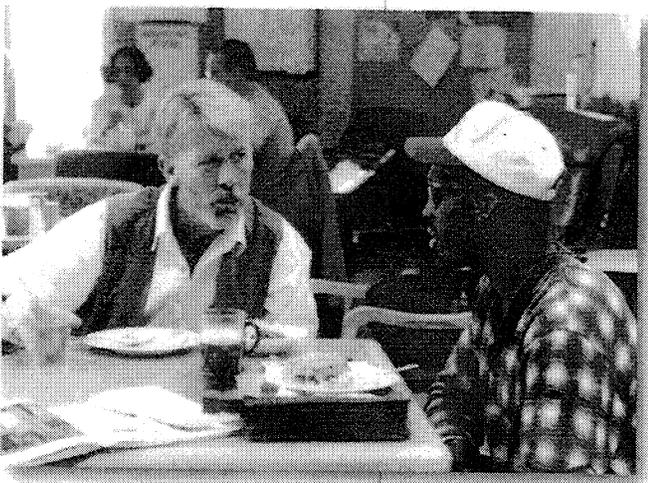
Nursing Facilities

Nursing facilities provide 24-hour, supervised nursing care, personal care, therapy, nutrition management, organized activities, social services, room, board, and laundry services.

If you currently live in a nursing facility and are there for rehabilitation, short-term intensive nursing care, or want to return home or to a residential care facility, it is important to review your housing and care options.

With the proper support, you may not need to stay in the nursing facility. A nursing facility case manager will come to the facility, review your options with you, and help develop a discharge plan for you.

With support, you may not need to stay in a nursing facility.



You Have a Choice...

This booklet has given you information on applying for Medicaid and your options for care if you are eligible to receive it.

There are many people, options, and resources available to help you stay as independent as possible.

Once you start receiving services, always contact your social worker if you have questions or your care needs change.

Additional Information

Ordering Publications

You may order this booklet and other DSHS publications through the Washington State Department of Printing (DOP). Go to the DOP's website at: www.prt.wa.gov and click on General Store.

Publication requests may also be placed by:

E-mail at: fulfillment@prt.wa.gov

Phone at: (360) 586-6360

Fax at: (360) 586-6361

Make sure to include the name of the publication, publication number, and a contact name and street mailing address.

All publications listed in this booklet and more can be found and read on-line at www.adsa.dshs.wa.gov. Translated versions of all publications can also be found there in Spanish, Russian, Cambodian, Chinese, Korean, Laotian, and Vietnamese.



Senior Information and Assistance (I&A)

Many of the care options discussed in this booklet are available to an adult paying privately or through other insurance for long-term care services. If you are not eligible for Medicaid and want to talk with someone about what services and resources are available where you live, call your I&A office.

To find your local I&A office, visit the Area Agency on Aging (AAA) website at www.agingwashington.org and click on "local AAAs" or look for the AAA office in the yellow pages of your telephone book under "Senior Services".

Resources for Caregivers

There are several resources to help support family and friends providing unpaid care. You do not have to be applying for or receiving Medicaid to take advantage of these resources.

Family Caregiver Support Program

The Family Caregiver Support Program helps unpaid caregivers of older adults. Services are free or low cost and generally include:

- Caregiver support groups and counseling
- Caregiver training and education
- Respite care
- Information and help getting services

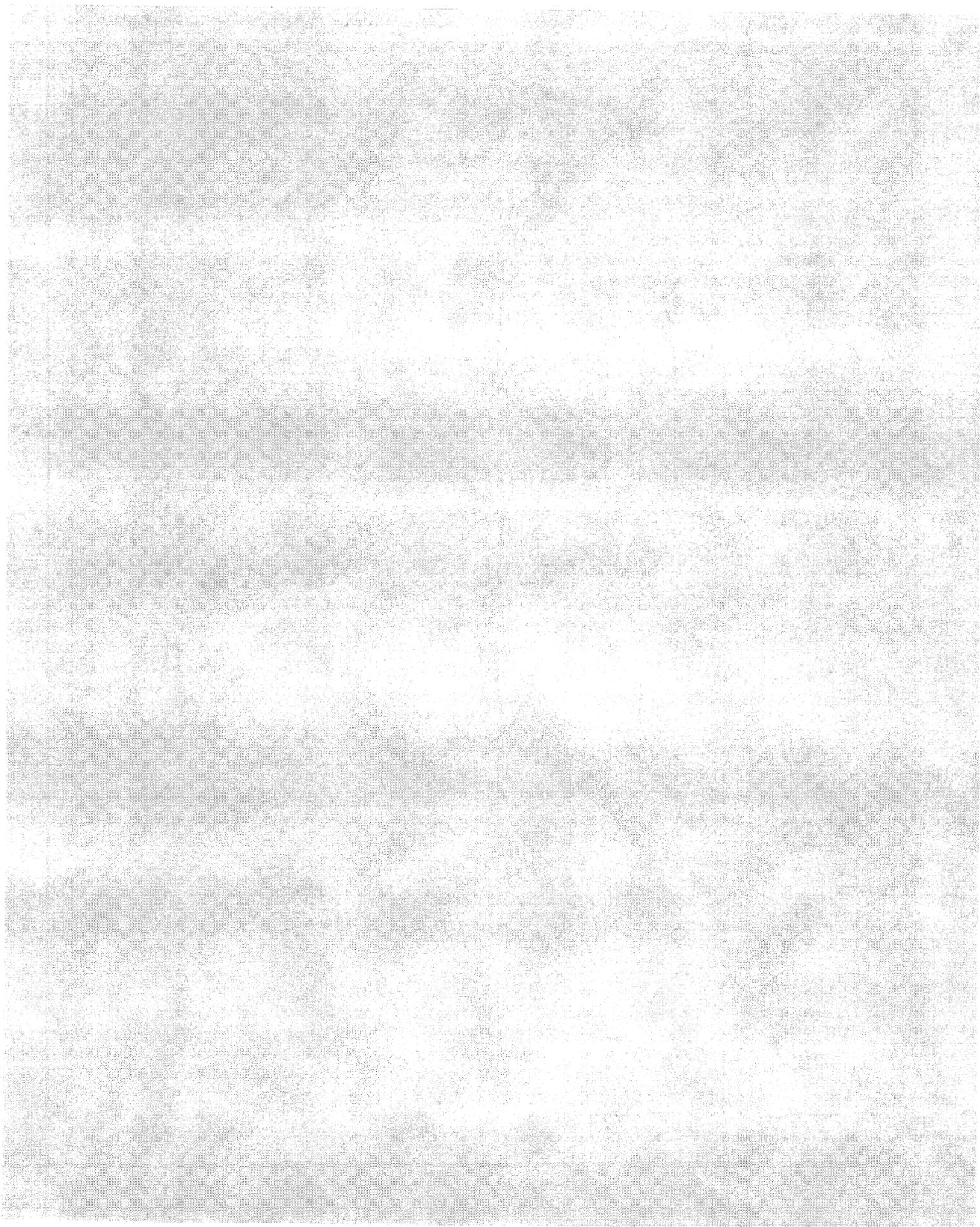
Respite care

Respite care is when another person or facility temporarily takes care of a frail adult so the person caring for them at home can have a break. Some eligibility rules apply and services vary depending on where you live.

Contact your local Senior Information and Assistance office for more information on either of these programs.

Free booklet

The *Caregivers' Handbook* (DSHS 22-277) is a free booklet that can help you learn more about all aspects of providing care. See page 16 for ordering information or read it on the internet at www.adsa.dshs.wa.gov (click on Publications).



ADSA Website

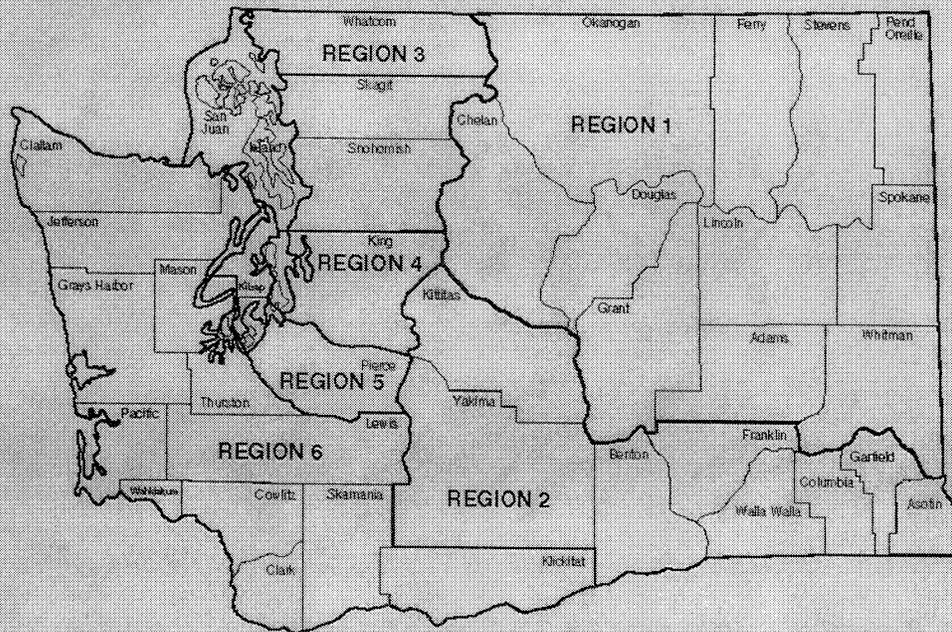
Visit the ADSA website to learn more about:

- ◇ The types of care services, programs, and resources available and how to find them.
- ◇ Residential housing options for a person who can no longer live at home and how to find them.
- ◇ State, federal, and local resources that help pay for care and prescription drugs.
- ◇ Information, resources, and programs for people who are caring for a loved one.
- ◇ Long-term care planning:
 - The legal and financial steps necessary to help plan wisely for the future.
 - Tips on healthy aging.
- ◇ Translated versions of this booklet in Cambodian, Chinese, Korean, Laotian, Russian, Spanish, and Vietnamese.

Visit **www.adsa.dshs.wa.gov** today!

Home and Community Services Regional Phone Numbers

See map to find the region you live in. Call the number listed for your region and ask for the local HCS office nearest you.



Region 1 1-866-323-9409
TTY 509-456-2827

Spokane, Grant, Okanogan, Adams, Chelan, Douglas, Lincoln, Ferry, Stevens, Whitman, and Pend Oreille Counties

Region 3 1-866-608-0836
TTY 360-416-7404

Snohomish, Skagit, Island, San Juan, and Whatcom Counties

Region 5
Pierce County 1-800-442-5129
TTY 253-593-5471

Kitsap County 1-800-422-7114
TTY 360-478-4928

Region 2 1-800-822-2097
TTY 509-225-4444

Yakima, Kittitas, Benton, Franklin, Walla Walla, Columbia, Garfield, and Asotin Counties

Region 4 1-800-346-9257
TTY 1-800-833-6384

King County

Region 6 1-800-462-4957
TTY 1-800-672-7091

Thurston, Mason, Lewis, Clallam, Jefferson, Grays Harbor, Pacific, Wahkiakum, Cowlitz, Skamania, Klickitat, and Clark Counties

We are all partners against adult abuse

Abuse of vulnerable adults (people who need help to care for themselves) can happen anytime, anywhere. DSHS investigates alleged abuse, neglect, exploitation, or abandonment of vulnerable adults.

If you suspect abuse, neglect, or exploitation of a vulnerable adult:

Call DSHS toll-free



ADAA Aging & Disability
Services Administration

APP C



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SERVICES
RESEARCH
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Status Report: Litigation Concerning Home and Community Services for People with Disabilities

May 23, 2007

I. Introduction

This periodic report tracks the status of lawsuits concerning home and community services for people with disabilities. We caution that the report is not necessarily inclusive of all lawsuits in this arena. The report tracks three broad categories of lawsuits:

- **Access to Medicaid Home and Community Services.** These lawsuits challenge state policies that prevent people with disabilities from promptly obtaining Medicaid home and community services. Many of these lawsuits involve people with developmental disabilities who have been wait-listed for services. Individuals with other disabilities who want but cannot obtain home and community services also have filed several lawsuits.
- **Community Placement of Institutionalized Persons.** These lawsuits principally (but not exclusively) have been brought by persons served in publicly-operated institutions who want supports in the community.
- **Limitations on Medicaid Home and Community Benefits.** These lawsuits challenge state policies that affect the scope and quality of Medicaid services in the community. Some lawsuits concern the adequacy of state payments for community services. Others challenge state restrictions on access to Medicaid benefits.

The following sections discuss the issues that have prompted these lawsuits and the lawsuits are summarized along with their current status.

II. Access to Medicaid Home and Community Services

A. Medicaid Home and Community Services

The Medicaid program underwrites over one-half of the costs of long-term services for individuals of all ages. Because the Medicaid program looms so large in the provision of long-term services, it has attracted a high volume of litigation.

In the past and still today, the majority of Medicaid long-term dollars pay for institutional services in nursing facilities, intermediate care facilities for the mentally retarded (ICFs/MR) and other settings. Federal Medicaid law (Title XIX of the Social Security Act) requires that every state cover nursing facility services in its Medicaid program. States also have the option to offer ICF/MR services. Initially, ICF/MR services were concentrated in state-operated institutions. Now, the majority of ICF/MR residents

are served by non-state providers and the number of public institutions has declined. (Prouty *et al.*, 2006).

Medicaid home and community services include home health care, personal care/assistance provided as a Medicaid state plan benefit, and home and community-based services (HCBS) furnished under federal waivers. All states must cover home health in their Medicaid programs. States may elect to provide personal care/assistance and/or operate HCBS waivers. As provided by the Deficit Reduction Act of 2005, effective January 2007, states may provide home and community-based services as Medicaid state plan benefits in addition to operating HCBS waivers.

Under the HCBS waiver program, a state may provide community services as an alternative to institutional services (e.g., nursing facility and ICF/MR) to persons

This report is updated and reissued periodically as developments warrant. When you receive an update, discard the previous version because the report is cumulative. Changes since the January 10, 2007 update are highlighted in yellow. The report has links to materials available on the Internet that provide additional information concerning a topic or lawsuit. With each update, these links are checked to confirm that they work. The report is distributed at no charge and only by e-mail; it may be freely shared. To receive the report directly, e-mail the author. The report also is posted on HSRI's web-site (<http://www.hsri.org/index.asp?id=news>). Please e-mail the author if there are developments concerning the lawsuits summarized here or new litigation of interest not described here.

who meet institutional eligibility criteria. A state may offer services under a waiver that it could but does not provide under its Medicaid program (e.g., personal assistance) and other services that cannot be offered as regular Medicaid benefits but aid individuals to remain in the community. Federal law (§1915(c) of the Social Security Act) permits a state to select the services that it offers in a waiver and target waiver services to specific Medicaid beneficiary groups (e.g., individuals with developmental disabilities). (ASPE, 2000) A state also can limit the number of persons who participate in an HCBS waiver.

While institutional spending still dominates Medicaid long-term services, spending for home and community services has been growing rapidly. For more than a decade, HCBS spending has risen more rapidly than institutional services. Between 1996 and 2005, HCBS waiver expenditures grew nearly four-fold, reaching \$22.7 billion. In 2005, the share of Medicaid long-term services expenditures devoted to HCBS reached 37% compared to a little over 10% in 1990.¹ In developmental disabilities services, waiver spending surpassed ICF/MR spending in 2001.²

Several factors are prompting lawsuits to expand access by people with disabilities to Medicaid HCBS. The most important factor is that growing numbers of individuals with disabilities want to remain in and be supported in their own homes and communities rather than institutions. Despite the expansion of Medicaid HCBS, most states have not kept pace with upward spiraling demand for long-term services. (Smith, 1999) Demographic and other factors lie behind rising demand for community services. Since the supply of community services has not kept pace with demand, the result has been the wait listing individuals for services and a backlog of persons in nursing facilities and other institutional settings who cannot return to the community. Frustration over the lack of access to community services has boiled over into litigation.

Under Medicaid law, there is an entitlement to the institutional services that are covered in a state's Medicaid program. Lawsuits aim to establish that Medicaid beneficiaries with disabilities must have access to community services on equal footing with "entitled" institutional services. Until nine years ago, there had been relatively little litigation concerning Medicaid

home and community services. In the arena of developmental disabilities services, the 1998 11th U.S. Circuit Court of Appeals decision in the *Doe v. Chiles* lawsuit held that a state cannot limit access to entitled ICF/MR services. This decision (described below) triggered lawsuits elsewhere to challenge state restrictions on access to Medicaid services by people with developmental disabilities. In 1999, the U.S. Supreme Court issued its landmark *Olmstead v. L.C.* ruling that Title II of the American with Disabilities Act (ADA) requires states to make diligent efforts to serve individuals in the most integrated setting. This decision sparked lawsuits to secure community services for institutionalized persons as well as people who potentially face institutionalization absent community services. While there are differences among the lawsuits, their common theme is securing prompt access by people with disabilities to long-term services in the community.

B. Legal Issues

Lawsuits in this category assert that federal Medicaid law and the ADA oblige a state to furnish home and community services to eligible individuals when needed and thereby challenge the premise that states can restrict access to HCBS. In many cases, the *Olmstead* decision serves as the grounds for claims that the ADA dictates that states must furnish long-term services in the most integrated setting.

Most lawsuits have been filed in federal court, although a few have been brought in state court when violations of state law also are alleged. Federal Medicaid law does not provide an avenue for a beneficiary's seeking relief through the federal courts for alleged violations of Medicaid law. Federal law requires that a state operate an administrative appeals process (called Fair Hearing) through which a person may appeal adverse decisions concerning eligibility or services. Otherwise, if a state does not comply with Medicaid law and regulations, the principal statutory federal remedy is to withhold or deny payments to the state.

In order to bring suit in federal court concerning alleged violations of Medicaid law, plaintiffs rely on the Civil Rights Act of 1871 (42 U.S.C. §1983), which grants citizens a private right of action to seek relief in federal court when state officials are alleged to violate the Constitution or federal law. This act has long served as the basis for bringing lawsuits in federal court involving Medicaid services. When §1983 serves as the vehicle to access the federal court system, plaintiffs must seek prospective relief from alleged state violations of federal law and show that federal law confers an *individually enforceable right*.

¹ For information concerning Medicaid long-term services spending nationwide and by state, go to: hcbs.org/moreInfo.php?type_tool/129/ofs/40/doc/1637/

² In 2005, HCBS waiver expenditures for persons with developmental disabilities reached \$17.2 billion compared to \$12.1 billion for ICF/MR services. There were about 444,000 HCBS waiver participants with developmental disabilities compared to 102,000 ICF/MR residents. (Prouty et al., 2006)

Usually, these lawsuits also seek certification as a class action complaint because, in addition to the named plaintiffs who allege that their rights have been violated, there are many other individuals in the same situation. Class action certification is subject to a separate determination by the courts.

In defense, some states have claimed “sovereign immunity” from these lawsuits under the provisions of the 11th Amendment to the U.S. Constitution. The 11th Amendment generally bars suits against states in federal court. Federal courts usually reject this defense.

More recently, states have challenged the premise that Medicaid law confers individually enforceable rights that fall under the protections of §1983. These challenges often rely on the 2002 U.S. Supreme Court *Gonzaga University v. Doe* decision that set forth more stringent conditions for bringing §1983 complaints. Relying on this decision, states argue that federal Medicaid law only governs a state’s overall administration of its Medicaid program but does not grant beneficiaries individually enforceable rights.

Since the *Gonzaga* decision, there have been several decisions concerning whether Medicaid law confers individually enforceable rights.³ Increasingly, federal courts have ruled that some provisions of Medicaid law do not confer such rights but other provisions are grant such rights. Going forward, the fundamental question of whether individuals can seek relief through the federal courts for alleged violations of Medicaid law likely will continue to be litigated.

While claimed violations of federal Medicaid law vary from lawsuit to lawsuit, they often include:

- **Reasonable Promptness.** §1902(a)(8) of the Social Security Act (hereinafter, “the Act”) and associated federal regulations mandate that a state promptly determine the eligibility of persons who apply for services. The regulatory standard for processing Medicaid applications for long-term care is no more than 90-days. Federal courts have ruled that §1902(a)(8) bars a state from wait listing individuals for entitled Medicaid services. In *Doe v. Chiles*, the court held that this provision requires a state to furnish ICF/MR services promptly once an application has been approved because wait-listing individuals indefinitely violates the intent of §1902(a)(8).⁴
- **Comparability.** §1902(a)(10) of the Act requires a state to make Medicaid services available on a

“comparable” basis to all eligible individuals. In some lawsuits, plaintiffs claim that, by furnishing HCBS to some but not all eligible persons, a state violates this provision.

- **Freedom of Choice.** §1915(c)(2)(C) of the Act requires that a state afford an individual the freedom to choose between receiving waiver and institutional services. In some complaints, plaintiffs claim that, under this provision, a person who meets eligibility requirements for institutional services has the right to select waiver services instead. In other words, a person’s eligibility for entitled institutional services should translate into an entitlement for waiver services. But, pursuing this claim has run up against the authority of a state to limit the number of individuals served in HCBS waivers.
- **Right to Apply.** §1902(a)(3) of the Act affords individuals the right to apply for services and have a decision rendered concerning their applications. If a person’s application is denied, then the individual has the right to appeal. In some cases, plaintiffs argue that wait listing individuals for services instead of determining their eligibility short-circuits this basic protection. Often, claims also are made that a state’s policies violate the Constitution’s due process protections.

Alleged violations of Medicaid law often are accompanied by claimed violations of Title II of the ADA and §504 of the Rehabilitation Services Act of 1973. Title II requires public entities to provide services in the “most integrated setting” appropriate to a person’s needs. Plaintiffs assert that Title II mandates that individuals have access to community services on equal footing with institutional services. By making institutional but not community services available, it is claimed a state violates the ADA. Claimed §504 violations are similar except that this statute dictates that recipients of federal funds furnish services in the “least restrictive setting” and may not discriminate among individuals based on disability.

The *Olmstead* decision⁵ directly addressed Title II of the ADA. While the underlying litigation revolved around the denial of community placement of two institutionalized persons, the Court expressed the view that a state would not violate Title II if it had a “comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings” and “a waiting list that moved at a reasonable pace.” But, the Court also added the proviso that a state would not be deemed to violate

³ See Jane Perkins (2005) *Using Section 1983 to Enforce Federal Laws* located at: healthlaw.org/library.cfm?fa=detail&id=76446&appView=folder

⁴ This decision is at laws.findlaw.com/11th/965144man.html.

⁵ This decision is at supct.law.cornell.edu/supct/html/98-536.ZS.html. For more about the decision, go to the Atlanta Legal Aid Society website: atlantalegalaid.org/impact.htm

Title II if achieving compliance forced it to make a “fundamental alteration” in its programs. Courts are grappling with the question of what constitutes a fundamental alteration.⁶

C. Lawsuits Involving Individuals with Developmental Disabilities

There has been a high volume of lawsuits that challenge wait listing individuals with developmental disabilities for Medicaid home and community services. States have experienced a sharp increase in the number of individuals seeking community services and have had difficulty keeping pace with this rapidly growing service demand. Also, many states have limited or reduced ICF/MR services in favor of expanding waiver services. But, the total supply of ICF/MR “beds” and HCBS waiver “slots” often has not kept up with service demand, resulting in individuals queuing up on waiting lists. In some states, waiting lists have grown very large. The combination of ICF/MR bed limits and HCBS waiver “slot” caps often means that neither type of service is readily available to individuals. Waiting lists are a major problem in nearly all states, thereby explaining the large number of lawsuits to secure access to services for persons with developmental disabilities.

As noted, in March 1998, the 11th U.S. Circuit Court of Appeals handed down a watershed ruling in the Florida *Doe v. Chiles* litigation that made it clear that federal Medicaid law does not allow a state to wait list individuals for ICF/MR services indefinitely. Florida had sought to limit the availability of both ICF/MR and waiver services. The Court ruled that ICF/MR services were no different than any other non-waiver Medicaid service and, hence, must be furnished with reasonable promptness to eligible applicants. Also, the court rejected the state’s attempt to justify limiting services due to budgetary considerations, noting that courts had repeatedly found that “inadequate state appropriations do not excuse noncompliance.” The *Doe* decision triggered lawsuits elsewhere.

The 11th Circuit decision spoke directly to ICF/MR but not HCBS. Most developmental disabilities waiting list lawsuits have been filed by people who seek HCBS but are wait-listed. In many of these lawsuits, plaintiffs attempt to establish the principle that a person’s eligibility for ICF/MR services also extends to “equivalent” or “ICF/MR level” services under the HCBS waiver program.

In the West Virginia *Benjamin H* litigation (see below), the district court confronted a situation where a state

had placed a moratorium on the development of new ICF/MR beds, nearly all available HCBS waiver slots were filled, and only persons in crisis were offered services. Other individuals had little or no prospect of receiving services in the near term. The court ruled that “Medicaid provides entitlements” and the state’s restrictions violated the reasonable promptness requirement. The court rejected the state’s defense that it lacked the funds to provide the services because, in the court’s view, allowing this defense would permit states to “easily renege on their part of the Medicaid bargain by simply failing to appropriate sufficient funds.” In short, the court found that the state could not impose limits on the number of people who could receive ICF/MR or HCB waiver services. The state was ordered to implement a plan to eliminate the waiting list and ensure that individuals had free choice in selecting between institutional and community services.

Developmental disabilities waiting list lawsuits have varied with respect to the plaintiffs’ situations and the services they seek. In particular:

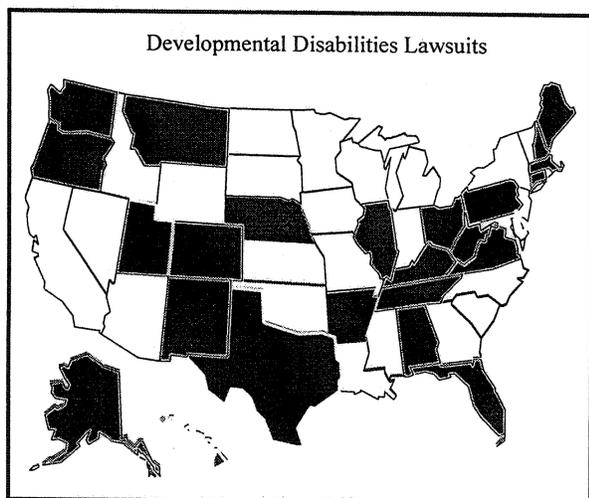
- In many cases, the lawsuit involves individuals who receive no services at all and are seeking HCBS waiver services (e.g., KY, TN, UT);
- Other lawsuits involve persons who already participate in a waiver program but have been wait listed for or denied some services offered in the program, most often residential services (e.g., CT, MA, WA);
- In a few lawsuits, the plaintiffs seek ICF/MR services in small community group homes as opposed to HCBS (e.g., CO); and,
- In other lawsuits, plaintiffs also include individuals who reside in ICFs/MR or large public institutions who are seeking HCBS instead as well as persons in the community waiting for services (e.g., NM, TX)

Status of Lawsuits

As of May 2007, lawsuits seeking community services for people with developmental disabilities had been filed in twenty-five states. Presently, waiting list lawsuits in three states (AL, NE, WA) remain active. Settlements have been reached in sixteen lawsuits (AK, CT, DE, FL, HI, IL, KY, ME, MA, MT, OH, OR, TN, TX, VA, WA (in one of two lawsuits), and WV). Six other lawsuits (AR, CO, NH, NM, PA, UT) have been dismissed.

Settlement agreements spell out the steps to resolve a lawsuit’s central issues in a fashion satisfactory to each side. When the parties arrive at an agreement, the court usually must conduct a “fairness hearing” before approving the settlement. In the settlements, states

⁶ See Sara Rosenbaum and Joel Teitelbaum. (2004). *Olmstead at Five: Assessing the Impact*. Kaiser Commission on Medicaid and the Uninsured (kff.org/medicaid/kcmu062104pkg.cfm).



typically have agreed to increase the number of individuals who receive Medicaid HCBS over a multi-year period (e.g., three to five years). Depending on the case, the agreement may address other issues. Settlements also specify the circumstances that might void the agreement (e.g., the state's not securing funds to implement the agreement), and how disputes will be resolved, including returning to court if need be.

1. Alabama: Susan J. et al. v. Riley et al.

This complaint (00-CV-918) was filed in July 2000 in U.S. District Court for the Middle District of Alabama on behalf of plaintiffs with mental retardation. The lawsuit alleges that Alabama fails to furnish ICF/MR or HCBS waiver services to all eligible individuals but instead limits the number of persons who receive Medicaid long-term services and thus violates: (a) the requirement that services must be furnished with reasonable promptness per §1902(a)(8) of the Act; (b) the requirement that services be furnished to all eligible individuals on a comparable basis, as provided in §1902(a)(10)(B) of the Act; and, (c) the 14th Amendment to the U.S. Constitution by depriving individuals of their right to apply for services.

The state moved to dismiss the complaint, arguing that: (a) waiver services differ from other Medicaid services and, thus, are not subject to the same requirements; (b) states have the authority to limit the number of individuals served through an HCBS waiver program; and, (c) the plaintiffs have no enforceable right under federal or state law to the services they seek and, thereby, an action cannot be brought in federal court.

This lawsuit was quiet until June 2004 when the court denied the state's motion to dismiss and ordered it to answer the plaintiffs' complaint. In August 2005, the state answered the complaint, arguing that the plaintiffs lacked standing to bring the lawsuit because

they have no right to private action. The state also asserted a sovereign immunity defense under the 11th Amendment to the U.S. Constitution.

Alabama Attorney General Troy King derailed a tentative settlement agreement because he opposed putting the state under federal court jurisdiction. Under the settlement, the state would have provided waiver services to an additional 600 persons per year for a three-year period, a number sufficient to eliminate the waiting list. In February 2006, King filed a motion for summary judgment for dismissal, contending that the Medicaid Act does not confer individually enforceable rights and, hence, the plaintiffs do not have standing to bring an action under §1983. In March 2006, the plaintiffs urged the court to reject this motion, arguing that several courts have affirmed that Medicaid beneficiaries have individually enforceable rights under the Medicaid Act.

In June 2006, the court rejected the state's motion to dismiss, finding no reason to reverse its 2004 decision rejecting a similar motion. The state then filed a motion requesting that the court certify an interlocutory appeal of its decision to the 11th Circuit. In September 2006, the court denied this motion, ruling that the state had not demonstrated that its ruling was at odds with other decisions concerning similar topics.

In January 2007, the court scheduled trial for February 2008. In April 2007, the plaintiffs filed a motion to certify the complaint as a class action and proposed to define the class as:

All Alabama residents with mental retardation who are eligible for Medicaid services under the ICF/MR program ... or a Home and Community Based Services waiver for the Mentally Retarded and Developmentally Disabled ... who request services under these programs but (1) are denied the opportunity to apply for such services; (2) whose application for services under these programs is denied; or, (3) are placed on a DMHMR waiting list for services under these programs.

The class is estimated to include at least 1,500 individuals.

2. Alaska: Carpenter et al. v. Alaska Department of Health and Social Services

This lawsuit was filed in January 2001 on behalf of 15 individuals in the U.S. District Court for Alaska. The lawsuit asserted that Alaska violated federal Medicaid law, the ADA, §504 of the Rehabilitation Act, and the 14th Amendment to the U.S. Constitution by indefinitely wait listing eligible children and adults with developmental disabilities for services. The complaint argued that Alaska violated the ADA

integration mandate as well as Medicaid's reasonable promptness requirement. The plaintiffs also alleged that Alaska violated federal requirements by improperly processing Medicaid applications and not giving individuals the opportunity to appeal adverse decisions about their services. The plaintiffs did not seek class certification. In March 2002, the Court accepted a stipulated agreement by the parties to dismiss the suit.

3. Arkansas: Tessa G. v. Arkansas Department of Human Services et al.

Filed in June 2003 in the U.S. District Court for Eastern Arkansas, this lawsuit (03cv493) challenged Arkansas' practice of wait listing individuals for its HCBS waiver for people with developmental disabilities rather than allowing them to submit an application. In Arkansas, the state's practice had been to place individuals seeking services on a "request list." The lawsuit was not brought as a class action.

The plaintiff argued that the state violated §1902(a)(8) of the Act by denying her the opportunity to apply for services and have her application acted upon promptly. The plaintiff also alleged violations of: (a) §1915(c)(2) of the Act for short circuiting her freedom to choose between ICF/MR and waiver services; (b) denying her access to the Medicaid Fair Hearing process under §1902(a)(3); and, (c) violating the procedural due process component of the 14th Amendment to the U.S. Constitution

At hearing, the court indicated that it was strongly inclined to order the state to provide an application to all individuals on the request list. The state conceded that federal law required that individuals be allowed to apply and have their applications acted upon promptly. It also agreed to offer waiver services to individuals on the request list up to its approved waiver participant cap. Reportedly, there were 1,000 available "slots" as a result of additional funding approved by the Arkansas legislature in its prior session. Based on the state's willingness to voluntarily comply, the Court dismissed the case in August 2003.

4. Colorado: Mandy R. et al. v. Owens et al.

Private attorneys filed this class action complaint (00-CV-01609) in the U.S. District Court for Colorado in August 2000. The complaint asserted that Colorado violated federal Medicaid law, the ADA, §504 of Rehabilitation Services Act of 1973, and the U.S. Constitution by failing to provide ICF/MR services with reasonable promptness to eligible persons. The plaintiffs specifically sought ICF/MR small (4-bed) group home services rather than waiver services. In Colorado, only a few individuals are served in ICFs/MR. Almost all individuals receive residential services

through the state's Comprehensive Services HCBS waiver. The Arc of Colorado supported this lawsuit.

In March 2002, Judge Richard P. Matsch ruled on the accumulated motions in the case. First, he denied the state's motion to dismiss the claim that Colorado is violating the §1902(a)(8) reasonable promptness requirement, relying on the opinion handed down by the 10th Circuit Court of Appeals in the New Mexico *Lewis* litigation (see below). Second, Matsch granted a motion by the Colorado Association of Community Centered Boards (CACCB) to intervene. CCBs are non-profit agencies designated in Colorado law to provide or arrange for community services for individuals with developmental disabilities. The CACCB intervened because the litigation could have a substantial impact on CCBs. In its motion to intervene, the CACCB introduced a new claim that Colorado violated §1902(a)(30)(A) of the Social Security Act because the state's payments for community services were inadequate and, thereby, caused quality to erode. Under federal judicial rules, an intervener may raise new claims germane to the litigation. The CACCB also claimed that wait listing individuals violated federal law. But, it argued that this violation should be remedied by expanding waiver services rather than ordering the state to furnish ICF/MR services.

Third, Judge Matsch denied the plaintiffs' motion for class action certification. Matsch ruled that the plaintiffs (who seek ICF/MR group home services) were not representative of the class as proposed (which would have included individuals who may want different services). Matsch also observed that, if the plaintiffs prevailed, systemic change would follow, thereby making class certification unnecessary. Last, he denied the plaintiffs' motion for a preliminary injunction on two grounds. First, it was unclear that the plaintiffs would prevail on the merits. Second, he noted that granting the immediate relief sought by the plaintiffs would cause major changes in the Colorado Medicaid program and have a major budgetary impact. Matsch decided that he did not have a basis to issue a preliminary injunction in light of its potential impact.

In July 2002, the state moved to dismiss the lawsuit. The state argued that it had no affirmative responsibility to develop ICFs/MR but instead that its role was akin to an "insurer," limited solely to paying for services once delivered. In August 2002, the plaintiffs filed a motion for partial summary judgment. In their brief, the plaintiffs attacked the state's reasoning, arguing that the state's responsibilities under Medicaid law go beyond mere claims payment to include assuring that necessary services are furnished to eligible persons. The plaintiffs asked the court to summarily find that the state was in violation of §1902(a)(8) and

§1902(a)(10) of the Act for failing to furnish ICF/MR services with reasonable promptness and providing them to some but not all eligible persons. The plaintiffs asked that the court to take up their ADA and §504 claims after deciding the ICF/MR entitlement question. Plaintiffs urged the court to apply the ADA and §504 to remedy the alleged Medicaid Act violations by ordering the state to develop small ICF/MR group homes that meet the ADA integration standard.

In September 2003, Judge Matsch ruled on the outstanding summary judgment motions. He denied the plaintiffs' motions for summary judgment. But, he also denied the state's motion to dismiss the plaintiffs claims that Colorado violated §1902(a)(8) and §1902(a)(10) of the Social Security Act. Matsch also denied the state's motion to dismiss the CACCB claim that Colorado's payments for community services violate §1902(a)(30).

Matsch dismissed the plaintiffs' ADA Title II and §504 claims, ruling that these claims were not "viable." He rejected the plaintiffs' argument that Colorado's policies run afoul of the *Olmstead* decision, pointing out that "*Olmstead* does not stand for the proposition that a state must create, expand, or maintain programs for the purpose of preventing disabled individuals from becoming institutionalized." He also rejected the plaintiffs' plea that to consider the plaintiffs' ADA and §504 claims in fashioning remedies for the Medicaid violations, ruling that each claim must stand on its own merits.

Trial took place in June 2004. Finally, in February 2005, Judge Matsch dismissed the plaintiffs' and CACCB intervenor claims.⁷ In the end, Matsch decided that he could not order the relief sought because it would amount to mandating that the state provide or actively develop ICF/MR services. Such an order, Matsch reasoned, would have the effect of his ordering an increase in state taxes or appropriations and/or cause the state to withdraw other services from its Medicaid program, actions that Matsch believed would be tantamount to "an exercise of federal judicial authority [that] would encroach upon the fundamental powers of the State government" and undermine the "no more fundamental principle of democratic government than that which reserves to the people the power to tax and spend."⁸ He decided that "the court

⁷ The decision is located at:

thearcofco.org/documents/MandyRvOwensMatschDecision.pdf

⁸ Colorado has a constitutional tax and expenditure limit (known as the TABOR amendment) that dictates that government expenditures and revenues not grow faster than inflation and population. Judge Matsch reasoned that ordering the relief that plaintiffs sought would require overriding the limit. The plaintiffs argued that the limit could be exceeded

cannot order the State to provide any particular level of ICF/MR services or to continue them in its State Plan."

In March 2005, the Mandy R plaintiffs and CACCB appealed the dismissal to the 10th Circuit (05-1150 and 05-1148, respectively). The Circuit consolidated the appeals for procedural purposes. In September 2005, the Mandy R plaintiffs and the CACCB filed their appellant briefs. Each sharply criticized the district court's reasoning in dismissing the lawsuit due to its potential budget impact, arguing that it is well established that a state must provide sufficient funding for its Medicaid program. The Mandy R plaintiffs reasserted that Colorado violated Medicaid law by not furnishing ICF/MR services with reasonable promptness and not making such services available on a comparable basis to all Medicaid beneficiaries. They further argued that the state's position that it merely functions an "insurer" and thereby has no affirmative responsibility to furnish Medicaid services to eligible individuals is contrary to fundamental Medicaid statutory requirements.

The CACCB brief advanced many of the same arguments. The brief, however, argued that Colorado could meet the needs of the plaintiffs by substituting HCBS waiver for ICF/MR services, a position with which the Mandy R plaintiffs disagreed. The CACCB asserted that the district court did not properly consider its claims regarding the inadequacy of the state's payments for waiver services. The CACCB also argued that the 9th Circuit ruling in the California *Sanchez v. Johnson* lawsuit (see below) was at odds with other U.S. Supreme Court decisions and should not serve as the basis for the 10th Circuit rulings with respect to the payment issues raised by the CACCB.

In November 2005, the state replied, reasserting that it had no affirmative responsibility to ensure that beneficiaries could obtain Medicaid services, only to pay for services once delivered. The state also contended that its payments for services were adequate because providers met applicable requirements.

In September 2006, the Circuit Court affirmed the District Court decision and dismissed the appeal.⁹ With respect to the comparability and reasonable promptness claims, the court found that the plaintiffs had standing to bring suit under §1983. In its ruling, the court concentrated on the question of what constitutes "medical assistance" under the Medicaid Act and whether the Act compels a state to ensure that services

when necessary to comply with a federal court order. In November 2005, Colorado voters approved a ballot measure to suspend the TABOR limit for a period of five-years.

⁹ Ruling is located at: ck10.uscourts.gov/opinions/05/05-1148.pdf

are furnished to beneficiaries rather than merely functioning as a payer of services. The court decided that "the State must pay for medical services, but it need not provide them." The court ruled that Colorado was not impeding the creation of new ICFs/MR. With respect to the CACCB claim that the state's payments for HCBS services violated §1902(a)(30) of the Act, the court ruled (relying on rulings in other circuits) that this provision does not create individually enforceable rights and dismissed the claim.

In January 2007, the plaintiffs petitioned the U.S. Supreme Court to take up the case. The court denied this petition on March 26, 2007.

5. Connecticut: Arc/Connecticut et al. v. O'Meara and Wilson-Coker

This complaint (01-cv-1871) was filed in October 2001 in U.S. District Court for Connecticut by Arc/Connecticut against the Commissioners of the Departments of Mental Retardation (DMR) and Social Services (the state's Medicaid agency) on behalf of persons with mental retardation wait-listed for Medicaid waiver services. The plaintiffs included persons who received some waiver services but were wait listed principally for residential services and persons who did not receive any waiver services at all.

The lawsuit challenged several state policies. A central issue was plaintiffs' allegation that Connecticut restricted waiver services to available funding. The plaintiffs argued that this practice violated federal policy which requires that waiver participants receive the full range of services offered in a state's program that are necessary to meet their needs. The state was alleged to have wait listed individuals who receive day and other supports for waiver residential services. In support, the plaintiffs pointed to January 2001 policy guidance set forth in the Centers for Medicare & Medicaid Services (CMS) *Olmstead* Letter #4. Among its provisions, the CMS letter spelled out the requirement that waiver participants must be furnished any covered service that they require within a reasonable period. The plaintiffs also alleged that the state masked the operation of the waiver in a fashion that led to individuals and families not being allowed to apply for the waiver and thus leaving them unaware of its benefits. Finally, the plaintiffs argued that, unless Connecticut was directed to change how it operates its program, individuals faced the prospect of waiting years for services.

In January 2003, the court granted class certification, thereby expanding the lawsuit's scope to the then 1,700 individuals on the state's waiting list. The class included all persons eligible for DMR services who have applied for and are eligible for the waiver

program or would be eligible if they had the opportunity to apply. In February 2003, the plaintiffs filed a second amended complaint.¹⁰ The second amended complaint alleged that the state violated: (a) §1902(a)(10)(B) of the Act by not making Medicaid services available on a comparable basis to all eligible persons; (b) §1902(a)(8) by not furnishing services with reasonable promptness and denying persons the opportunity to apply; (c) §1915(c)(2)(C) by not giving individuals a choice between institutional and waiver services; (d) §1915(c)(1) and §1915(c)(4) for limiting services under the waiver to those available and funded rather than providing the services needed by each person; (e) the ADA by not permitting ICF/MR residents to apply for the waiver until they already had been placed in the community and operating its Medicaid program in a way that does not afford equal access to covered benefits; (f) §1902(a)(3) for not giving individuals the opportunity to appeal decisions concerning services; and, (g) the plaintiffs' due process protections under the U.S. Constitution.

In August 2004, the state moved to dismiss. It contended that the issues in this litigation were no different than those settled in a similar case (*Birks v. Lensink*) that established the state's current waiting list priority system. The state also argued that the Medicaid Act does not confer individually enforceable rights, especially with respect to waiver services. The state also challenged the applicability of the ADA, contending that it cannot serve as the basis for requiring a state to expand services and that the *Olmstead* integration mandate applies only to institutionalized persons.

In late 2004, the parties arrived at a settlement agreement. In February 2005, the Connecticut legislature agreed to underwrite the costs of the settlement. In March 2005, the parties submitted the agreement to the court.¹¹ The court approved the agreement and dismissed the lawsuit in May 2005. The agreement provides for the following:

- The class includes persons who have been found eligible for DMR services and (a) have applied for and been found eligible for waiver services or (b) would be eligible for services had they had a reasonable opportunity to apply;
- Over the five-year period commencing in FY 2005 year and ending in FY 2009, the state committed to expand its HCBS waiver to accommodate an additional 150 persons each year at an average annual cost of \$50,000 per person and furnish family support services to another 100 persons per

¹⁰ Located at: arct.com/WaitingListComplaint0203.htm.

¹¹ The agreement, is at: dmr.state.ct.us/WLSettlement.htm

year at an average cost of \$5,000 per person. Over the five-year settlement period, Connecticut committed to spend an additional \$41 million in state funds to underwrite the settlement. Persons with urgent or high priority immediate needs will have priority for waiver services;

- The state also agreed to create a new Individual and Family Support HCBS waiver that offers flexible supports, incorporate self-direction, and complement the “comprehensive services” offered under the state’s existing waiver. The state also agreed to revamp its current waiver, including providing for independent service brokers; and,
- The state agreed to revise its procedures to ensure that individuals have the opportunity to apply for waiver services, are provided information about such services, and receive a prompt determination of their eligibility for such services.

The settlement agreement is being implemented. The number of persons receiving services has increased as per the agreement. The state redesigned its comprehensive services waiver and secured federal approval to launch the individual and family support waiver.

6. Delaware: The Arc of Delaware et al. v. Meconi et al.

In April 2002, nine individuals – joined by The ARC of Delaware, Homes for Life Foundation, and Delaware People First – filed a class action complaint (02-CV-255) against the Delaware Department of Health and Social Services and its Division of Developmental Disability Services (DDDS) in the U.S. District Court for Delaware. The lawsuit charged that Delaware failed to serve more than 1,180 individuals who were eligible for but denied Medicaid HCBS waiver and/or community ICF/MR services. The Public Interest Law Center of Philadelphia and Community Legal Aid Society Disability Law Program (Delaware’s P&A agency) represented the plaintiffs.

The plaintiffs included individuals who live with aging caregivers along with residents of Stockley Center (Delaware’s public institution) assessed as appropriate to return to the community. The complaint alleged that these individuals have waited years for services but had little prospect of receiving them any time soon. The proposed class included: (a) all individuals on the DDDS waiting list for community residential services; (b) all individuals receiving DDDS services eligible for but not receiving HCBS waiver or ICF/MR services; and, (c) all institutionalized persons who qualified for services in the community.

The plaintiffs argued that Delaware operates its service system in violation of Medicaid law, the ADA and the U.S. Constitution, thereby leading to the “denial of

necessary care and services, inappropriate placement in state institutions, restraint [of] ... liberty without due process, unnecessary and needless deterioration and regression in health status, the loss of opportunities to maximize self-determination and independence, and the loss of opportunities to live in integrated settings and to receive programs and services development in accordance with professional standards.”

The plaintiffs claimed that Delaware violated: (a) §1902(a)(8) of the Act by failing to provide Medicaid services with reasonable promptness and denying individuals the opportunity to apply for services; (b) Title II of the ADA and §504 of the Rehabilitation Act by not furnishing services in the most integrated setting. The complaint also alleged that Delaware did not have a “comprehensive effectively working plan” for placing qualified persons in less restrictive settings and the waiting list was not moving at a reasonable pace, as provided by the *Olmstead* decision; (c) §1902(a)(10) of the Act by not providing Medicaid services in adequate amount, duration and scope; (d) the Due Process Clause of the 14th Amendment to the Constitution and §1983; and, (e) §1915(c)(2)(C) of the Act by not providing a choice between ICF/MR or waiver services.

In September 2003, the parties announced that they had arrived at an agreement to dismiss the lawsuit. In April 2004, the plaintiffs submitted a notice of dismissal to the court, based on a Memorandum of Understanding (MOU) agreed to by the parties. The MOU provided that the state would fund 79 new community residential placements in FY 2005, including community placements for 24 Stockley residents. It also provided that the state would add a new waiver to provide supports for persons who live with their families. The state also agreed to collaborate with the plaintiffs to improve waiting list management and needs assessment and strengthen community infrastructure. The MOU provided that the state would place additional Stockley residents in the community and seek increased funds to expand home and community services. In August 2004, the court approved the agreement and dismissed the case.

7. Florida: John/Jane Doe v. Bush et al./Wolf Prado-Steiman et al. v. Bush et al.

In 1992, a class action complaint was filed (as *Doe v. Chiles et al.*) on behalf of individuals who had been wait-listed for ICF/MR services. The *Doe* complaint asserted that Florida violated federal Medicaid law by not furnishing ICF/MR services with reasonable promptness to eligible Medicaid recipients with developmental disabilities. In March 1998, the U.S. 11th Circuit Court of Appeals upheld the District Court’s 1996

ruling that wait listing individuals for ICF/MR services violated federal Medicaid law (see above). A second complaint – *Prado-Steiman* (98cv06496) – was filed by The Advocacy Center (Florida’s P&A agency). This complaint directly challenged Florida’s policies in operating its HCBS waiver for people with developmental disabilities (especially by not furnishing needed services) and was amended to contest the state’s wait listing individuals. In August 2001, the District Court approved a settlement agreement in the *Prado* litigation that provided that all individuals waiting for services in July 1999 would be served by 2001. The state also committed to make substantial changes in how it operated its waiver. The complaint was dismissed in 2004.

Led by Governor Jeb Bush, Florida undertook a major expansion of its HCBS waiver program for people with developmental disabilities. Funding for developmental disabilities services tripled and now exceeds \$1.2 billion. Between 1998 and 2001, the number of persons participating in Florida’s waiver for people with developmental disabilities doubled from 12,000 to 24,000. Among its other provisions, the *Prado* settlement agreement included an “operational definition” of how the state will comply with the reasonable promptness requirement.

8. Hawai’i: Makin et al. v. State of Hawai’i/The Disability Rights Center et al. v. State of Hawai’i et al.

Makin. In December 1998, the Hawaii Disability Rights Center – state’s P&A agency – filed this class action complaint (98cv997) on behalf of 700 wait-listed individuals in the U.S. District Court for Hawai’i. The complaint alleged that the state’s practice of wait listing individuals for HCBS violated federal Medicaid law and the ADA. The state challenged the applicability of the ADA, arguing that the *Olmstead* decision dealt with only institutionalized persons. The district court rejected this argument, reasoning that the lack of community services would leave institutionalization as the only option available to individuals.

In April 2000, the state and plaintiffs forged a settlement agreement¹² wherein the state agreed to expand its HCBS waiver to serve approximately 700 more individuals over the three-year period ending June 2003. The agreement also provided that the state would not change its eligibility policies but would make other changes, including employing person-centered planning methods to identify the supports that individuals should receive.

¹² The lawsuit and agreement are at hawaiidisabilityrights.org/General_NewsDetail.aspx?nid=1009.

Disability Rights Center. In September 2003, the Disability Rights Center evaluated the implementation of the *Makin* settlement agreement. Based on its evaluation, the Center filed a new class action complaint (03-00524) seeking declaratory and injunctive relief based on its view that the state had not complied with the settlement agreement. In essence, the Center alleged that the state policies and practices had caused 300 *Makin* class members to remain on the waiting list. The Center contended that the state furnished services to individuals who sought services after the settlement rather than to the class members and, in FY 2002, reverted funds that could have been used to serve the class members. Moreover, the Center argued that some class members were not receiving the full range of services that they required. The Center claimed that the state’s policies and practices violated: (a) the ADA; (b) §504 of the Rehabilitation Act; (c) the Constitution’s procedural due process provisions; (d) §1902(a)(8) of the Act; (e) §1915(c)(2)(A) by furnishing inadequate waiver services; and, (f) provisions of Hawai’i state law.

In August 2005, the parties entered into a new settlement agreement.¹³ The state agreed to revise its policies and procedures for accepting and processing waiver applications and adhere to specified timelines for processing applications and initiating waiver services, provided that funding is available. In particular, the state will evaluate the eligibility of individuals for waiver services following the receipt of an application rather than placing such persons on a deferred action waiting list.

9. Illinois: Bruggeman et al. v. Blagojevich et al.

This lawsuit (00-cv-5392) was filed in September 2000 in the U.S. District Court for Northern Illinois on behalf of five named plaintiffs with developmental disabilities eligible for but not receiving Medicaid long-term services. The complaint alleged that Illinois did not furnish Medicaid services with reasonable promptness nor afford individuals freedom of choice to select between ICF/MR and HCBS. The suit alleged violations of other provisions of the Social Security Act, the ADA, §504 of the Rehabilitation Act and the 14th Amendment to the U.S. Constitution. The plaintiffs asked the court to “issue preliminary and permanent injunctive relief requiring the [state] ... to offer the Plaintiffs the full range of ICF/MR ... or HCB waiver services and other services for which they are eligible within 90 days or some other specifically defined, reasonably prompt period.”

¹³ At: [hawaiidisabilityrights.org/forms/S.M.SETTLEMENT8-12-05\(final-redact\).DOC](http://hawaiidisabilityrights.org/forms/S.M.SETTLEMENT8-12-05(final-redact).DOC)

In response, the state moved to dismiss, claiming sovereign immunity under the 11th Amendment and challenging the plaintiffs' other claims. In May 2001, siding with the state, the court dismissed the plaintiffs' ADA claim because the complaint was filed against public officials whereas Title II of the ADA speaks to the policies of a "public entity." But, the court rejected the state's motion to dismiss the other claims.

In February 2002, the court dismissed the lawsuit, deciding that the plaintiffs' main claim was their lack of access to residential services near their families. The court was persuaded by the state's arguments that (a) federal law does not require that it arrange for services on the basis of proximity to family and (b) the services the plaintiffs sought might be available elsewhere in Illinois. The court also ruled that the plaintiffs lacking standing to bring the lawsuit.

In March 2002, the plaintiffs appealed the dismissal to the 7th Circuit Court of Appeals. The plaintiffs asked the Circuit to review the district court's rulings on the Medicaid, ADA, and Rehabilitation Act claims and argued that facts unearthed during trial showed that the state was not in compliance with federal law. In June 2002, the U.S. Department of Justice (USDOJ) Civil Rights Division submitted an *amicus* brief. The brief addressed only the district court's dismissal of the ADA claim. The brief noted that the dismissal was based on a previous 7th Circuit ruling that USDOJ contended was in error. USDOJ argued that there was ample support for the proposition that individuals may sue public officials not just public entities in federal court to enjoin alleged violations of the ADA.

In July 2002, another *amicus* brief was filed by the American Civil Liberties Union (ACLU) of Illinois, Equip for Equity (the Illinois P&A agency), and a coalition of Centers for Independent Living. This brief argued for reinstating the ADA claim because the district court paid insufficient attention to the interplay of Illinois' policies and their impact on access to services in the most integrated setting. The brief urged the Circuit to "leave for another day the many larger legal questions ... regarding whether the Illinois system for providing services ... complies with federal law."

In October 2002, the state replied, arguing that the plaintiffs lacked standing to bring suit and also that there was no enforceable federal requirement that individuals receive services near their families. Next, the defendants asserted that their only responsibility under federal Medicaid law was to "provide appropriate rates of payment" but not to ensure that individuals receive necessary services. Finally, the state asserted that it had not waived its 11th

Amendment rights and urged dismissal of the lawsuit on sovereign immunity grounds.

In April 2003, the Circuit held that the district court erred in ruling that the plaintiffs lacked standing to pursue their Medicaid claims but upheld the lower court decision rejecting the claims, finding that federal law does not dictate that services be available near the individual's family home. The Circuit also conceded that its prior ruling that suits brought under the ADA must be filed against public entities rather than state officials was in error, based on decisions elsewhere.

But, the Circuit decided that the district court erred in ruling that the plaintiffs lacked standing to sue under the Rehabilitation Act. The Circuit set aside the dismissal of the plaintiffs' Rehabilitation Act and ADA claims. The Circuit remanded the lawsuit and "commended" to the district court the *Olmstead* decision, especially pointing to that part of the decision that provided "if... the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated," the state would not be violating Title II.¹⁴

In July 2004, the parties announced that they had arrived at a stipulated settlement of the lawsuit. The details of this settlement are not available but reportedly it is limited to providing services to the named plaintiffs. The court then dismissed the case.¹⁵

10. Kentucky: Michelle P et al. v. Holsinger et al.

In February 2002, the Kentucky Division of Protection and Advocacy filed a lawsuit (02-CV-00023) in the U.S. District Court for Eastern Kentucky on behalf of four people with mental retardation and their family caregivers against the Cabinet for Health Services along with the Departments for Medicaid Services and Mental Health and Mental Retardation. The lawsuit charged that Kentucky improperly wait listed individuals for Medicaid services. The plaintiffs also sought class certification on behalf of an estimated 1,800 wait-listed persons.

The plaintiffs argued that, despite their eligibility for ICF/MR level services, they had been wait-listed and had indefinite prospects for ever receiving services. They also complained that even individuals in emergency status were unable to receive services

¹⁴ The opinion is on the 7th Circuit's web site at: ca7.uscourts.gov/fdocs/docs.fwx?dname=opinion. Enter case number 02-1730.

¹⁵ A new lawsuit was subsequently filed in Illinois concerning access to residential services. See in Part IV of this report.

promptly despite their priority status. The complaint claimed that Kentucky violated: (a) §1902(a)(10)(A) of the Act for failing to provide ICF/MR level services to all Medicaid beneficiaries who are eligible for them; (b) §1902(a)(8) for failing to furnish services with reasonable promptness; (c) §1902(a)(10)(B) for making ICF/MR level services available to some Medicaid beneficiaries but not all; (d) Title II of the ADA and §504 of the Rehabilitation Act by failing to serve individuals in the most integrated setting; and, (e) §1915(c)(2)(C) by not giving eligible individuals a practical choice between ICF/MR or other available alternatives through the HCBS waiver program.

In March 2002, the District Court granted class certification and ruled in the plaintiffs' favor on the other outstanding motions over the state's objections. The class is "all present and future Kentuckians with mental retardation and/or related conditions who live with caretakers who are eligible for, and have requested, but are not receiving Medical Assistance community residential and/or support services." In June 2002, the 6th Circuit Court of Appeals denied the state's petition to overturn the class certification. Trial was scheduled to begin in January 2005.

In December 2004, the state filed a last-minute motion to dismiss, thus delaying the start of trial. The court turned down this motion in February 2005. Kentucky P&A reported that the court "upheld our position on every provision of Medicaid law that we alleged in our case. In addition, the Court ruled that our claims under the Americans with Disabilities Act (ADA) and Section 504 were still viable. It also ruled that the state's attempt to limit the *Olmstead* ruling to people in institutions was misplaced."

In particular, the court affirmed that federal Medicaid law *unambiguously* confers individually enforceable rights under the provisions of §1902(a)(10)(A), §1902(a)(8) and §1915(c)(2)(C) and that §1905(a)(15) – in combination with other provisions – confers an individually enforceable right to ICF/MR services. The court also rejected the state's motion to throw out the ADA and §504 claims.

In January 2006, the parties announced that they had arrived at a settlement. The agreement provides for the infusion of an additional \$45 million in state funds during the 2006-2008 biennium to expand community services and continued increases in funding through 2010. Total funding for community services would increase from \$303 million in 2006 to \$485 million in 2010. In March 2006, the court approved the

settlement, rebuffing last minute efforts by institutional advocates to set aside the agreement.¹⁶

11. Maine: Rancourt et al. v. Maine Department of Human Services et al.

In August 2001, a complaint (01-CV-00159) was filed in the U.S. District Court for Maine on behalf of three adults with developmental disabilities waiting for services. The lawsuit was filed against the Maine Departments of Human Services (the Medicaid agency) and Behavioral and Developmental Services (which administers Maine's HCBS waiver). The lawsuit charged that the state did not furnish services to people with developmental disabilities in a "reasonably prompt" manner. Class-action certification was sought on behalf of 1,000 adults with developmental disabilities who were not receiving timely services.

In November 2001, the court denied the state's motion to dismiss the lawsuit on 11th Amendment sovereign immunity grounds. The court pointed to previous 1st Circuit decisions affirming federal court jurisdiction. In May 2002, the court certified the class over the state's objections. The state petitioned the 1st Circuit to review the class action certification. In July 2002, the 1st Circuit rejected the petition.

In May 2003 the parties filed a joint motion asking the court to approve a settlement. In July 2003, the court approved the agreement.¹⁷ The agreement took effect in January 2004. The agreement encompasses "all developmentally disabled individuals who: (1) are current or future recipients of Medicaid in the State of Maine; (2) are no longer entitled to receive benefits and services through the Maine public school system; and, (3) are eligible to receive intermediate care facilities and/or other services for the mentally retarded, or care under the Home and Community-Based Waiver Services for Persons with Mental Retardation."

The agreement provides that the state will furnish Medicaid state plan day habilitation and case management services within 90-days to all individuals who had sought them in the past. Individuals who newly qualify for services will receive case management and day habilitation services within no more than 225 days. When individuals also qualify for the waiver program and require "residential training services," the agreement defines "reasonable promptness" as starting services in no more than 18-months. This timeframe reflects the state's experience about the amount of time to develop a residential setting that matches the needs and preferences of an individual, although state

¹⁶ A description of the settlement is located at: kypa.net/drupal/node/431/#Federal

¹⁷ A description of the agreement and its full text are located at: drcme.org/publications.asp?pubid=33

officials note that often less time is required. However, the agreement did not require the state to expand the waiver program over and above the already approved number of slots.

12. Massachusetts: Boulet et al. v. Cellucci et al.

This class action complaint (99-10617; (originally *Anderson v. Cellucci*)) was filed in March 1999 in the U.S. District Court for the District of Massachusetts by private attorneys with support by The Arc of Massachusetts on behalf of the plaintiffs and their families who were dissatisfied with the state's pace in reducing its waiting list. The complaint asserted that Massachusetts violated federal Medicaid law and the ADA by failing to provide residential services with reasonable promptness to otherwise eligible individuals and by wait-listing them indefinitely. While the state had reduced the waiting list, the plaintiffs sought to accelerate the expansion of residential services.

In July 2000, the District Court issued a summary judgment in the plaintiffs' favor, ruling that the state was required to furnish Medicaid residential services with reasonable promptness. But, the Court certified a narrower class than proposed by the plaintiffs who had asked that it include all individuals wait listed for Medicaid residential services along with persons who would be eligible in the future. The Court narrowed the class to individuals already participating in the HCBS waiver program who were wait listed for residential services or wait listed persons not served in the waiver program who could be accommodated under its participant cap. The Court directed the state to furnish residential services to class members within 90-days or, if not feasible, to propose a plan to comply with the reasonable promptness requirement.

In January 2001, the court approved a settlement agreement arrived at by the parties. The agreement modified the class to include all individuals wait listed as of July 2000, regardless of whether the person was receiving or would be eligible to receive HCB waiver services. Under the agreement, the state committed to provide residential services to 300 more individuals in FY 2001. Over the next five years (FY 2002 – 2006), the state agreed to seek funding to provide residential services to an additional 1,975 individuals at a pace of 375 – 400 persons per year. Individuals who did not receive residential services right away would receive "interim services" (in-home, family support and other services) until residential services became available. The parties also agreed to revised procedures for preparing residential and interim service plans. Over the five-year period 2002 – 2006, the state committed \$355.8 million in total funding to expand services.

Since the settlement, each year additional funds have been appropriated in accordance with the agreement.

13. Montana: Travis D. et al. v. Eastmont Human Services Center

Filed in 1996 by the Montana Advocacy Program (the state's P&A agency), this complaint alleged that Montana violated federal Medicaid law, the Americans with Disabilities Act integration mandate and the U.S. Constitution by failing to provide community services to residents of the state's two public MR/DD institutions and individuals in the community at risk of institutionalization.

Court action stalled for a variety of reasons, including off and on settlement negotiations between the parties, the presiding judge's ill-health, and a one-year stay pending the U.S. Supreme Court's *Olmstead* decision. In August 2001, the court declared all the pending motions moot, deciding that starting over with a fresh set of motions would expedite the case. The parties submitted new briefs in May 2002. The lawsuit was narrowed to a class of an estimated 200 individuals served at Montana's two public institutions (Eastmont Human Services Center and Montana Developmental Center (MDC)) since August 1996. The remaining claims concerned community integration under the ADA, the Rehabilitation Act, and the U.S. Constitution. Meantime, in its 2003 session, the Montana legislature approved the closure of Eastmont and the Center closed in December 2003.

The parties arrived at a mediated settlement agreement in February 2004.¹⁸ The agreement provides that the state will move 45 MDC residents into community living arrangements over the next four years. MDC serves approximately 90 individuals. The state also agreed to: (a) the repeal of a Montana law that allows court commitment of individuals who have "near total care" requirements. This law had been a leading source of new admissions to state facilities; (b) commit \$200,000 annually for crisis prevention and intervention services to help maintain people in the community and reduce crisis admissions to MDC; (c) make improvements in MDC services; (d) improve its community quality assurance program; and, (e) take additional steps to strengthen community services for individuals with developmental disabilities.

14. Nebraska: Bill M. et al. v. Department of Health and Human Services et al.

In May 2003, six individuals with developmental disabilities filed suit (03-cv-03189) against the Nebraska Department of Health and Human Services in the U.S.

¹⁸ The settlement agreement and related materials are located on Montana Advocacy Program website at: www.mtadv.org/.

District Court for Nebraska. The lawsuit charges that Nebraska has impermissibly wait listed individuals for HCBS waiver services and, furthermore, that the state's policies result in inadequate services being furnished to numerous waiver participants. The plaintiffs are represented by private attorneys and Nebraska Advocacy Services, the state's P&A. Class action certification also was sought for:

All present and future individuals with developmental disabilities in Nebraska who are eligible for Medical Assistance Home and Community-Based Services but either are not receiving funding for such services, or are not receiving sufficient funding for such services to reasonably achieve the purpose of the service, assure the class member's health and safety, or ensure progress toward independence, interdependence, productivity and community integration.

The lawsuit alleged that about 800 individuals were waiting for services. In addition to seeking services for these individuals, plaintiffs challenge the state's methods of authorizing services. The state uses an "Objective Assessment Process" (OAP) to authorize the number of hours of services a person may receive. The plaintiffs contend that the OAP is flawed because it leads to a large but unknown number of individuals not receiving enough service hours to meet their essential health and safety needs and/or make progress in achieving their individual goals.

The plaintiffs claim that the state violates: (a) the ADA and §504 of the Rehabilitation Act because the waiting list does not move at a reasonable pace and Nebraska does not have an effective working plan as called for in the *Olmstead* decision; (b) §1902(a)(8) of the Act by denying individuals the opportunity to apply for the waiver program and not providing services with reasonable promptness; (c) §1902(a)(10)(B) because the OAP impermissibly restricts the amount, duration and scope of services; (d) §1915(c)(2)(A) because the OAP does not assure the health and welfare of waiver participants [N.B., The plaintiffs also allege that the state violates the requirements spelled out in CMS *Olmstead* Letter #4]; (e) Nebraska state law and regulations that require assisting individuals to achieve critical life outcomes; and, (f) the U.S. and Nebraska Constitutions and federal Medicaid law by not providing adequate due process protections and the right to a Medicaid Fair Hearing.

By way of relief, the plaintiffs asked the court to direct the state to prepare and implement a comprehensive effective working plan that moves the waiting list at a reasonable pace, immediately provide waiver services to eligible individuals up to the number of waiver slots currently authorized, expand the waiver to serve more

persons over the next three years, and revamp its service authorization mechanism.

In July 2003, the state moved to dismiss the ADA and §504 claims. The state argued that it enjoys sovereign immunity protection against lawsuits brought under the ADA and has not discriminated against individuals under either the ADA or §504. Furthermore, it asserted that the ADA, §504 and the *Olmstead* decision do not require a state to increase its spending for community services. Since none of the plaintiffs are institutionalized, the state argued that they cannot make *Olmstead*-based claims.

In August 2003, the plaintiffs replied to the state's motion to dismiss. They argued that, by accepting federal Medicaid funds, the state waived sovereign immunity. They also disputed the state's interpretation of the *Olmstead* decision on several grounds, including the assertion that it applies only to institutionalized persons. The plaintiffs also filed an amended complaint.¹⁹

In October 2003, the state filed another motion to dismiss. The state reiterated its arguments concerning the ADA and §504 claims and again asserted sovereign immunity. It also contended that plaintiffs' grievances were more properly addressed through state administrative appeals processes, which are subject to state judicial review. The state disputed the validity of plaintiffs' claims under federal Medicaid law. Finally, it argued that claims based on Nebraska state law are outside the jurisdiction of federal courts in litigation brought under §1983. In November 2003, the plaintiffs replied to the state's motion to dismiss, disputing each of the state's arguments.

In July 2004, the plaintiffs filed a motion for class certification. The plaintiffs estimated that the class now included 1,400 individuals who had waited for services for more than 90 days and 2,200 persons who are receiving inadequate community services or at risk of having their services reduced.

In August 2004, the court denied the state's motion to dismiss the ADA claim on sovereign immunity grounds. In September 2004, the state appealed this decision to the 8th Circuit Court of Appeals (04-3263).

In May 2005, the Circuit Court agreed with the state and ordered the district court to dismiss the ADA claim, finding that Congress did not abrogate the state's sovereign immunity under Title II of the

¹⁹ The complaint and other documents related to the litigation are located at:

nebraskaadvocacyservices.org/resources/legal_resources.html

ADA.²⁰ The plaintiffs sought *en banc* review of this decision but the request was denied in August 2005.

In September 2005, the district court accepted a magistrate judge's recommendation to deny class certification. The magistrate judge found that the proposed class was too diverse and amorphous to meet federal court requirements for certification. In October 2005, the parties requested a stay in proceedings to explore a potential settlement. The court agreed to this request and settlement discussions are ongoing.

In December 2005, the U.S. Department of Justice filed a petition for a writ of certiorari (05-777) asking the U.S. Supreme Court to review the 8th Circuit decision concerning the ADA claim.²¹ USDOJ asked for this review because the effect of the 8th Circuit decision would have been to declare parts of the ADA unconstitutional. USDOJ contended that the decision ran contrary to other Supreme Court decisions. In April 2006, the Supreme Court vacated the 8th Circuit decision and remanded the case to the Circuit with an instruction to reconsider its decision in light of the court's January 2006 decision in the *United States v. Georgia* litigation. The parties then petitioned the Circuit to dismiss the appeal, which it did in July 2006.

In June 2006, the plaintiffs filed an amended complaint to cure issues with respect to class certification and further clarify their complaint. In the amended complaint, the plaintiffs propose to define the class as:

All residents of Nebraska with developmental disabilities who have requested home or community-based services and who either have had the extent of their services determined by the State's use of the "Objective Assessment Process" ("OAP") or have been placed on a wait list (the "Register of Persons with Unmet Needs") for such services.

In the amended complaint, the plaintiffs list the questions of law raised by the lawsuit as: "(a) whether it is permissible under federal Medicaid law, the ADA and Section 504 for Defendants to adopt and use a practice, or practices, which fail to provide Medicaid-funded community-based services within a reasonable time after request of an eligible individual; (b) whether it is permissible under the Due Process Clause of the Fourteenth Amendment and federal Medicaid law to deny Medicaid-funded home or community-based services without notice and an opportunity to be heard; (c) whether it is permissible under the ADA to fail to provide individuals who are eligible for developmental

disabilities services with such services in the most integrated setting appropriate to them; and (d) whether it is permissible under federal Medicaid law, the ADA, and Section 504, as well as applicable state law, for Defendants to adopt and use practices (e.g., the "OAP" as devised and implemented by Defendants) to determine the funding they will provide each eligible individual for their developmental disabilities services when such practices are arbitrary, inflexible, and fail to obtain necessary input, and when those practices routinely result in the under funding of services."

In January 2007, the court scheduled the complaint for trial in January 2008. The state has opposed class certification.

15. New Hampshire: Cuming et al. v. Shaheen et al.

In January 2002, the Disabilities Rights Center (the state's P&A agency) filed a class action complaint in Hillsborough County Superior Court, arguing that New Hampshire failed to provide adequate community-based services for people with developmental disabilities. The suit alleged that there are "well over 500 individuals" in the proposed class, including 325 Medicaid-eligible individuals wait-listed for services and a large number of persons who receive inadequate or inappropriate services. The plaintiffs demanded that the state furnish a "comprehensive array" of individualized community services.

The suit charged the state had not developed an adequate system of community services and programs, "including sufficient numbers of ICF/MR and other community living arrangements that meet the individualized needs of persons with developmental disabilities..." The suit asked the court to order the state to furnish improved services not only for the wait listed persons but also for individuals who receive services but have been "...left to languish in inappropriate and, sometimes, overly restrictive placements." The plaintiffs expressed dissatisfaction with the state's attempts to develop programs and services for this group, portraying such efforts "piece-meal and inadequate."

This lawsuit suit was filed in state court and relied both on state and federal law as its basis. In particular, the suit claimed that the state violated: (a) New Hampshire law (RSA 171-A:13) which provides that "every developmentally disabled client has a right to adequate and humane habilitation and treatment including psychological, medical, vocational, social, educational or rehabilitative services as his condition requires to bring about an improvement in condition within the limits of modern knowledge"; (b) §1902(a)(8) of the Act for waiting listing otherwise eligible persons and §1902(a)(3) for failing to provide

²⁰ The opinion is at:

caselaw.findlaw.com/data2/circs/8th/043263P.pdf

²¹ The petition is located at:

usdoj.gov/osg/briefs/2005/2pet/7pet/2005-0777.pet.aa.pdf

a Fair Hearing for individuals whose claim for Medicaid services has not been acted upon with reasonable promptness; (c) Title II of the ADA for not having developed a sufficiently comprehensive program so that all persons with developmental disabilities can "remain in the community with their family and friends," thereby putting them "at risk of being provided with inadequate, inappropriate or overly restrictive programs and services"; (d) the 5th and 14th Amendments to Constitution and §1983 for abridging the plaintiffs' due process rights; and, (e) the 14th Amendment for violating individuals' right to equal protection by serving some individuals but wait-listing others.

In April 2002, the court denied the plaintiffs' petition for injunctive and declaratory relief. The court concluded that the petition did not meet New Hampshire's tests for such relief. Deciding that the "proposed class members' claims... include claims that extend far beyond those of the named plaintiffs," the court also denied class certification.

In a subsequent proceeding, the court reversed itself concerning class certification. But, then in March 2003, the court again decided to deny certification, ruling that the proposed class was too broad and likely included individuals whose service needs were different and therefore might have different interests.

The plaintiffs appealed the denial of class certification to the New Hampshire Supreme Court, which refused to hear the appeal. The parties then agreed that the lawsuit would be treated as a voluntary non-suit without prejudice (i.e., the plaintiffs are free to refile later) and the case was dismissed (Priaulx, 2005).²²

16. New Mexico: Lewis et al. v. New Mexico Department of Health et al.

This lawsuit (99-00021) was filed in January 1999 in the U.S. District Court for New Mexico by the state's P&A agency with the support of The Arc of New Mexico. The class action complaint alleged New Mexico violated federal Medicaid law and the ADA by failing to provide Medicaid services in the community to eligible individuals with disabilities, thereby causing them to go without services or forcing them to accept institutional services. The proposed class included: (a) people with developmental disabilities wait-listed for HCBS; (b) persons served in ICFs/MR who would benefit from waiver services; (c) persons served in nursing facilities who want community services; and, (d) wait-listed persons with disabilities who seek access to the state's waiver for persons who are aged or disabled.

In April 2000, the court rejected the state's motion to dismiss the lawsuit on sovereign immunity grounds and upheld the plaintiffs' right to access to waiver services with "reasonable promptness." In May 2000, the state asked the 10th U.S. Circuit Court of Appeals to reconsider its immunity claim. Under federal judicial rules, an appeal based on a sovereign immunity claim stays further lower court action until the appeal is decided. Finally, in August 2001, the 10th Circuit denied the state's appeal.²³

In September 2001, the state moved again to dismiss the complaint, arguing that the lawsuit was moot because all the original named plaintiffs either were receiving waiver services or deceased. The state also challenged the P&A's standing to pursue this litigation in its own right. In November 2001, the P&A filed a counter brief, arguing that it had standing under federal law to pursue the lawsuit.

In July 2002, the plaintiffs moved for summary judgment, contending that the "case presents a simple, straight forward question of law: Are the Defendants required to provide Medicaid waiver services to all eligible individuals with reasonable promptness? The law is clear and unequivocal: the defendants are so required." In support, the plaintiffs pointed out that 2,600 individuals were wait listed for the state's HCBS waiver for people with developmental disabilities. The waiver served 2,300 individuals and has a federally approved cap of 3,200. There were 2,500 persons wait listed for the state's HCBS waiver for individuals who are disabled or elderly; that program served 1,500 individuals or 450 fewer than the federally-approved "cap." The plaintiffs also noted that the average period that persons with developmental disabilities must wait for services was worsening. The plaintiffs argued that these facts supplied ample evidence that New Mexico did not furnish waiver services with reasonable promptness. The plaintiffs also took the state to task for not properly taking applications for waiver services. Instead, individuals are assigned to a "Central Registry" and eligibility is only determined once their name comes up. The state portrayed individuals on the Registry as having "applied to be considered" for waiver services rather than actual applicants. The plaintiffs argued this practice violated Medicaid law.

In August 2003, the court granted the plaintiffs' motion for summary judgment, ruling that the state had not furnished waiver services with reasonable promptness. However, the court decided that the Medicaid reasonable promptness requirement extends only so far as there are funds and waiver slots available but not beyond. Thus, the court did not require that the state

²² See drcnh.org/DDWaitlist.htm

²³ Decision is at: laws.findlaw.com/10th/002154.html

expand its waiver to serve all people on the waiting list. The court noted that the state had in the past not made full use of all available funds and admonished it to step up its efforts to diligently deploy its resources to serve as many individuals as possible each year.

The plaintiffs then submitted a proposed order to implement the ruling. In October 2003, the state challenged the proposed order, which asked that the court to enter a permanent injunction to require that the state comply with applicable federal laws. The state argued that its policies met the court's ruling. The state also argued that the proposed order went beyond the court's ruling because it would require the state to serve more people in its waiver programs than could be supported by funds appropriated by the legislature. The state proposed that the court enter judgment in its favor.

In November 2003, the plaintiffs replied that the state had misconstrued the court's August 2003 order. They asserted that the order provided that: (a) the state must promptly determine the eligibility of applicants rather than entering their names into a registry for future consideration when waiver slots become available and (b) the state must serve all eligible individuals until it reaches its federally-approved participant cap, irrespective of whether the legislature had earmarked sufficient dollars.

In February 2004, the court entered its judgment. The court ordered the state to allocate waiver slots as soon as they become available and determine an individual's eligibility for waiver services within 90 days. It also ordered the state to provide waiver services within 90-days of finding that a person is eligible for waiver services. It also ordered the state to spend all funds appropriated for waiver services within the year appropriated. New Mexico advocates expected that 300 – 500 individuals will come off the waiting list as a result of this decision.

In September 2004, the plaintiffs filed a motion for the court to hold the state in contempt. The plaintiffs argued that the state was violating the court's order to offer waiver services up to the federally approved participant limit for each waiver. In October 2004, the state responded, arguing that the plaintiffs misunderstood the court's ruling and that the state's obligation to furnish waiver services goes only so far as available funds, not the waiver participant limit. Finally, in September 2005, the court denied the plaintiffs' motion for contempt, ruling that New Mexico was obligated to furnish waiver services only to the extent supported by available funds.

17. Ohio: Martin et al. v. Strickland et al.

Filed in 1989 by Ohio Legal Rights Services (OLRS - the state's P&A agency), this class action complaint

(89cv0362) alleged that Ohio violates Medicaid law and the ADA by failing to provide integrated residential services to all persons with developmental disabilities eligible for them. In 1993 the court denied the state's motion to dismiss the ADA claim on 11th Amendment sovereign immunity grounds, holding that Congress had the authority to abrogate immunity. In 1998, the parties agreed to stay further district court proceedings in the hope of working out an agreement to expand services. In July 2000, OLRS filed a motion for partial summary judgment asking the court to find the state in violation of the ADA integration mandate because its waiver waiting list was not "moving at a reasonable pace."

In September 2002, the court ruled on various motions. It denied the state's motion to dismiss on sovereign immunity grounds and upheld some of the plaintiffs' claims but turned down the plaintiff's motion for partial summary judgment. The court urged the parties to settle the more than decade old lawsuit.

In June 2004, the parties announced that they had arrived at a settlement agreement. The class affected by this agreement included: "[A]ll mentally retarded or developmentally disabled Ohioans who are, or will be, in need of community housing and services which are normalized, home-like and integrated, and a subclass who, in addition to being members of the class, are or will be, Medicaid recipients." The agreement focused on providing community-integrated services to individuals who resided in state-operated residential centers, nursing homes, and large ICFs/MR.

Under the terms of the agreement, Governor Taft, in his executive budget, agreed to propose "... the elimination of intermediate care facilities for the mentally retarded under the State of Ohio's Medicaid [state] plan." If the legislature approved legislation authorizing this action, the state then would submit a waiver request to the U.S. Department of Health and Human Services to afford all ICF/MR residents the right to choose the setting in which they receive services. The agreement also provided that the state would earmark waiver slots to support the community transition of ICF/MR and nursing facility residents with developmental disabilities. The state also agreed to survey state developmental center and ICF/MR residents to identify people who want to transition to the community. A fairness hearing was scheduled for September 2004.

The proposed settlement unleashed a torrent of protest. Dozens of objections to the settlement were filed. The objections revolved around the proposed elimination of ICF/MR services from the Ohio Medicaid program. The objectors, many of whom are ICF/MR residents

and their guardians, believed that this step would undermine their entitlement to services under federal law. The objectors petitioned the court to decertify the class, arguing that the agreement and the plaintiff attorneys did not adequately represent their interests. The high volume of objections prompted the court to cancel the fairness hearing. In response, the state and the plaintiffs filed "points of clarification" concerning the agreement and, in October 2004, filed a memorandum in opposition to dissolving the class. The state and the plaintiffs argued that the settlement allowed individuals to continue to reside in their current living arrangements but would clear the way for Ohio to comply with the ADA integration mandate.

Additional plaintiff objectors filed motions to dissolve the class. The controversy about the settlement grew. In December 2004, Governor Taft announced that the state was withdrawing its objections to decertifying the class. The Taft Administration expressed the view that the policy changes incorporated in the settlement agreement would be more properly addressed in the legislative arena.

In mid-February 2005, the court – over the objections of the ever-growing number of parties – appointed a Special Master to broker a new settlement agreement. But, no progress was made. In September 2005, the Special Master recommended that the court not dissolve the class.²⁴ In November 2005, the court accepted this recommendation. It also refused the objectors' request to direct Ohio to not eliminate ICF/MR services, ruling that the issues posed by the litigation revolved around the right of individuals to obtain services in the most integrated setting rather than preserving specific types of settings. Meantime, the state's plan to eliminate ICF/MR services in favor of providing Medicaid long-term services under a broad federal waiver was sidetracked by the Ohio legislature, which required that actions affecting ICF/MR services be subject to its authorization.

In September 2006, the parties notified the court that they had arrived at a new settlement agreement and the court postponed trial. The new settlement agreement provides for Ohio to offer waiver services to an additional 1,500 individuals over the next two years, including persons who are in ICFs/MR or at risk of ICF/MR placement.²⁵ In March 2007, the court approved the settlement agreement.

²⁴ See: olrs.ohio.gov/asp/MartinRandR.asp

²⁵ Go to olrs.ohio.gov/asp/Martin.asp to obtain the settlement and the March 2007 consent order. Information about how the settlement is being implemented is located at: odmrdd.state.oh.us/topics/martin/settlement.htm.

18. Oregon: Staley et al. v Kulongoski et al.

Filed in January 2000, this complaint (00cv00078) alleged that the state violated federal Medicaid law and the ADA by failing to furnish Medicaid long-term services to otherwise eligible individuals with developmental disabilities with reasonable promptness. In September 2000, the parties agreed to settle the lawsuit. The U.S. District Court for Oregon approved the settlement agreement in December 2000.

The settlement agreement was designed to implement the Universal Access Plan. The Plan provided that all eligible adults would receive at least a basic level of supports. The parties agreed that the settlement would include not only the named plaintiffs but also "all other similarly-situated individuals with developmental disabilities under the federal Medicaid program." The settlement extended to 2007 and provided that the state would increase community funding by a cumulative total of \$350 million. Under the agreement, the number of persons receiving "comprehensive services" (including 24-hour residential services) would grow by 50 per year over and above the number of individuals who receive such services due to emergencies. The state also agreed to furnish comprehensive services to all individuals in crisis. The number of persons receiving "support services" (defined as "in-home and personal supports costing up to \$20,000 per year") would increase by 4,600 over the agreement's six-year period. Also, the agreement called for making additional investments in system infrastructure.

In its 2001 session, the Oregon Legislature funded the first two-years of the settlement. Also, to implement the plan, Oregon launched a new "self-directed support services" waiver to implement Universal Access. But, Oregon then experienced a sharp drop in state revenues. In August 2002, the Oregon Advocacy Center (the state's P&A agency) warned that it was prepared to return to court to seek relief under the material breach provisions of the settlement if budget cuts led the state not to fund the agreement. In February 2003, the state imposed a moratorium on enrollments in its waivers. By then, about 3,000 individuals were participating in the supports waiver.

In October 2003, the parties presented a modified settlement agreement to the court. The modified agreement acknowledged that Oregon's severe budget crisis meant that the original agreement's timetable could not be followed. Under the modified agreement,²⁶ the state was given until 2011 to fully implement the original agreement. The pace of expansion of both comprehensive and support services was slowed but

²⁶ Information about the modified agreement is available at the Center's website: oradvocacy.org/staley2003.htm.

the agreement still provided that in the end all eligible individuals would receive at least support services. The modified agreement provides for an additional 500 persons to receive support services each year through June 2007, when the number of persons served is expected to reach 5,122 individuals compared to 3,112 in June 2003. The agreement provides that all eligible persons will receive support services by June 2009. The agreement also preserves the network of support brokerages that Oregon created for individuals who receive support services. The parties agreed that the modified settlement was preferable to re-opening the litigation. In January 2004, the court approved the modified agreement because no affected class members objected.

19. Pennsylvania: Sabree et al. v. Richman

In May 2002, the Disability Law Project filed a class action complaint (02-CV-03426) in the U.S. District Court for Eastern Pennsylvania against the Department of Public Welfare on behalf of four individuals who contended that the state had improperly wait listed them for ICF/MR services. The complaint was filed in reaction to a proposed reduction of the dollars committed reducing Pennsylvania's community waiting list.

The plaintiffs' complaint was brief. It argued that Pennsylvania had not furnished ICF/MR services as required under its Medicaid state plan to eligible individuals with reasonable promptness, in violation of §1902(a)(10)(A) (by not making entitled ICF/MR services available to all eligible persons) and §1902(a)(8) of the Act. The plaintiffs sought class action certification. The proposed class would include "all Pennsylvanians with mental retardation living in the community who are entitled to, in need of, but not receiving appropriate residential and habilitative programs under the Medical Assistance program."

The state filed moved to dismiss the complaint and opposed to class certification. The state argued that the complaint did not satisfy the test for bringing a lawsuit under §1983 because there is no federally enforceable individual right to ICF/MR services in small community residences and the reasonable promptness requirement applies in the "aggregate" but not to individuals. In July 2002, the plaintiffs urged the Court to deny the motion to dismiss, arguing that ICF/MR services are an individual entitlement under federal law and citing several federal court decisions that declared reasonable promptness is an enforceable individual right. The plaintiffs also argued that Congress had affirmed the enforceability of these rights.

In January 2003, the district court dismissed the lawsuit, accepting the state's arguments. The court based its dismissal on: (a) its view that Medicaid law

does not confer an individually enforceable right to services and, hence, the action does not meet the criteria for bringing a lawsuit under §1983. The court found that: (a) the Medicaid Act has an "aggregate" focus (e.g., whether the state is following its overall plan) rather an "individual focus;" (b) the availability of a mechanism for individuals to appeal adverse decisions (the Fair Hearing process) means that an action cannot be brought under §1983, based on the Supreme Court's *Gonzaga* decision; and, (c) in any case, the court found that federal Medicaid law does not require that a state furnish ICF/MR services in small community group homes, and, thus, the plaintiffs cannot assert a right to such services. The court concluded that the "individuals referenced [in the lawsuit] are merely beneficiaries, not persons entitled to privately enforce the statute." The court also concluded that only the federal government could sue the state over the operation of its Medicaid program.

In January 2003, the plaintiffs appealed the dismissal to the 3rd Circuit Court (03-1226). Ilene Shane, director of the Disabilities Law Project said, "We're appealing because we believe it's not a correct decision. If this decision were to be followed, it would reverse 30 years of jurisprudence where people with disabilities have litigated their rights." Several organizations filed amicus briefs in support of the appeal, including AARP, Arc US, Families USA, and others.

In May 2004, the Circuit Court handed down a "precedential" opinion in this appeal.²⁷ In a nutshell, the Circuit Court reversed the district court ruling. The Circuit ruled that – the *Gonzaga* decision notwithstanding – federal Medicaid law confers individually enforceable rights under the provisions that served as the basis of the lawsuit's legal claims.

In November 2004, the plaintiffs filed an amended complaint in district court, reasserting their right to receive ICF/MR services with reasonable promptness. But, in September 2005, the plaintiffs moved that the court dismiss the lawsuit because a settlement agreement had been worked out on behalf of the three named plaintiffs. The court accepted this motion.

20. Tennessee: Brown et al. v. The Tennessee Department of Mental Health and Developmental Disabilities and Rukeyser & People First of Tennessee v. Neal et al.

Brown. Filed in July 2000 by the state's P&A agency, this class action complaint (00cv00665) alleged that Tennessee has violated federal Medicaid law by not furnishing ICF/MR or HCB waiver services with reasonable promptness to otherwise eligible individuals

²⁷ The opinion is at: ca3.uscourts.gov/opinarch/031226p.pdf

with developmental disabilities. The complaint estimated that about 850 individuals were wait listed for waiver services.

People First. In March 2001, People First of Tennessee filed another class action complaint (01cv00272), also in the U.S. District Court for Middle Tennessee. This complaint asserted that the state: (a) had failed to provide ICF/MR or HCB waiver services with reasonable promptness; (b) violated the ADA by failing to make reasonable modifications and accommodations so that individuals (including institutionalized persons) are served in the most integrated setting; (c) did not comply with §1902(a)(10) of the Act since it had not made ICF/MR or waiver services available to all eligible persons; (d) had denied individuals the right to apply for or be made aware of Medicaid services; (e) had discriminated against people with disabilities by not permitting all otherwise eligible persons to obtain services to which they are entitled, in violation of the ADA; (f) violated §1902(a)(3) of the Act and the Due Process Clause of the U.S. Constitution's 14th Amendment by not providing individuals written notice of denial of Medicaid services, thereby preventing them from exercising their appeal rights; (g) had denied individuals free choice in receiving HCB waiver or ICF/MR services; and, (h) violated the Individuals with Disabilities Education Act by denying Medicaid payment for services to which school-age children are entitled.

The complaint alleged that approximately 2,000 persons with developmental disabilities were waiting for waiver services in Tennessee. The plaintiffs contend that the state had given insufficient attention to a growing backlog of people who need community services because most new resources were committed to placing residents out of state-operated institutions to comply with court orders in earlier institutional treatment lawsuits (*People First v. Clover Bottom, et al* and *United States of America v. State of Tennessee*).

In May 2003, the presiding judge asked the parties to consider consolidating the cases. The court arranged for a mediator and halted further proceedings pending the outcome of mediation. The court also denied both sets of plaintiffs' and the state's motions for summary judgment.

In February 2004, the Court provisionally approved to separate settlement agreements in both cases. These agreements are described below. A fairness hearing was held in April 2004 to hear objections to the agreements. In June 2004, the Court gave its final approval to the agreements.

Brown Settlement. Under the terms of this agreement, the state agreed to formulate and seek federal approval

of a new Self-Determination HCBS waiver program to serve individuals wait listed for services. The aim of the agreement is to eliminate or substantially reduce the waiting list. The new waiver program would provide up to \$30,000 in services to each person and designed to give individuals (or, their families, if appropriate) latitude in selecting and directing their services. This funding is supplemented, if necessary, by additional short-term crisis and/or one-time diversion dollars to provide temporary additional services. The agreement provides that the new program would serve 600 individuals in its first year of operation and an additional 900 persons in the second year. Beyond the second year, the parties will reach agreement concerning further expansion of the program to address unmet needs. The agreement directs the state to offer services through the new waiver on a priority basis to individuals who are in crisis or have urgent needs. In the event that a person's needs cannot be met through the self-determination waiver, the individual will have the option to choose services through another waiver. The new waiver was approved by CMS and is being implemented.

The agreement also provides for the expansion of the state's current HCBS waiver program. Moreover, persons who remain on the waiting list are to receive \$2,280 per year in "consumer-directed support" funding. The agreement also commits the state to implementing a Medicaid targeted case management program to support individuals on the waiting list. The agreement provides for additional improvements in community services infrastructure.

People First Settlement. This settlement agreement acknowledges and complements the Brown settlement. The focus of this agreement is to "assure that all Tennessee citizens who might be eligible for waiver services are given a reasonable opportunity to learn of the availability of waiver services and to apply for them." The state has agreed to conduct a public information campaign to provide information to individuals who might be Medicaid-eligible regarding the waiver programs. The state also is to compile information concerning the number of individuals with mental retardation who are eligible for Medicaid waiver services but not receiving them.

21. Texas: McCarthy et al. v. Hawkins et al.

In September 2002, eleven individuals and The Arc of Texas filed a class action complaint in the United States District Court for Eastern Texas against the Commissioners of the Texas Health and Human Services Commission (THHSC), the Texas Department of Mental Health and Mental Retardation (TDMHMR) and the Texas Department of Human Ser-

vices (TDHS). The complaint charged that Texas has failed to “provide the plaintiffs and other Texans with mental retardation and developmental disabilities with community-based living options and services to which they are legally entitled that meet their needs.” The lawsuit asked the court to direct Texas to expand Medicaid home and community-based waiver services.

After the lawsuit was filed, Texas has restructured its human services agencies; The Department of Aging and Disability Services (DADS) replaced the previous named state agencies. This lawsuit revolved around two HCBS waivers: the home and community-based services (HCS) waiver for persons with mental retardation and the Community Living Assistance and Support Services (CLASS) waiver for persons with developmental disabilities other than mental retardation. Advocacy Inc., the state’s P&A agency, filed the complaint with support by The Arc of Texas.

The complaint charged that about 17,500 people with mental retardation were wait listed for the HCS waiver and another 7,300 individuals had requested but not received CLASS waiver services. The plaintiffs sought certification of a class that would include “all persons eligible to receive Medicaid waiver services, who have requested but not received waiver services with reasonable promptness.” The class also would include 11,000 individuals served in ICFs/MR who “are eligible to be considered for the kind of residential services that will enable them [to] become more fully integrated into the community.”

The complaint claimed that the state violated: (a) §1902(a)(10)(A) of the Act by failing to make ICF/MR level services available in an adequate amount, duration and scope to all eligible persons; (b) §1915(c)(2)(C) by failing to provide individuals a choice between institutional and home and community-based services; (c) §1902(a)(8) by (i) not allowing individuals to apply for waiver services and instead wait listing them and (ii) not furnishing services to eligible individuals with reasonable promptness; (d) the 14th Amendment to the U.S. Constitution by not affording individuals equal protection; (e) the Due Process Clause of the U.S. Constitution; (f) the ADA and §504 of the Rehabilitation Act by failing to provide services in the most integrated setting. The state filed a motion to dismiss. In March 2003, the court granted the state’s motion to transfer the lawsuit to the Western District of Texas. (03-CV-231)

In May 2003, the court issued an order that addressed eleven motions filed by both sides. First, the court denied the state’s motion to dismiss The Arc of Texas as a plaintiff in the litigation. The court, however, granted the state’s motions to dismiss the plaintiffs’

claims with respect to most provisions of Medicaid law, including comparability, HCBS waiver freedom of choice, and reasonable promptness. With respect to these claims, the court held that states were authorized to limit the number of persons who participate in a waiver and, thus, individuals cannot assert an enforceable right to such services once the waiver participant limit is reached. But, the court turned down the state’s motion to dismiss the plaintiffs’ claims concerning due process under Medicaid law and the U.S. Constitution as well as the ADA and §504 claims. The court found that, with respect to these claims, the plaintiffs had individually enforceable rights and, hence, could seek redress in federal court under the provisions of §1983. In this part of the decision, the court relied heavily on the *Olmstead* decision, although it noted that the fundamental alteration defense might stand as a substantial barrier to the plaintiffs’ ultimately prevailing. The court also rejected the state’s sovereign immunity defense.

In June 2003, the state appealed the parts of the decision that ran against it to the 5th Circuit Court of Appeals (03-50608), again claiming that sovereign immunity insulates the state from lawsuits based on the ADA and §504. District court proceedings were stayed until the Circuit disposed of the state’s interlocutory appeal. The Circuit allowed the U.S. Department of Justice to intervene on behalf of the plaintiffs. In its brief,²⁸ USDOJ urged the court to turn down the appeal, arguing that it is well-established that states may be sued in federal court for alleged violations of the ADA and §504. A coalition of national organizations, including ADAPT, The Arc of the United States, the American Association of People with Disabilities and others also petitioned the court to file *amici* brief on behalf of the plaintiffs.

In August 2004, the three-judge panel handed down a split 2-1 decision. This decision solely addressed the relatively narrow issue of whether state officers are proper defendants in a lawsuit brought under Title II of the ADA.²⁹ Texas had argued that only public entities could be sued under Title II. The panel ruled that state officers could be sued in their official capacity, a ruling that is consistent with similar rulings in other cases. The panel refused to hear the state’s arguments to dismiss the remaining claims, because the issues were not proper subjects for interlocutory appeal. In September 2004, the state petitioned for *en banc* hearing before the full Circuit. In December 2004, this petition was denied and the case remanded to the

²⁸ The brief is at: usdoj.gov/crt/briefs/mccarthy.pdf.

²⁹ Opinion is at: caselaw.lp.findlaw.com/data2/circs/5th/0350608pv2.pdf.

district court for further action. The state considered but decided against pursuing an appeal of the Circuit Court decision to the U.S. Supreme Court.

In August 2006, the parties arrived at a settlement agreement³⁰ which provides that:

- Within 12 months the state will initiate an informal assessment of individuals requesting HCS and/or CLASS services and who are subsequently placed on a waiting list. The assessment will obtain information about the functional status and diagnosis of the individual, ensure that the individual is presented information about all services for which he/she might be eligible and facilitate placement of the individual on the correct waiting lists(s).
- Over the next three biennia, the state agreed to include in its Legislative Appropriations Request (LAR) sufficient funding to:
 - (1) Offset the estimated increase in the number of persons listed on the HCS and CLASS waiver waiting lists during the preceding biennium.
 - (2) Achieve a 5-10% reduction in the number of persons listed on the HCS and CLASS waiver waiting lists each year.

Should the Texas legislature approved these funding requests, the number of persons receiving services would increase by an estimated 6,000 to 8,000 persons per biennium.³¹ The court dismissed the lawsuit in October 2006.

22. Utah: D.C. et al. v. Williams et al.

In December 2002, the Utah Disability Law Center (the state's P&A) filed suit (02cv01395) against the Utah Department of Health and the Division of Services for People with Disabilities in the U.S. District Court for Utah on behalf of nine individuals and the Arc of Utah challenging the wait listing of persons with developmental disabilities for waiver services. The plaintiffs argued that wait listing violated federal Medicaid law, the ADA, and §504. Class certification was sought for roughly 1,300 individuals who had been found to have an immediate need for services but had been wait listed.

Plaintiffs contended that the state has: (a) refused to provide medically necessary waiver services to individuals; (b) failed to operate its Medicaid program in

the best interest of recipients, as required in §1902(a)(19) of the Act; (c) not operated its Medicaid program to assure that services are sufficient in amount, scope and duration; (d) violated §1915(c)(2)(C) by not making waiver services available to individuals who qualify for ICF/MR services; (e) violated §1902(a)(8) of the Act by not making services available with reasonable promptness; (f) violated the ADA's integration mandate by placing individuals at risk of institutionalization; and, (g) violated §504 of the Rehabilitation Act. The plaintiffs sought declaratory and injunctive relief in the form of an order that the state prepare a plan to serve wait listed individuals.

In January 2003, the state moved to dismiss the complaint, contending that:

"[the] plaintiffs lack standing because they have no protected right to HCBS waiver services. Specifically, plaintiffs possess no protected right to HCBS waiver services because of the upper limit [on the number of participants] and other Medicaid limitations placed on HCBS waiver services, and the substantial discretion granted [the state] in administering and providing HCBS waiver services."

The state argued that, because federal law allows it to limit the number of individuals served by the waiver, wait-listed people cannot have an enforceable right to waiver services. Since they lack such a right, the state contended that the reasonable promptness requirement does not apply. Also, absent a right to waiver services, the state argued that plaintiffs do not have standing to bring suit under §1983. With respect to the plaintiffs' claim that the state is violating §1915(c)(2)(C) by not giving individuals eligible for ICF/MR services a choice of waiver services, the state argued that it is only obligated to inform individuals of the "feasible alternatives, if available under the waiver." If services are not available, then a "feasible alternative" does not exist. The state also asserted that the Supreme Court's *Olmstead* ruling does not apply because "plaintiffs are not being held in institutional placements against their will, [and hence] the ADA and Rehabilitation Act are inapplicable." Lastly, the state argued that, in order to serve all wait-listed individuals, it would be forced to make a "fundamental alteration" by having to shift funds away from other programs in order to serve the plaintiffs. The state pointed out that ADA regulations as well as the *Olmstead* decision "allows states to resist modifications that entail a 'fundamental alteration' of the state's services and programs."

In March 2003, the plaintiffs filed a memorandum opposing the motion to dismiss. They contended that the HCBS waiver program is no different than any other Medicaid service and, therefore, the state cannot

³⁰ A summary of the settlement is located at: thearcoftexas.org/resources/mccarthy%20lawsuit%20settlement.doc

³¹ For reference, in July 2006, there were 30,000 individuals on the HCS interest list and 15,000 persons on the CLASS waiting list. For the current biennium, the Legislature approved expansions of both waivers. However, the interest lists continue to grow.

waitlist individuals. The plaintiffs also disputed the state's *Olmstead* interpretation, pointing out that other courts had found that the integration mandate applies to both individuals who are institutionalized and persons at risk of institutionalization.

In August 2003, the court addressed the pending motions. It decided to grant class certification. However, the court threw out the plaintiffs' Medicaid claims, following the district court's reasoning in the Pennsylvania *Sabree* lawsuit that the Medicaid Act does not grant individually-enforceable rights. The court then took up the state's motion to dismiss the ADA and §504 Rehabilitation Act claims. It rejected the state's argument that such claims may only be pursued by institutionalized persons and denied the motion to dismiss the claims. It also rejected the state's sovereign immunity defense.

Trial was held in January 2006. In February 2006, the court dismissed the complaint. The court decided that Utah was not obligated to serve more individuals in its HCBS waiver program because the costs of doing so would cause a fundamental alteration by requiring shifting funding away from other services for people with developmental disabilities. The court also found that Utah's policies did not discriminate against people with disabilities because the state has an explicit method of determining who is selected for waiver services when openings become available. The court also found that, while individuals on the waiting list were eligible for waiver services, they did not meet the federal requirement that they would need institutional services within a month.

23. Virginia: *Quibuyen v. Allen and Smith*

Filed in December 2000 in the U.S. District Court for Virginia by a coalition of attorneys, this complaint alleged that the state impermissibly wait-listed individuals already enrolled in the state's HCBS waiver program rather than furnishing the additional services that they required including residential services. The complaint argued that Virginia imposed limits on services to waiver participants that "...are foreign to the statutory and regulatory Medicaid scheme, and indeed are inimical to it in that they establish additional unapproved barriers for otherwise eligible persons to obtain assistance to which they are entitled under federal law." Especially at issue was a June 1999 directive by the Department of Medical Services that restricted the circumstances when additional services (including residential services) would be provided. The directive limited new or expanded services only when a person no longer can remain in the family home due to caregiver incapacity or other critical situations. The complaint argued that

this and other policies led to impermissible wait listing of persons for services for which they were otherwise eligible. In September 2001, the state agreed to change its policies so that individuals would receive all the services that they have been determined to require. As a result, the plaintiffs agreed to dismiss the lawsuit.

24. Washington: *The Arc of Washington State et al. v. Lyle Quasim et al. & Boyle et al. v. Arnold-Williams*

The Arc of Washington State. Filed in November 1999 in the U.S. District Court for Western Washington, this class action complaint (99cv5577) charged that Washington violated Medicaid law and the ADA by failing to provide long-term services with reasonable promptness to persons with developmental disabilities. The complaint alleged that there are several thousand individuals with developmental disabilities in need of Medicaid funded services but not receiving them and current Medicaid recipients who could benefit from additional services.

In rulings in this lawsuit, the court decided that: (a) eligibility for ICF/MR services is not sufficient to establish an entitlement to waiver services but (b) Medicaid law requires services to be furnished with reasonable promptness. In December 2000, the Court granted the state's motion for summary judgment to dismiss the plaintiffs' ADA claims. The plaintiffs claimed that the ADA requires that, if a state makes waiver services available to some individuals, it must furnish services to all similarly situated individuals. The Court ruled that the ADA cannot serve as the basis for ordering a state to increase the number of individuals who receive waiver services because such an order would constitute a "fundamental alteration."

In April 2001, the parties reached a settlement and submitted it to the court in August. The agreement hinged on action by the Washington legislature to authorize \$14 million in funding to expand services in FY 2003 and annualize these dollars to \$24 million in future years. The legislature approved the first installment. The agreement also called for the parties to identify additional dollars to serve more individuals in the next biennium. Some 1,800 individuals were expected to benefit from the agreement.

But, in December 2002, the court rejected the settlement agreement. Washington Protection and Advocacy Services (WPAS, which represents institutionalized individuals in two other lawsuits) and Columbia Legal Services (which represents individuals in the *Boyle v. Braddock* litigation described below) objected to the settlement. Both parties argued that the agreement did not assure that the class members (including individuals they represent) would receive

the services that they require. The court was persuaded by these arguments and expressed additional reservations about the settlement. As a result, the court rejected the settlement, dissolved the class, and lifted its stay on proceedings.

In June 2003, the court dismissed the lawsuit entirely, following much the same reasoning upon which it dismissed the *Boyle* lawsuit (see below). The court decided that The Arc of Washington State did not have standing to bring the lawsuit. In moving for dismissal, the state argued that the case was no longer “ripe” for decision because the state was in the process of changing its waiver program. The court accepted this argument. Next, as it had in dismissing the *Boyle* lawsuit, the court decided that the plaintiffs had not exhausted their administrative remedies. Finally, the court ruled that its intervening into how the state administers its programs would cause “needless conflict with the state’s administration of its own regulatory scheme.”

In July 2003, the Arc of Washington appealed the dismissal to the 9th Circuit (03-35605). In July 2004, the state moved that the Circuit dismiss the appeal. This case was consolidated with *Boyle* for purposes of oral argument. In March 2005, the court handed down its decision concerning the interplay between the ADA and the Medicaid Act. The Arc argued that the ADA was violated by the state’s limitation on the number of individuals who can receive waiver services. The court rejected this argument, deciding that the ADA does not override provisions in the Medicaid Act that permit a state to limit the number of HCBS waiver participants. The court based this decision on the principle that a specific statute (the Medicaid Act) is not controlled or nullified by a general statute (the ADA). As a result, the court dismissed the Arc’s ADA claim.³² However, the court remanded the case back to the district court to reconsider other aspects of its dismissal of the case.

The case was reassigned to a different district court judge. The parties proposed that a new trial be conducted. The parties also agreed that the issues in this case revolve around whether current HCBS waiver participants are receiving all the services to which they are entitled. Trial is scheduled for September 2007.

The parties are attempting to work out a settlement. Proceedings are stayed in the interim.

Boyle v. Arnold-Williams. This class action complaint (01cv5687) was filed by Columbia Legal Services in December 2001 in the U.S. District Court for Western Washington. The complaint alleges that

Washington has failed to furnish or make available the full range of services offered through the Community Alternatives (HCBS waiver) Program (CAP) to waiver participants. The plaintiffs cited examples of individuals not receiving necessary services or not being informed about services offered in the waiver. This complaint somewhat paralleled the *Arc of Washington State v. Quasim* complaint but focused more narrowly on the alleged problems that current waiver participants were having in accessing the full range of CAP services. The proposed class was composed of all current or future CAP participants.

Specifically, the complaint alleged that the state has: (a) violated §1902(a)(8) of the Act by not advising waiver participants of the availability of CAP services, failing to instruct them on how to request such services and not approving or providing needed services; (b) violated the requirement that the state put into place necessary safeguards to protect the health and welfare of waiver participants; (c) failed to provide or arrange for appropriate assessments; (d) not furnished necessary services with reasonable promptness; (e) not permitted participants to exercise free choice of providers; (f) failed to provide participants with adequate written notice and an opportunity for a Fair Hearing when their service requests are denied, reduced or terminated; and, (g) deprived individuals of their property interest in Medicaid services without due process of law in violation of the 14th Amendment.

Proceedings in this case were stayed while the court weighed the *Arc of Washington State v. Quasim* settlement agreement. When the court rejected that settlement, it lifted the stay. State officials declared to the court that waiver policies had changed in the interim to make it clear that lack of funding “... is not a valid reason to deny a needed service to someone on the ... waiver.” They also declared that they had made numerous other changes to waiver policies that addressed issues raised by the plaintiffs.

The state opposed class certification and raised other objections to the lawsuit. The state argued that changes already made in CAP in response to a CMS review had addressed the plaintiffs’ issues. Also, the state asserted that it was converting CAP to four separate waivers and, hence, certifying the class with respect to the CAP program would be inappropriate.³³ The state also argued that in any event there is no right of private action to enforce individual claims for Medicaid services. Finally, because each person’s situation should be addressed individually, the state contended that class certification would be inappropriate.

³² The opinion is located at: caselaw.lp.findlaw.com/data2/circs/9th/0335605p.pdf.

³³ CMS approved this change. The four waivers that replaced CAP provide for different services and levels of support.

In April 2003, the court dismissed the case after denying class certification. The court concluded that the issues in question were the proper subject of state administrative procedures, which also provide for state judicial review in Washington. The plaintiffs countered that the issues in dispute were more properly addressed in a class action context and appealed the dismissal (03-35312) to the 9th Circuit Court.

This case was consolidated with *Arc of Washington State* for purposes of oral argument. Circuit proceedings in both *Arc of Washington State* and *Boyle* were suspended while the parties explored a mediated settlement. In mid-February, the parties notified the Court that they could not arrive at a settlement. In April 2005, the Circuit Court upheld the district court's decision in part and reversed the decision in part.

In September 2005, the plaintiffs filed an amended complaint at the district court, alleging that the state continued to fail to furnish necessary waiver services with reasonable promptness. Plaintiffs also argued that how the state assigned waiver participants to the four waivers that replaced the CAP waiver deprived individuals of the opportunity to request a Medicaid Fair Hearing and exercise their due process rights under the U.S. Constitution. In particular, some individuals were assigned to a new waiver that provided less comprehensive services than the CAP waiver rather than to a waiver that covered the services that they required. Plaintiffs claim that these individuals should have had the right to appeal the assignment to a waiver that provides fewer benefits. Also in September, the state filed its answer to the amended complaint, arguing that the plaintiffs lacked standing to pursue relief in federal court and reasserting 11th Amendment sovereign immunity.

In September 2006, the parties announced that they had arrived at a settlement agreement. The settlement³⁴ provides that:

- By April 2007, the state will implement a new automated comprehensive annual assessment process to evaluate each waiver participant's needs;
- Individuals will have the right to request a transfer to a different waiver;
- Waiver services will be documented in each individual's service plan and services authorized in the plan will be provided within 90-days;
- The state will respond promptly to requests for new services by waiver participants;
- The appeal rights of waiver participants will be clarified; and,

- The state will provide the plaintiffs with randomly selected waiver participant files so that the plaintiffs can evaluate whether the agreement is being followed.

In December 2006, the court approved the settlement, retaining jurisdiction over its implementation.

25. West Virginia: Benjamin H. et al. v. Ohl

This class action complaint (99-0338) was filed in April 1999 in the U.S. District Court for the Southern District of West Virginia and alleged that West Virginia violated federal Medicaid law and the ADA by failing to provide Medicaid long-term services with reasonable promptness to eligible individuals. In July 1999, the court quickly granted the plaintiffs' motion for a preliminary injunction based on its finding that the plaintiffs were likely to prevail at trial based solely on the requirements of Medicaid law. The state was ordered to develop a plan to eliminate waiting lists; establish reasonable time frames for placing persons in the waiver; allow persons to exercise their freedom of choice in selecting institutional or home based care; and, develop written policies to inform persons of the eligibility process along with policies and forms to afford proper notice and an opportunity for a fair hearing when applications for ICF/MR level services are denied or not acted on with reasonable promptness.

In March 2000, the court approved agreements between the parties to address the topics identified in the preliminary injunction. West Virginia agreed to increase the number of individuals with developmental disabilities who receive HCB waiver services by 875 over a five-year period. The parties also agreed on revised procedures concerning service applications and giving individuals proper notice concerning the disposition of their applications. The state also submitted an application to HCFA to renew its HCBS waiver program, incorporating policy changes based required by the agreement and boosting the number of persons served. This request was approved in December 2000. The court dismissed this case in August 2002 but retained jurisdiction to enforce its orders.

D. Lawsuits Involving Individuals with Other Disabilities

There also have been several lawsuits filed on behalf of individuals with other disabilities who are seeking community services. In general, the legal issues raised in these lawsuits parallel those in lawsuits concerning persons with developmental disabilities. These lawsuits have been filed by nursing facility residents who want to be in the community as well as persons with disabilities who are at risk of institutionalization due to the lack of home and community services.

³⁴ A copy is located at: [wpas-rights.org/Boyle%20Docs/Proposed Settlement Agreement.pdf](http://wpas-rights.org/Boyle%20Docs/Proposed%20Settlement%20Agreement.pdf)

1. Florida: Dubois et al. v. Rhonda Medows et al.

In April 2003, three individuals with traumatic brain or spinal cord injuries filed a class action complaint (03-CV-107) in the U.S. District Court for Northern Florida against the Florida Agency for Health Care Administration and Department of Health alleging that the state violated Medicaid law and the ADA by failing to provide them Medicaid-funded long-term services in the community. These individuals had sought but not received community services through Florida's Brain or Spinal Cord Injury (BSCI) waiver program. The lawsuit alleged that there are 226 (and possibly more) individuals impermissibly wait-listed for services. One plaintiff resides in a nursing facility; the other two plaintiffs are in the community but at risk of institutionalization. The plaintiffs are represented by Southern Legal Counsel, a Gainesville non-profit public interest law firm and National Health Law Project attorneys.³⁵

The plaintiffs argue that they all have sought but been denied BSCI services due to lack of funds even though it is alleged that only a little more than one-half of the program's approved slots are used. As a result, they have been unnecessarily segregated in nursing homes or are at imminent risk of segregation. The complaint charges that Florida has violated: (a) the ADA for failing to provide individuals with disabilities services in the most integrated setting and not administering its waiting list so that it moves at a reasonable pace; (b) §504 of the Rehabilitation Act; (c) §1902(a)(8) of the Act for not making home and community services available with reasonable promptness; (d) §1915(c)(2)(C) for failing to give individuals the choice between institutional and HCB waiver services; and, (e) the U.S. Constitution and Medicaid law by not affording the plaintiffs the opportunity to apply for services. Class certification also was sought.

In May 2003, the state moved to dismiss the lawsuit, contending that, although its federally-approved HCBS waiver application had 300 "slots," the state had the latitude not to use all of them if appropriations were insufficient. In addition, the state argued on various grounds that, even if slots were available, it was not necessarily the case that the plaintiffs would be next in line to receive services. The state also objected to the plaintiffs' ADA and Rehabilitation Act claims.

In June 2003, the plaintiffs opposed the state's motion to dismiss. The plaintiffs argued that the state's motion was flawed in several respects, including raising issues that more properly should be addressed at trial. The

plaintiffs pointed out that their claims might be remedied if the state had a comprehensive working plan for placing individuals in the community and a waiting list that moved at a reasonable pace, as provided in the *Olmstead* decision.

In March 2004, the court ruled on various motions. The court denied the state's motion to dismiss, finding that the plaintiffs' claims had potential merit. The court also approved class certification, defining the class as: "All individuals with traumatic brain or spinal cord injuries who the state has already determined or will determine to be eligible to receive BSCI Waiver Program Services and have not received such services."

In October 2006, the parties arrived at a settlement. The court approved the settlement in January 2007 and dismissed the lawsuit. The settlement provides that:

- The state will make good faith efforts to obtain funding sufficient to expand the waiver to serve an additional 200 individuals over the next three years;
- The state agreed to revamp the waiver application process to ensure that applications are acted on promptly and establish a priority-based system for enrolling wait-listed to the waiver.

2. Georgia: Birdsong et al. v. Perdue et al.

In January 2003, private attorneys filed a class action complaint (03-CV-288) in the U.S. District Court for Northern Georgia on behalf of individuals with physical disabilities who reside in nursing homes and want community services or are at risk of nursing home placement if not furnished community services. The plaintiffs argued that Georgia's policies cause them to be unnecessarily segregated when they could be supported in the community. The complaint alleged that "[i]n the three and one-half years since the *Olmstead v. L.C.* decision, the State has made no significant effort to operate its long-term care services in an even-handed manner so that persons who need [home and community-based] services have this option."

The plaintiffs were persons who have severe physical disabilities and, except for one, resided in nursing facilities. They asserted that, with appropriate supports, they could live in the community. Georgia operates two waivers – the Community Care Services Program and the Independent Care Waiver Program – for persons with disabilities. The plaintiffs were wait listed for these waivers; but, the waiting lists are quite lengthy. In their complaint, the plaintiffs contended that Georgia spends about five times as much on institutional as community services.

The plaintiffs alleged that Georgia's policies violate: (a) ADA and §504 of the Rehabilitation Act due to the state's failure to furnish services in the most integrated

³⁵ Background information concerning the suit is at: newswise.com/articles/2003/4/SLC.PIL.html

settings and its utilization of discriminatory criteria and methods of administration in its programs; (b) §1915(c)(2)(C) of the Act for failing to provide timely and adequate notice to individuals who might benefit from waiver services and provide individuals freedom of choice between institutional and waiver services; and, (c) §1902(a)(8) of the Act for failing to promptly provide community services to individuals.

In April 2003, the state answered the complaint, denying that its policies violated the plaintiffs' rights. The state also argued that the complaint did not state a claim for relief that the court could grant.

In August 2004, the plaintiffs filed a class certification motion. The proposed class would include all persons with physical disabilities who: "(1) are qualified to receive long-term health-care and supportive services under Medicaid and state-funded programs administered by the state, and, (2) would prefer, and are qualified (with or without reasonable accommodations) to receive such services in a more integrated setting than a nursing home ... but (3) are either unnecessarily confined and segregated in nursing homes, or on community-based services waiting lists that do not move at a reasonable pace."

Also in August 2004, the state moved to dismiss the plaintiffs' Medicaid Act and Title II ADA claims. With respect to the Medicaid Act claims, the state argued that, based on the Supreme Court's *Gonzaga* decision, the plaintiffs do not have standing because the Medicaid Act does not confer individually enforceable rights. With regard to the ADA, the state contended that Congress exceeded its authority when it enacted Title II and thus its provisions cannot be applied to the administration of the state's waivers. This challenge to Title II prompted the U.S. Department of Justice to intervene as an *amicus*.

In September 2004, the plaintiffs responded to the state's motion to dismiss the Medicaid Act and ADA Title II claims. They argued that the Medicaid Act provisions at issue clearly include "rights creating" language and, therefore, satisfy the Supreme Court's tests for bringing action under §1983. They also argued that Congress did not exceed its authority in enacting Title II and, thus, Title II is applicable to Medicaid services. In March 2005, the court disposed of various motions.

In June 2006, the parties arrived at a settlement agreement and the court dismissed the lawsuit. The state committed to continue to improve its efforts to improve access to HCBS by people with disabilities,

including obtaining additional funding to expand its waivers.³⁶

3. Indiana: *Inch et. al. v. Humphrey and Griffin*

In July 2000, the Indiana Civil Liberties Union filed this class action lawsuit in Marion County Superior Court on behalf of individuals with disabilities who resided in nursing homes or who were at risk of nursing home placement but want to live in integrated settings with services from Indiana's HCBS waiver for individuals who are elderly or disabled. The Indiana Family and Social Services Administration was the defendant. The lawsuit alleged that 2,000 individuals with disabilities are either on waiting lists for community services or suffering "unjustified institutional isolation" and, hence, experiencing discrimination prohibited by the ADA. The complaint pointed out that Indiana spent less than 9% of its elderly and disabled budget to support individuals in integrated home and community settings. It further alleged that new enrollments in the state's community programs had been closed for two years and new applications were not being taken. The plaintiffs argued that people in nursing home facilities or at risk of nursing home placement must be given the choice of waiver services rather than *de facto* limited to institutional services. The plaintiffs sought preliminary and permanent injunctions to enjoin the state from continuing violations of the ADA and direct that Medicaid eligible individuals be offered community services.

In June 2003, the parties arrived at a settlement that applies to all nursing facility residents eligible for Indiana's waiver program and individuals at imminent risk of nursing facility placement. The state has agreed to expand the waiver to serve an additional 3,000 individuals and provide more information about community services to nursing facility residents. This settlement reflects Indiana's plan to reduce the use of nursing facilities in favor of expanding community services. In addition, the "settlement sets out specific criteria for assessing the community support needs of class members and requires the state to develop a quality assurance plan for completing these assessments and discharges." (Priaulx 2005)

In December 2000, a second class action complaint was filed in St. Joseph County Superior Court (South Bend) on behalf of individuals with developmental disabilities placed in nursing facilities due to the lack of HCB waiver services. In September 2004, this lawsuit was settled. The state agreed to provide waiver services to 450 nursing facility residents with developmental disabilities over the next eight years. It

³⁶ A press release concerning the agreement is located at: tilrc.org/docs/0706georgians.htm

is estimated that there are about 1,900 nursing facility residents with developmental disabilities statewide. In addition, the state agreed to meet face-to-face with the guardians of these residents to provide them with information about community alternatives.

**4. Kentucky: Kerr et al. v. Holsinger et al.
Oregon: Watson et al. v. Goldberg et al.**

These lawsuits are similar. Both were filed in response to state actions to narrow eligibility for Medicaid long-term services in order to reduce state spending to address budget deficits. In each instance, the state raised the threshold level of assessed functional impairment necessary to qualify for Medicaid long-term services. This caused individuals with disabilities and older persons to lose eligibility. Predominantly but not exclusively, the persons affected by these actions are supported in the community through the HCBS waiver program rather than nursing facilities. In both cases, the plaintiffs challenge whether the state's modified standards for determining eligibility are reasonable under the provisions of §1902(a)(17) of the Act and whether the state properly terminated the services of these individuals. In both cases, federal courts were asked to rollback the new restrictions.

Oregon. Eligibility for long-term services is based on an assessment mechanism. There are 17 "levels" of assessed need. In February 2003, as part of its efforts to balance its budget, the state cut off services to individuals who qualified for long-term services at lower levels of assessed need. This action caused several thousand individuals to potentially lose eligibility; most of whom were receiving waiver services. The state, however, permitted these individuals to ask for a reassessment. This resulted in restoring services for many but not all individuals. In the budget for the current biennium, the Legislature directed that services be resumed for all but six levels of need. However, the net effect of these changes still was to narrow eligibility and cause individuals to lose services. In implementing these cuts, the state amended its HCBS waiver to incorporate these changes.

In response to the eligibility restriction, the Oregon Advocacy Center (OAC) filed suit in February 2003 in the U.S. District Court for Oregon (03-227) to enjoin the state from terminating benefits for affected persons. OAC argued that the state's assessment process was flawed and, consequently, did not constitute a reasonable standard for determining eligibility under federal law. OAC also argued that the state did not properly notified individuals that their eligibility would be terminated. In June 2003, the court denied the request for a preliminary injunction. The court reasoned that Oregon was free to reduce its HCBS waiver

because it is optional. In addition, relying on the *Gonzaga* decision, the court decided that affected individuals did not have an enforceable right to services.

The magistrate judge assigned to the case prepared "Findings and Recommendations" that the court dismiss all the plaintiff motions, based on the optional nature of waiver services and the interpretation that individuals do not have individually enforceable rights for Medicaid services. In June 2004, the district court accepted these recommendations, dismissed the plaintiff motions and granted the state's motion to dismiss. Meantime, because the state's budget picture brightened somewhat, the Oregon Legislature approved restoring additional two levels of assessed need, effective July 2004. In August 2004, the plaintiffs appealed the dismissal to the 9th Circuit (04-35704).

Oral argument took place in December 2005. In February 2006, the Circuit handed down its decision.³⁷ The court found that §1902(a)(10)(A) of the Medicaid Act confers an individually-enforceable right and, hence, alleged violations of this provision may be pursued in federal court under §1983. The Court ruled that, in this instance, Medicaid's Fair Hearing mechanism did not offer an alternative protection to individuals because it permitted them to contest only their assessed level of need but not their eligibility for services. However, the Circuit decided that the language of §1902(a)(17) of the Act does not confer an individually-enforceable right and, furthermore, its language is "too vague and amorphous" to permit a court to decide whether a violation has transpired. The court remanded the case to the district court for further proceedings.³⁸ In April 2006, the state filed a petition for an *en banc* rehiring before the Circuit. In June 2006, this petition was denied.

In January 2007, the plaintiffs filed an amended complaint that asked the court to enjoin the state to not make ineligible individuals who previously qualified for community services.

Kentucky. In January 2003, Kentucky made \$250 million in Medicaid cuts in order to balance its budget. Among those cuts was an action to eliminate both nursing home and waiver services for individuals who had a "low intensity level of care." This cut took effect in April 2003 and was expected to reduce Medicaid spending by \$41 million.

In October 2003, Kentucky Legal Services Programs filed a class action complaint (03-68) in the U.S. District Court for Eastern Kentucky seeking preliminary

³⁷ Decision is located at:

caselaw.lp.findlaw.com/data2/circs/9th/0435704p.pdf

³⁸ For additional discussion of this opinion, go to:
nslc.org/news/06/02/watson_9thcir.htm

and permanent injunctions to rollback the eligibility change. Attorneys with the National Senior Citizens Law Center assisted in this litigation. KLS alleges that the change in program eligibility criteria resulted in about 200 nursing facility residents and 1,200 HCBS waiver participants who are elderly and/or disabled losing eligibility. In addition, about 600 waiver applicants were denied services as a result of the change. As in Oregon, the plaintiffs challenged the state's method of assessing individuals and whether the state's procedures for terminating benefits met Medicaid and Constitutional requirements. The claims in this lawsuit roughly paralleled those in the Oregon litigation.

In October 2003, the state moved to dismiss. In its motion, the state argued that the changes it made were well within the discretion afforded states in operating the Medicaid program. In addition, the state argued that the plaintiffs lacked standing to bring suit in federal court because the Medicaid Act does not confer enforceable rights. The state also contended that, if it were required to roll back the changes, it might have no other choice but to eliminate its waiver program.

In November 2003, the plaintiffs moved for class certification and, in early December, responded to the state's motion to dismiss. The plaintiffs disputed the state's contention that the Medicaid Act does not confer enforceable rights, citing 6th Circuit rulings and other cases that ran counter to the state's arguments.

In early January 2004, Governor Ernie Fletcher signed an emergency order to reverse many of the changes that triggered the lawsuit. While encouraged by this step, the plaintiffs contended that the state had not gone far enough. As a consequence, they continued to press their case. In January 2004, the plaintiffs moved for a preliminary injunction, asking the court to require the state to roll its policies back to those in effect prior to the April 2003 change. In February 2004, the state filed a motion opposing the injunction and submitted a proposed order to dismiss the lawsuit.

In March 2004, the court ruled on the state's motion to dismiss and the plaintiffs' motion for a preliminary injunction. The court denied the state's motion, finding that federal Medicaid law grants the plaintiffs individually enforceable rights. The court agreed with the plaintiffs' contention that Medicaid's comparability requirement (§1902(a)(10) (A) of the Act) and statutory provisions concerning the HCBS waiver program require that a state must make waiver services available to individuals who qualify for nursing facility services. The court also agreed that "there is no precedent that a state can alter eligibility for a mandatory Medicaid service simply because the

state does not wish to pay the price required to provide the service to all eligible recipients." The court further observed that "reducing benefits to qualified recipients by manipulating eligibility standards in order to make up for budget deficits is unreasonable and inconsistent with Medicaid objectives since it exposes recipients to 'whimsical and arbitrary' decisions ..." The court then granted the plaintiffs' motion for a preliminary injunction and ordered the immediate restoration of benefits to all persons who had lost them. In a separate order, the court also granted class certification.

In June 2004, the court preliminarily approved a settlement agreement. Under the agreement, the state committed to adopt revised eligibility regulations for nursing facility and waiver services. The plaintiff attorney characterized these rules as more liberal than the rules in effect place prior to the April 2003 change that triggered the lawsuit. The settlement also provides for a re-evaluation of persons who were denied services under the previous rules. In August 2004, the Court approved the settlement agreement but kept jurisdiction over the case for a period of two years.

5. Louisiana: Barthelemy et al. v. Louisiana Department of Health and Hospitals

In April 2000, five individuals (two with developmental disabilities and three with physical disabilities) along with Resources for Independent Living filed a complaint (00cv01083) in the U.S. District Court for Eastern Louisiana against the Louisiana Department of Health and Hospitals (DHH) alleging that the state was violating the ADA and §504 of the Rehabilitation Act by restricting the availability of services to "unnecessarily segregated settings" (i.e., nursing facilities). The plaintiffs with non-developmental disabilities sued for access to the state's elderly and disabled and/or personal care attendant waiver programs; the plaintiffs with cognitive disabilities wanted access to Louisiana's developmental disabilities and personal care attendant waivers. The plaintiffs charged that Louisiana spends "90% of its Medicaid funds on institutional services." They asked the Court to: 1) grant class action status to Louisianans with disabilities who are unnecessarily institutionalized and 2) find the state in violation of the ADA and §504 of the Rehabilitation Act.

In August 2001, the state unveiled a settlement agreement that provided for boosting state spending by \$118 million for HCBS over a four year period, provide community services to 1,700 more individuals and reduce waiting time for services to 90 days or less. The settlement plan approved by the court addressed four broad areas: (a) reducing the waiting time for community-based services; (b) supporting people to

make informed choices about service options; (c) adding a Medicaid state plan personal care services option; and, (d) instituting individualized long-term care assessments through a new single point of entry system. Persons covered by the agreement are “all persons with disabilities who are receiving Medicaid-funded services in nursing facilities, or who are at imminent risk of being admitted to a nursing facility to receive such services, who have applied for Medicaid-funded services in the community through one or more Medicaid-funded home and community-based waivers ... , who have not been determined ineligible for such community-based services, and who have not received such Medicaid-funded community-based services.” In the agreement, the state committed to eliminate the waiting list for waiver services by 2005.

The agreement was later modified to delay the addition of entitled personal care services to the Medicaid state plan until July 2003; in exchange, the state agreed to add 500 more “slots” to its three waivers for adults with disabilities. The Louisiana Nursing Home Association objected to the personal care coverage but the court turned the objection aside. As a result of the expansion of waiver services, waiting lists have been reduced substantially.

In 2003, the DHH submitted a \$38 million request to the Louisiana legislature to pay for the addition of personal care to the Medicaid state plan. But, the legislature balked at this request. Instead, it appropriated \$28 million, instructed DHH to delay adding personal care to the Medicaid state plan, and directed state officials to return to court to modify the settlement agreement to expand waiver programs in lieu of covering personal care. The Legislature expressed concern about the long-range costs of adding a new entitlement to the state’s Medicaid program. The plaintiffs warned that they would regard failure to implement this part of the settlement as a material breach.

In July 2003, as directed by the legislature, the state moved to amend the settlement. The state proposed to expand waivers to serve an additional 2,000 individuals instead of adding personal care coverage. In support, the state pointed out that more class members would qualify for waiver services than the state plan service because the waiver has higher income eligibility thresholds. Also, the state argued that class members could access a wider range of services through the waiver. The state argued that its proposed waiver was sufficient to serve all remaining individuals waiting for services and individuals who would be likely to seek services in the near to mid-term. Lastly, the state argued that the legislature had shown a willingness to underwrite the costs of expanded waiver services and thereby using the waiver would provide stable funding.

The Louisiana Advocacy Center (LAC), which represents the plaintiffs, opposed changing the agreement. The plaintiffs argued that – absent an entitled personal care benefit – there was a danger that waiting lists would reemerge in Louisiana. In August 2003, LAC moved that the court enforce the settlement agreement. In its motion, LAC argued that was no material change to justify modifying the agreement. LAC pointed out that the coverage of personal care services had been expressly included in the settlement agreement to ensure that individuals have immediate access to services whether or not waiver slots were available. LAC also pointed out that the personal care benefit would provide more hours per week of services than were available through the waivers and, furthermore, individuals served in the waiver could also access state plan personal care benefits. LAC urged the court to order the state to implement state plan personal care services as rapidly as possible.

National AARP filed an *amicus* brief in support of the LAC motion. In the meantime, nursing home interests tried to intervene in support of the state’s proposed modification, expressing concern that the activating the personal care option might put their businesses at risk. In August 2003, the state replied to the plaintiff motion in opposition. The state reiterated that it was not seeking to escape its obligations but only to alter how services are provided.

In September 2003, the court denied the state’s motion to modify the settlement, directed it to comply with the settlement order and rejected the nursing home request to intervene. However, the court turned down the plaintiffs’ request that the court enforce the settlement agreement. DHH affirmed it would comply with the court order. The Legislature then gave DHH officials the go ahead to submit a Medicaid plan amendment to add personal care but directed that DHH return to the Legislature for approval in the event that CMS required modifications in the plan amendment.

After encountering some difficulties in securing CMS approval of the plan amendment, the state got the go ahead to offer personal care in January 2004. State officials expected that 2,300 individuals would receive personal care by June 2004. Reportedly, within three weeks of the program’s launch, the state had received 1,000 applications.³⁹ However, due to delays in processing applications, LAC returned to court in July 2004 to demand that the state establish timelines for prompt action on requests for personal care services. In August 2004, the state opposed the plaintiff motion that the court intervene to enforce the agreement. The

³⁹ More information about the lawsuit’s “successes and challenges” is at advocacyla.org/news/barthelemy.htm.

state argued that it had done all that was possible to expand services and court intervention was not appropriate. Later that month, the court refused to intervene.

In March 2006, the plaintiffs petitioned the court to extend the settlement agreement which expired in December 2005. The plaintiffs argued that a principal objective of the agreement – that persons eligible for waiver services receive them within 90 days – had not been met. About 10,000 people were wait listed for elderly and disabled waiver services and wait times for entry into the waiver were more than two years. The state opposed this motion, pointing to its rapid-paced expansion of waiver and personal care services over the past five years. In May 2006, the court approved an extension of the agreement until December 2006.

6. Massachusetts: Hutchinson et al. v. Patrick et al.

On May 17, 2007, four individuals who have experienced a brain injury and the Brain Injury Association of Massachusetts (BIAMA) filed a complaint (07-30084) in the U.S. District Court for Massachusetts alleging that the Commonwealth's policies cause them and similarly situated individuals to be unnecessarily confined in segregated nursing and rehabilitation facilities when they could be supported in the community. The complaint was filed by the Center for Public Representation and private attorneys against the Governor of Massachusetts and state agencies that are responsible for furnishing services to persons who have had a brain injury.

The complaint alleges that there are 8,200 people served in Massachusetts nursing and rehabilitation facilities who have had a brain injury. At least 25% of these individuals want to return to the community and have been assessed as able to live in the community. The plaintiffs also contend that these individuals are not receiving appropriate rehabilitative and other therapeutic services in institutions and, consequently, their condition is worsening. It also is believed that there are hundreds of additional individuals in the community who are at risk of institutionalization due to a brain injury. The plaintiffs point out that the Commonwealth operates a HCBS waiver for persons who have experienced a traumatic brain injury but the waiver only accommodates 100 individuals.

The complaint was brought as a §1983 action and charges that Massachusetts: (a) is violating the ADA's integration mandate; (b) also violating the ADA by operating its programs in a discriminatory manner that limits access to community services to people who have had a traumatic brain injury but not persons who have experienced other acquired brain disorders (e.g., a stroke); (c) §504 of the Rehabilitation Act; (c)

§1902(a)(8) of the Social Security Act for failure to provide individuals services with reasonable promptness; and, (d) §1915(c)(2)(C) of the Social Security Act for not affording individuals a choice between community and institutional services. The proposed class includes individuals who: "(1) are Medicaid eligible; (2) have suffered a brain injury; (3) reside in a nursing or rehabilitation facility or are eligible for admission to such a facility; and, (4) would benefit from community support services." The plaintiffs are asking the court to instruct the Commonwealth to develop a comprehensive working plan that ensures that institutionalized persons who have a brain injury receive appropriate services and enables qualified individuals to transition to community support services within a five year period.

7. Michigan: Eager et al. v. Granholm et al.

In March, 2002, six individuals and five advocacy organizations filed a lawsuit (5-02-00044-DWM) in the U.S. District Court for Western Michigan to overturn the state's freeze on enrollments to the MIChoice Program, a Medicaid waiver for persons with disabilities and seniors otherwise eligible for nursing facility services. The approved capacity of the MIChoice program was 15,000 individuals. As a result of an October 2001 freeze on enrollments, the plaintiffs contended that fewer than 11,000 individuals were participating in the program even though service demand remained high. The lawsuit was filed by Michigan Protection and Advocacy Services and the Michigan Poverty Law Program with support by a coalition of disability advocacy organizations.

The plaintiffs advanced two major legal claims. The first is that the freeze on enrollments violated the ADA by forcing individuals to seek nursing facility care rather than receive services in the most integrated setting. The second claim was that Michigan – under the terms of the waiver as approved – cannot close enrollments so long as fewer than 15,000 individuals participate. The plaintiffs also claim that Michigan did not provide individuals a choice between institutional and waiver services, maintain a proper waiting list for the MIChoice program, and violated the reasonable promptness requirement. The proceedings were put on hold to give newly-elected Governor Granholm's administration time to formulate its position concerning the litigation. The Governor subsequently announced that she was reopening program enrollments to a limited extent.

In February 2004, the court approved a settlement agreement. In part, the agreement provides that the state will: (a) provide for no less than \$100 million in funding for MIChoice in the current fiscal year, ask the

legislature to approve a change in Medicaid policy that would permit an additional \$25 million to be allocated to MI Choice, and pursue additional changes that might result in yet another \$25 million to be allocated to the program; (b) distribute informational materials concerning MI Choice services to individuals receiving Medicaid long-term care services and make them available to future applicants; (c) ensure that individuals are provided information about the full-range of available long-term services, including MI Choice; (d) adopt uniform medical/functional eligibility criteria that apply equally to waiver and nursing facility services; (e) develop procedures regarding the maintenance of waiting lists and obtain CMS approval for these procedures; (f) seek more funding for transitional services to individuals moving from nursing facilities to the community; and, (g) establish a Medicaid Long Term Care Task Force to develop options to expand the availability of home and community services and improve long-term services.

8. Mississippi: Billy A. and Mississippi Coalition for Citizens with Disabilities v. Jones et al.

In May 2002, the Coalition for Citizens with Disabilities filed a class action complaint (02cv00475) on behalf of the five nursing facility residents in the U.S. District Court for Southern Mississippi alleging that Mississippi's policies lead to the unnecessary segregation of individuals with disabilities in nursing homes by not making home and community services available to them. The named defendants were the Division of Medicaid and the Departments of Human Services and Rehabilitation Services. Plaintiffs alleged that the state violated: (a) the ADA and §504 of the Rehabilitation Act by failing to provide Medicaid services in the most integrated setting; (b) the Medicaid Act by not informing individuals who qualify for nursing facility services of feasible alternatives to institutionalization and thereby denying them the freedom to choose home and community services as an alternative; (c) §1902(a)(8) of the Act by not providing services with reasonable promptness; and, (d) §1902(a)(30)(A) by not making payments for Medicaid services that are "consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers." (Priaux, 2005). The court granted class certification in September 2003.

In March 2005, the parties submitted a settlement agreement to the court. The court approved the agreement and dismissed the lawsuit. The agreement provides that the state will: (a) implement a screening process to determine whether nursing facility residents can be supported in the community; (b) put nursing facility residents who want to return to the community

on the referral list for waiver services; (c) provide up to \$800 for housing and utility deposits and moving expenses to assist nursing facility residents to return to the community; (d) increase payments to personal care attendants by \$0.50 per hour; and, (e) make additional changes to improve access to community services.⁴⁰

9. New Hampshire: Bryson et al. v. Stephen

In December 1999, two persons with neurological disabilities who reside in nursing facilities but are wait listed for the New Hampshire's Acquired Brain Disorder (ABD) "model" HCBS waiver filed a class action complaint (99-cv-558) in the U.S. District Court for New Hampshire to gain access to community services. The plaintiffs alleged that the program is operated with "inadequate, capped funding through the HCB/ABI program, arbitrary limits [on] home health and other HCB services, and lack of coordination between the various public and private agencies which administer the Medicaid program."

The plaintiffs argued that "states must ensure that services will be provided in a manner consistent with the best interests of the recipients" and that a state's Medicaid program must be "sufficient in amount, duration, and scope to reasonably achieve its purpose." Moreover, they argued that the state's "administration of the HCB/ABI program, which results in a failure to provide [HCB] services to eligible Medicaid recipients in a timely manner, defeats the purpose of the program and is insufficient in the amount, duration, and scope to reasonably achieve its purpose." The plaintiffs made additional claims, including: 1) failure to provide Medicaid services in a "reasonably prompt manner;" 2) violation of the ADA by making mainly facility-based services available to eligible persons; and, 3) the due process clause of the 14th Amendment as well as other provisions of Medicaid law.

In October 2001, the court ruled on both parties' motions for summary judgment.⁴¹ It dismissed two of the seven counts in the complaint, ruled in the plaintiffs' favor on a third and decided that a fourth was moot. The court deferred judgment on three central issues: (a) whether wait listing individuals violates Medicaid law concerning reasonable promptness; (b) whether New Hampshire's policies are at odds with the ADA; and, (c) whether the state's policies violate §504 of the Rehabilitation Act. The court rejected the state's motion to dismiss on 11th Amendment grounds.

In December 2001, the court entered a final order. It found that HCBS waiver services must be furnished

⁴⁰ A notice of this agreement is at: mscoalition.com/page6.html

⁴¹ This decision is found at: nhd.uscourts.gov/ (by searching "opinions" for keyword "Bryson").

with reasonable promptness and that individuals are entitled to model waiver services until 200 persons are served. Federal law provides that the Secretary of Health and Human Services may not limit model waiver programs to fewer than 200 individuals. The order incorporated a stipulated agreement between the parties that eligible individuals be enrolled in the program within twelve months of their date of eligibility.

The state appealed the district court ruling to the 1st Circuit Court of Appeals. In October 2002, the Circuit ruled that the district court erred in its interpretation of §1915(c)(10) of the Social Security Act.⁴² The district court interpreted the statute to require that a model waiver program must serve no fewer than 200 individuals. The Circuit found that this provision instead barred the Secretary of HHS from denying a state's request to serve up to 200 individuals but that a state could limit the number of individuals in a model waiver to fewer persons. The Circuit vacated the district court order but also made it clear that the state was obligated to furnish waiver services to individuals with reasonable promptness up to the limit it had established, characterizing the waiver participant cap as a limitation on eligibility. The Court also affirmed that the plaintiffs had standing to pursue their claims in federal court under §1983. The Circuit remanded the case to the district court to determine whether changes that New Hampshire had made in its notice provisions complied with federal requirements and whether the state operated the waiver in accordance with the reasonable promptness requirement.

Upon remand, the parties renewed their motions for summary judgment. In March 2004, the court denied both motions.⁴³ In its order, the court pointed out that the 1st Circuit's decision had effectively reduced the legal issues to those that revolve around the ADA and the principles laid down in the *Olmstead* decision. The court noted that its task was to sort out New Hampshire's policies in light of the *Olmstead* decision, a task that would require it to grapple with several complex questions, including whether New Hampshire's waiting list is moving at a reasonable pace and the dividing line between "reasonable modifications" and "fundamental alteration." The court indicated that it would not necessarily confine its consideration of these issues to the ABI waiver but might take into account the overall resources that might be available to meet the plaintiffs' needs. In denying the motions for summary judgment, the court noted that neither party had presented sufficient evidence to permit it to rule

⁴² The Circuit Court decision is at ca1.uscourts.gov/cgi-bin/getopn.pl?OPINION=02-1059.01A.

⁴³ Ruling located at drcnh.org/Brysondecision.pdf. See also drcnh.org/Bryson.htm

on the ADA/*Olmstead* claims. A three-day trial took place in October 2005.

Finally, in September 2006, the court handed down a decision.⁴⁴ Observing that "exploring the relationship between Medicaid and the integration mandates of the Americans with Disabilities Act ("ADA") and Section 504 of the Rehabilitation Act ("RA") requires navigating in murky waters," the court ruled that it did not have a basis for ordering the state to increase the number of people served through the ABD waiver and thereby eliminate the waiver waiting list. The court agreed with the state that such an order would cause a fundamental alteration. The court noted that the state had steadily increased the capacity of the ABD waiver over the years and that the waiting list had moved at a reasonable pace. As a result the court dismissed the ADA and §504 claims. At the same time, the court approved an August 2005 settlement agreement between the parties under which the state committed to make procedural changes in how requests for waiver enrollment are handled.

10. Washington: *Townsend v. Arnold-Williams*

Filed in the U.S. District Court for the Western District of Washington in 2000 (00-cv-00944), this lawsuit challenged Washington's policy of not extending eligibility for its Medicaid Community Options Program Entry Services (COPES) HCBS waiver program to "medically needy" individuals. Washington State limited eligibility for this program to individuals who are "categorically needy," including persons whose income is less than 300% of the federal SSI benefit. Medically needy individuals (e.g., persons whose income exceeds categorically needy levels but who may spend down their income to qualify for Medicaid) may not participate in this program but they are eligible for nursing facility services. In this instance, the plaintiff had been participating in the COPES program but a slight increase in his income caused his status to change to medically needy. The state initiated action to terminate him from the COPES program and suggested that the plaintiff seek care in a nursing facility. The plaintiff filed suit, arguing that the state's policy violated the ADA because he could not continue to receive services in his own home. The complaint was certified as a class action.⁴⁵

⁴⁴ The decision is available at: nhd.uscourts.gov/Isys/isysquery/db38228a-0a4f-4dd1-8e43-f42d6be5a4c3/7/doc/06NH113.PDF

⁴⁵ Another lawsuit challenging a state's Medicaid financial eligibility policies for home and community-based services is *Hermanson et al. v. Commonwealth of Massachusetts et al* (00-cv-30156). This class action complaint challenged the state's policy of applying more restrictive financial eligibility criteria

In 2001, the district court ruled in the state's favor. The Court found that the state was exercising its prerogative under the Medicaid Act to limit the services it provides to medically needy individuals. Under Medicaid law, coverage of medically needy individuals is optional for the states. In addition, a state is not required to offer the same services to medically needy persons that it offers to categorically needy beneficiaries. In light of this latitude, the district court decided that the state's policy did not violate the ADA.

In 2001, the plaintiffs appealed this decision to the 9th Circuit (01-35689). In May 2003, a three-judge Circuit Court panel reversed the district court decision by a 2-1 margin and remanded the lawsuit back to the district court for reconsideration.⁴⁶ The majority based its reversal on the ADA "integration mandate," deciding that Washington's policy of offering only nursing facility services to medically needy individuals would cause their needless segregation in institutional settings. However, a strong dissent was filed.⁴⁷ The dissenting judge took the majority to task for failing to reconcile the ADA integration mandate with the latitude afforded states under the Medicaid Act and, implicitly, requiring Washington State to expand services by requiring the state to make what amounted to a fundamental alternation. Immediately, the state petitioned the Circuit for a rehearing *en banc*. This petition was rejected in June 2003.

In January 2004, the parties entered into a settlement agreement. Under the terms of the agreement, court proceedings were stayed, contingent on the state's securing federal approval of a new HCBS waiver program for medically needy persons. The state then secured funding for this program from the legislature and CMS approved the state's waiver request. The new program was implemented in June 2004 and limits services to no more than 200 individuals. The plaintiffs reserved the right to reinstate the lawsuit if a

waiting list for the new waiver program emerges. In June 2006, the court dismissed the case, finding that the state had implemented the settlement agreement.

to seniors than working age adults with disabilities. In essence, Massachusetts permitted younger persons with disabilities to qualify for Medicaid without spenddown when their income did not exceed 133% of poverty but older persons faced spend down requirements once their income exceeded 100% of poverty. As a consequence, older persons could less readily access Medicaid personal assistance services than younger persons and, thus, the plaintiffs argued, were placed at greater risk of institutionalization. The plaintiffs claimed this policy violated the ADA's integration mandate and its non-discrimination provisions. This lawsuit was settled in February 2003 when the state agreed to adopt more liberal financial eligibility criteria for older persons who need personal assistance. (Priaulx, 2005)

⁴⁶ Decision at:

caselaw.findlaw.com/data2/circs/9th/0135689P.pdf

⁴⁷ The dissent is included in the file containing the majority opinion at the foregoing URL.

III. Community Placement of Institutionalized Persons

A. Overview

There is a long history of litigation concerning institutionalized persons with disabilities, dating back to the landmark Alabama *Wyatt v. Stickney* lawsuit in 1970.⁴⁸ In developmental disabilities services, this litigation revolved mainly around the conditions of public institutions and their lack of adequate and appropriate services. Over time, this litigation increasingly came to focus on the question of the necessity of institutional placement and led to court directives to place institutional residents in the community. There has been similar litigation concerning individuals confined to state mental health facilities.

The U.S. Supreme Court's historic 1999 *Olmstead* decision ruled that the unnecessary segregation of individuals with disabilities in institutions constitutes prohibited discrimination under the ADA. In its majority opinion, the Court concluded that Title II of the ADA requires a state to place institutionalized persons with disabilities in community settings when: (a) the state's treating professionals have determined that a community placement is appropriate; (b) the transfer from an institution to a more integrated setting is not opposed by the affected individual; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state along with meeting the needs of other persons. In the wake of the *Olmstead* decision, there have been several lawsuits concerning persons served in public institutions.

This part of the report tracks some of the lawsuits where the issue of the community placement of institutionalized persons has been engaged and where the principles set down by the Supreme Court are being adjudicated. In these lawsuits, Medicaid policy is typically not the main focus of litigation, although the Medicaid program might help underwrite the costs of community placement. Also included are lawsuits concerning individuals with mental disabilities who reside in nursing facilities where issues concerning community placement have arisen.

We also acknowledge that there have been several lawsuits filed to oppose the community placement of institutionalized persons with developmental disabilities. Many of these lawsuits have been filed in state court by institutional parent groups who are sometimes

aligned with public employee associations. Often, these lawsuits revolve around the question of the standing of guardian parents to refuse consent for community placement. Usually, the outcome of some of these lawsuits has been to slow but not halt the closure of state facilities.

B. Description of Lawsuits

1. Arkansas: Porter and Norman v. Knickreim et al.

In October 2003, two residents of the Southeast Arkansas Human Development Center filed suit (03-CV-812) in the U.S. District Court for Eastern Arkansas against state officials to challenge the constitutionality of the admission and discharge procedures at Arkansas' six large institutions for persons with developmental disabilities. The plaintiffs claim that the state's not providing for judicial hearings to determine whether they must continue to be confined at a Human Development Center violates the Due Process and Equal Protection clauses of the 14th Amendment. Under Arkansas state law, the parents of an individual with mental retardation may petition for their voluntary admission to a state facility and persons so admitted may be discharged at the request of parents. However, there is no provision for judicial review of the continued placement of an individual at a facility. The plaintiffs are asking the court to declare Arkansas' policies unconstitutional and to direct the state to institute appropriate judicial review procedures. This complaint was filed on behalf of the plaintiffs by the Arkansas Disability Rights Center (DRC), the state's P&A.⁴⁹ In February, 2004, the court turned aside the state's motion to dismiss the lawsuit. While dismissing the plaintiffs' Equal Protection claims, the court decided that there was a potential basis for their Due Process claims. In addition, the court permitted an association of Human Development Center families to intervene. In March 2004, the plaintiffs filed a second amended complaint. In July and August 2004, the plaintiffs and the state moved for summary judgment.

In November 2004, the court ruled on summary judgment motions. It decided that Arkansas admission policies met due process tests but ordered the state to develop post-admission review procedures to ensure that individuals admitted as a result of a parent/guardian petition would not be unnecessarily confined in an HDC when they have been determined to benefit from community placement. In June 2005, the court

⁴⁸ It is worth noting that, in December 2003, the *Wyatt* case was dismissed 33-years after the complaint was originally filed. The court found that Alabama had satisfactorily implemented a settlement agreement that was entered into in 2000. For more information: bazelon.org/newsroom/12-15-03wyatt.htm.

⁴⁹ There is additional information at: arkdisabilityrights.org/law/alerts.html

ruled that new procedures proposed by the state were sufficient and dismissed the complaint.

In July 2005, DRC appealed (05-2978) the judgment to the 8th Circuit Court of Appeals on two issues: "whether adults with mental retardation who are 'involuntarily confined' or at risk of 'involuntary confinement' in a human development center should be entitled to pre and post confinement hearings which provide the full panoply of protections guaranteed by the Fourteenth Amendment Due Process and Equal Protection clauses of the United States Constitution." The plaintiff asked for access to judicial review of involuntary placements.

In August 2006, the Circuit affirmed the District Court order.⁵⁰ The Circuit decided that the state had already put into place various protections and that it did not thereby have a basis for ordering the addition of more protections.

2. California: Davis et al. v. California Health and Human Services Agency et al.

In 2000, a class action complaint was filed in the U.S. District Court for the Northern District of California on behalf of present and potential residents of Laguna Honda Hospital (a 1,200-bed nursing facility in San Francisco). This lawsuit was triggered when plans were announced for a \$400 million renovation of the facility. The complaint argued that the City and County of San Francisco (which operates the facility) along with several state agencies were violating federal Medicaid law and the ADA by denying individuals with disabilities access to community services and thereby forcing them to remain or be institutionalized. Plaintiffs are represented by a coalition of disability and advocacy organizations. The US Department of Justice also filed an *amicus* brief in support of the plaintiffs. In August 2001, the Court rejected San Francisco's motion to dismiss the lawsuit. The facility was the subject of an ongoing investigation by USDOJ under the provisions of the Civil Rights for Institutionalized Persons Act (CRIPA). In April 2003, USDOJ wrote the City of San Francisco that it had found the operation of the facility did not comport with the principles enunciated by the Supreme Court in *Olmstead* decision. USDOJ faulted discharge planning at the facility and noted that many residents had been identified who could be served in a more integrated setting. It urged the City to expand home and community services and make other changes. Absent resolution of these issues, USDOJ warned that the Attorney General might institute a lawsuit to correct the deficiencies.

⁵⁰ The ruling is located at: caselaw.lp.findlaw.com/data2/circs/8th/052978p.pdf

In December 2003, the court gave preliminary approval to settlement agreements between the plaintiffs, the city and the state.⁵¹ Under the agreement, the city launched a targeted case management program to assess current residents and potential admissions to the facility to determine whether other community alternatives could be furnished to them instead. Also, the city agreed to furnish information about community services to current residents and take additional steps to encourage the use of community alternatives. In addition, California committed to revamp its pre-admission screening program for individuals with psychiatric disabilities to place greater emphasis on community alternatives to nursing homes. The settlement, however, has not stopped the renovation of the facility, which began in November and is expected to be completed in 2007. The plaintiffs reserved the option to refile elements of the lawsuit that involve community placement.

In October 2006, six Laguna Honda residents filed a new lawsuit (*Chambers et al. v. City and County of San Francisco*, 06-06346) in the U.S. District Court for the Northern District of California.⁵² The plaintiffs allege that the city is violating the ADA and §504 by not providing facility residents timely access to home and community-based services even though assessments have determined that the vast majority of residents are capable of and prefer to live in the community. The plaintiffs are seeking declaratory and injunctive relief to compel the city to comply with the *Olmstead* decision. In January 2007, the parties petitioned the court to stay proceedings while they negotiate a settlement. Settlement discussions are continuing.

3. California: Capitol People First et al. v. California Department of Developmental Services et al.

This class action complaint was filed in January 2002 in Alameda County Superior Court by California Protection and Advocacy, Inc. (PAI) on behalf of 12 individuals with developmental disabilities served in state Developmental Centers or other large congregate facilities (including nursing facilities), three community organizations and two taxpayers. The

⁵¹ A description of the settlement agreement along with the agreements are located on the Bazelon Center website at: bazelon.org/newsroom/1-5-04davis_settlement.htm. More information also is available at: pai-ca.org/BulletinBoard/DavisvsLHHSettlement.htm.

⁵² More information is available at: pai-ca.org/news/lhh/index.htm as well as bazelon.org/newsroom/2006/10-11-06SFNursingHomeSuit.htm. See also article at: http://online.wsj.com/public/article/SB117830578708292504-jibDmReelsV2gMYqxiK8t40DHu4_20070514.html

lawsuit was filed against the Departments of Developmental Services, Health Services and Finance along with California's Health and Human Services Agency and the 21 non-profit Regional Centers that manage community services for people with developmental disabilities.

The lawsuit charges that California has caused thousands of individuals to be "needlessly isolated and segregated" in large congregate public and private facilities and further contends that the lack of appropriate community services causes persons with disabilities to be put at risk of institutionalization. The plaintiffs argue that California's policies violate the state's Lanterman Act (especially its "integration mandate") and Constitution along with the ADA, federal Medicaid law, §504 of the Rehabilitation Act and the federal Constitution. The Lanterman Act governs the delivery of services for persons with developmental disabilities and requires that all eligible persons be provided services. The plaintiffs have asked the court to certify a class of "all Californians with developmental disabilities who are or will be institutionalized, and those who are or will be at risk of institutionalization in either public or private facilities, including but not limited to, the Developmental Centers, skilled nursing facilities, intermediate care facilities (ICF/DDs), large congregate care facilities, psychiatric hospitals or children's shelters." If the class is certified as proposed, it would include roughly 6,000 persons residing in large congregate facilities and an estimated 400 individuals who are at risk of institutionalization each year. According to the plaintiffs, some 1,000 of the 3,700 persons served at the state's Developmental Centers have been recommended for discharge to the community but continue to be inappropriately institutionalized.

The lawsuit asks the Court to order sweeping changes in California's services for people with developmental disabilities, including requiring the state to offer the full range of Medicaid home and community-based services to individuals and strengthening other dimensions of community services.⁵³ In March 2002, the court decided to treat the lawsuit as "complex litigation" (2002038715) and assigned it a division expressly charged with handling such cases. In November 2002, the California Association of State Hospital Parent Councils for the Retarded (CASH/PCR) and the California Association for the Retarded (CAR) petitioned to intervene in the litigation. These associations are composed of parents of some individuals served in state-operated facilities.

⁵³ More information is at paica.org/BulletinBoard/Index.htm#CPF

They sought intervenor status because they do not believe that the defendants will adequately represent the interests of institutionalized persons who might be endangered by community placement. This petition was opposed by the plaintiffs along with some Regional Center defendants. In January, 2003, the Court gave the parents leave to intervene but confined their intervention to the "parameters of the complaint." The court admonished the intervenors not to attempt to enlarge the issues in the litigation and confine themselves to two issues: "ensuring that the legal rights of parents to participate in the planning process and the ability of professionals to recommend placement in developmental centers are not adversely affected by any judgment in this action."

In August 2003, the state defendants (as distinct from the Regional Center defendants) filed a motion for summary adjudication concerning the plaintiffs' Lanterman Act claim to enforce the Act through court-issued "writs of mandate." The state argued that the Lanterman Act creates only discretionary duties upon the state defendants and thereby the court cannot compel action because the Act does not create a "mandatable duty" with respect to alleged violations. In addition, the state filed a motion to throw out the plaintiffs' claim that the state's policies violate the federal Medicaid Act.

In November 2003, the court handed down tentative rulings on the state's motions. With respect to whether the Lanterman Act creates a mandatable duty that courts can enforce through writ proceedings, the court decided in the state's favor and dismissed this cause of action. However, the Court noted that its dismissal did not address "whether Defendants are in compliance with the Lanterman Act or whether it can be enforced through other means." The Court also dismissed plaintiff claims alleging violations of the federal Medicaid Act. The Court was persuaded by the state's argument that the Medicaid Act does not create a right of private action for individual beneficiaries, concluding that the Act "merely describes what states must do to ensure continued [federal] funding and authorizes the Secretary to withhold or limit Medicaid payments to a state in violation of [its] provisions." In reaching this conclusion, the Court was persuaded by the federal district court decision in the Utah *DC v. Williams* litigation (see above) where the court decided that the application of the U.S. Supreme Court's *Gonzaga* decision led to the conclusion that the Medicaid Act does not confer individually enforceable rights.

In December 2003, the Court clarified its November decision. The Court decided that, while it could not use a writ of mandate to remedy any wrong under the Lanterman Act, there was the potential that it could

use injunctive relief to remedy violations of the Act. In addition, the Court gave the plaintiffs more time to fashion their petition for class certification. January 2004, the state filed a motion arguing that injunctive relief also could not be used to remedy violations of the Lanterman Act and asked the court to dismiss claims based on the Act. In February 2004, the court denied the state's motion. Also, in February 2004, the plaintiffs filed their motion for class certification and a hearing on the motion was scheduled for April 2004.

In April 2004, the state petitioned the California Court of Appeal in San Francisco to stay proceedings in the lawsuit until the court could review the lower court's Lanterman Act rulings. The Court of Appeal granted the stay. In its petition, the state once again argued that the Lanterman Act does not create a judicially enforceable "mandate" that requires people with disabilities to be served in the least restrictive setting. Instead, the statute should be regarded as merely intent language with implementation left to state and regional center discretion. The Court of Appeal issued a writ vacating the lower court's Lanterman Act rulings. However, the Court gave the plaintiffs the leeway to amend their complaint to reinstate a violation of the Lanterman Act as a cause of action.

In July 2004, the plaintiffs filed an amended complaint. They also petitioned the court to reinstate their claims of violations of the Medicaid Act, citing rulings in other cases that ran contrary to the court's view that Medicaid beneficiaries do not have individually enforceable rights, based on the *Gonzaga* decision. The State objected to the reassertion of Lanterman Act claims in the amended complaint. A hearing was held in late September concerning the reinstatement of the Medicaid Act claims and the state's objections to the renewed Lanterman Act claims.

In January 2005, the court ruled that the plaintiffs' could go forward to trial on their claim that the State has failed to exercise its discretion consistent with the statutory principles of the Lanterman Act and Medicaid law. The state had again challenged the sufficiency of the complaint, arguing, in essence, that it has unbridled discretion, and thus cannot be sued for how it implements the Lanterman Act or Medicaid laws.

The state appealed this decision. In March 2005, the Court of Appeal denied the state's petition. According to PAI attorneys, the "ruling means that plaintiffs in this case, and regional center consumers, generally, can enforce the requirements of the Lanterman Act and the Medicaid Act including the least restrictive environment, or integration, requirements if the state is not exercising its discretion within the proper limits or under a correct interpretation of the law."

In December 2005, the court denied class certification, ruling that the issues posed in the lawsuit revolved around highly individual circumstances. Also, the court decided that there was a lack of commonality among the plaintiffs. The plaintiffs have appealed this decision. In April 2006, the court declined to enter a ruling based on the pleadings to date. Proceedings are stayed while the Court of Appeals considers the appeal.

In early October 2006, the plaintiffs and four of the defendant Regional Centers (Kern, Redwood, Tri-Counties, and Valley Mountain; a.k.a., the Community Imperative Regional Centers) notified the court that they had arrived at a settlement agreement. These regional centers are hopeful that this agreement will serve as a model for the ultimate settlement of the entire lawsuit. Under the agreement, the four regional centers agreed to arrange community placements for more than one-half of Development Center residents from their service areas by 2012. In addition, these regional centers will perform a Comprehensive Community Needs Assessment of all residents of large, congregate facilities in their service areas and work with such facilities to downsize their operations.

In December 2006, the parent Interveners and the state filed motions opposing the settlement. The state objected on the grounds that the agreement required the state to take certain actions but the state itself was not a party to the agreement. In late January 2007, the settlement was withdrawn in order to modify it. It will be resubmitted once the California Court of Appeals rules on the appeal of the denial of class certification.

4. Connecticut: Office of Protection & Advocacy for Persons with Disabilities v. Connecticut Department of Social Services et al.

In February 2006, the Connecticut Office of Protection & Advocacy (OPA) filed a complaint (06-00179)⁵⁴ against the Connecticut Departments of Social Services, Public Health, and Mental Health and Addiction Services in the U.S. District Court for the District of Connecticut, alleging that individuals with mental illnesses are needlessly unnecessarily isolated and segregated in nursing home facilities in violation of the ADA and §504 of the Rehabilitation Services Act. The complaint centers on 200 individuals with mental illnesses who are served in three nursing facilities in New Haven. The Bazelon Center for Mental Health Law is serving as co-counsel.⁵⁵

⁵⁴ The complaint is located at: ct.gov/opapd/lib/opapd/documents/adobe/complaint_opa_v_st ate_of_ct.pdf

⁵⁵ Additional information about the complaint is located at: bazelon.org/newsroom/2006/2-6-06-OPA v CT.html

The complaint charges that individuals served in these nursing facilities are housed in locked units. The complaint alleges that the annual costs of nursing facility services is between \$50,000 and \$80,000 per year and these individuals could be served more appropriately and economically in community mental health settings, including supportive housing living arrangements. In part, a 2004 report of the Lieutenant Governor's Mental Health Cabinet⁵⁶ provides the basis of this lawsuit. Based on the report, the lawsuit notes that there are more than 2,700 individuals with psychiatric disabilities housed in Connecticut nursing facilities and that the number is growing at a rate of between 5 and 10 percent annually. Many of these persons are placed in nursing homes "solely to obtain mental health care that could easily be provided in an integrated, community-based setting." The high rate of placement to nursing facilities is attributed to the state's failure to expand community services in the wake of its shrinking state mental health hospital services. The lawsuit contends that Connecticut has no comprehensive working plan to meet the needs of these individuals in the community, as required by the *Olmstead* decision.

In May 2006, the state agencies filed motions to dismiss. These motions challenged the legal standing of OPA to bring a lawsuit of this nature. In September 2006, the parties informed the court that they were making progress in arriving at a settlement.

5. Florida: Brown et al. v. Bush et al.

This 1998 class action complaint (98cv673) was filed in the U.S. District Court for Southern Florida and sought a declaratory judgment and permanent injunction to prevent the state from unnecessarily institutionalizing individuals with developmental disabilities in violation of the ADA integration mandate, §504 of the Rehabilitation Services Act, Medicaid law, and the U.S. Constitution. In March 1999, the court certified the plaintiffs' proposed class of: "all persons who on or after January 1, 1998, have resided, are residing, or will reside in DSIs [Developmental Services Institutions] including all persons who have been transferred from [institutions] to other settings, such as ICF, group homes, or SNFs but remain defendant's responsibility; and all persons at risk of being sent to DSIs."

Florida appealed the class certification to the 11th Circuit. In 2000, The 11th Circuit agreed that the proposed class was overly broad and remanded the case to the district court with instructions to certify the class as

composed of "all individuals with developmental disabilities who were residing in a Florida DSI as of March 25, 1998, and/or are currently residing in a Florida DSI who are Medicaid eligible and presently receiving Medicaid benefits, who have properly and formally requested a community-based placement, and who have been recommended by a State-qualified treatment professional or habilitation team for a less restrictive placement that would be medically and otherwise appropriate, given each individual's particular needs and circumstances."

After extended negotiations and the assistance of a mediator, the parties arrived at a settlement agreement. In July 2004, a final proposed agreement was presented to the court for review. The agreement provided that, by June 2005, the state will prepare a plan to close Gulf Coast Center and close the facility by 2010. Coupled with the closure of Community of Landmark (another DSI facility located in Opa Locka that is slated for June 2005), the agreement will reduce from four to two the number of facilities that Florida operates. The agreement also provided for earmarking HCBS waiver "slots" to accommodate the transition of individuals from DSIs to the community.

The September 2004 notice of the proposed settlement agreement triggered numerous objections from groups interested in preserving institutional services. Among other things, the objectors claimed that the closure of the facilities would violate Medicaid free choice of provider requirements. In December 2004, court held a fairness hearing. Following the fairness hearing, a group of objectors filed an appeal at the 11th Circuit Court of Appeals. The Circuit denied objectors' petition. The court rejected the Medicaid claim, noting that two state facilities would remain open. The district court then approved the settlement order in August 2005. The objectors then filed a new appeal (05-15167) at the 11th Circuit in September 2005. The state opposes the appeal, arguing that the district court properly approved the settlement order. The state pointed out that the objectors seek to require that the state to continue to operate at Gulf Coast Center. The state argues that there is no basis in federal law that supports the assertion of a right to a placement in a specific facility or that requires a state to maintain the operation of a particular facility. In September 2006, the Circuit denied the objectors' effort to intervene.

6. Illinois: Ligas et al v. Maram et al.

This class action complaint (05-04331) was filed in July 2005 in U.S. District Court for the Northern District of Illinois. The complaint alleges that Illinois' policies result in the unnecessary institutionalization of individuals with developmental disabilities in large,

⁵⁶ Located at: ct.gov/ltgovksullivan/lib/ltgovksullivan/Connecticut_Mental_HealthKBS2_-_FINAL.pdf

congregate privately-operated ICF/DD facilities when such individuals could be supported in more integrated community settings. The plaintiffs are represented by Equip for Equality (the Illinois Protection and Advocacy agency), Access Living, the American Civil Liberties Union of Illinois, the Public Interest Law Center of Philadelphia, and a private law firm serving as trial counsel on a *pro bono* basis.⁵⁷

In Illinois, there are 250 large ICF/DD facilities that serve approximately 6,000 individuals. The complaint contends that Illinois prevents people who reside in these facilities from accessing more integrated home and community waiver services and forces other individuals to accept ICF/DD services when HCBS would meet their needs. This is the first lawsuit of this type that focuses exclusively on potential *Olmstead* violations with respect to private ICF/MR facilities.

In particular, the lawsuit alleges that Illinois is violating: (a) Title II of ADA; (b) §504 of the Rehabilitation Act; and (c) several provisions of Medicaid law, including §1902(a)(8) (reasonable promptness), §1915(c)(2)(C) (choice between waiver and institutional services), and §1902(a)(30)(B) (by fostering unnecessary utilization of ICF/MR services).⁵⁸

In September 2005, the state answered the complaint. In essence, the state argued that its administration of Medicaid services complies with federal law and challenged the plaintiffs' standing to bring suit.

In October 2005, the Illinois Health Care Association petitioned to intervene in the case, arguing that the litigation had major implications for the ICF/DD facilities that its members operate. Both the plaintiffs and the state have opposed this petition. Other parent advocacy groups associated with large ICF/MR facilities also petitioned to intervene.

In December 2005, the court rejected all petitions to intervene.⁵⁹ The court found that the petitioners sought to intervene out of the concern that ICF/DD residents might be forced to accept community placement when they preferred to remain in an ICF/DD. The court ruled that the complaint concerns only persons who voluntarily seek community placement and thereby does not implicate other residents. In January 2006, a group of parent interveners petitioned the 7th Circuit Court of

Appeals (06-1327) to allow them to intervene. In March 2007, the Circuit Court denied this petition.⁶⁰

In March 2006, the district court certified the class as follows:⁶¹

A class for injunctive relief consisting of all persons in Illinois with disabilities who (1) have mental retardation and/or other developmental disabilities and who qualify for long-term care services; (2) with appropriate supports and services, could live in the community and who would not oppose community placement; and (3) either are institutionalized in private ICF-DDs with nine or more residents or are living in a home-based setting and are at risk for institutionalization because of their need for services.

Trial has been tentatively scheduled for July 2008.

7. Illinois: Williams et al. v. Blagojevich et al.

This lawsuit (05-4673) was filed in the U.S. District Court for the Northern District of Illinois in August 2005 against Illinois Governor Blagojevich, the Department of Human Services and other state agencies. The lawsuit alleges that Illinois has unnecessarily segregated more than 5,000 individuals with mental illnesses in privately-operated "Institutions for Mental Disease" (IMDs) in violation of the ADA and §504 of the Rehabilitation Act. In April 2006, the plaintiffs filed an amended complaint⁶² and a motion for class certification. The plaintiffs are represented by Equip for Equality (the state's P&A) along with the Bazelon Center for Mental Health Law, the American Civil Liberties Union of Illinois, Access Living, and private attorneys.

An IMD is a facility that serves 17 or more individuals that is principally engaging in treating and housing persons with mental illnesses between the ages of 22 and 64. Federal law debar Medicaid payment for services rendered to IMD residents. According to the complaint, Illinois uses its own and IMD resident funds to pay for services rendered in privately-operated nursing facilities with IMD units that each reportedly "warehouse" more than 100 individuals with mental illnesses. The complaint alleges that these individuals receive little in the way of mental health treatment and that their lives are strictly regimented. The complaint contends that many of these residents could live more integrated lives in the community with

⁵⁷ A press release concerning this lawsuit is located at: equipforequality.org/news/pressreleases/july_28_2005illinois_residents.php

⁵⁸ The complaint is located on equipforequality.org/news/pressreleases/ligasmaramfiles.php the previously cited web page.

⁵⁹ The court's order denying the petitions to intervene also is located on previously cited web page.

⁶⁰ Decision located at: equipforequality.org/resourcecenter/ligas_interventiondecision.pdf

⁶¹ The memorandum and order granting class certification is located on previously cited web page.

⁶² A press release and copy of the complaint are located at: equipforequality.org/news/pressreleases/april_26_2006federal_court.php. See also bazelon.org/newsroom/2006/4-26-06-Williams-v-Blagojevich.html

proper supports that could be underwritten at least in part with federal Medicaid dollars. The plaintiffs are requesting relief in the form of an order that would require Illinois to offer and provide community services sufficient to permit IMD residents to reside in the most integrated community setting.

In its answer to the complaint, the state indicated that it would mount a "fundamental alteration" defense, contending that the relief that the plaintiffs are seeking would cause dislocations in other programs for individuals with mental illnesses. In July 2006, the state filed a motion opposing class certification. In November 2006, the court rejected the state's motion and certified the class as Illinois residents who: (a) have a mental illness; (b) are institutionalized in a privately-owned IMD; and, (c) "with appropriate supports and services may be able to live in an integrated community setting."

8. Maryland: Williams et al. v. Wasserman et al.

This 1994 lawsuit (CCB-94-880) was filed in the U.S. District Court for Maryland against the Maryland Department of Mental Health and Hygiene by institutionalized persons who had a traumatic brain injury or another developmental disability and were demanding that the state provide community services to them. The plaintiffs' alleged that Maryland violated (a) the U.S. Constitution by unnecessarily confining them to institutions and (b) the ADA by not serving them in the most integrated setting. In September 2001, the court dismissed the lawsuit, finding that Maryland had made a good faith effort to (a) meet the needs of the plaintiffs and (b) accommodate individuals in the community.

This lawsuit was filed prior to the *Olmstead* decision. The district court's final decision came after the *Olmstead* decision and hinged in part on the court's view that ordering Maryland to step up its efforts to support individuals in the community would cause a "fundamental alteration" in state programs for individuals with disabilities. In arriving at this conclusion, the court noted that Maryland had substantially reduced the number of persons served in its institutions and increased community services. With respect to the plaintiffs, the court noted that the state had tried to arrange community services on their behalf, sometimes successfully but sometimes not. The court decided that ordering the state to step up its efforts would lead to increased expenditures in the short run and thereby affect the state's capacity to serve other individuals. In the court's view, this result would lead to a fundamental alteration and thereby exceed the parameters laid down by the Supreme Court.

9. Massachusetts: Rolland et al. v. Patrick et al.

In October 1998, a complaint (98-30208) was filed in the U.S. District Court for the District of Massachusetts on behalf of seven Massachusetts residents with mental retardation and other developmental disabilities who were served in nursing facilities. The plaintiffs contended that they were denied alternative community placements or "specialized services" mandated by the federal Nursing Home Reform Amendments enacted in the Omnibus Budget Reconciliation Act of 1987. The law directed that states arrange alternative placements for inappropriately placed residents with developmental disabilities or mental illnesses or, if the person opts to remain in a nursing facility, furnish specialized services that addressed their impairments. The plaintiffs also alleged that the failure to provide such services violated Title II of the ADA.

In October 1999, the state agreed to offer community residential services and specialized services to nursing home residents with developmental disabilities under the terms of a mediated settlement agreement. The state consented to underwrite community placements to class members (858 individuals) unless it was determined that an individual could not "handle or benefit from a community residential setting." These placements would take place over a multi-year period.

In 2000, the plaintiffs filed a motion asking the court to find the state in violation of the agreement concerning the provision of specialized services to individuals still residing in nursing facilities. In March 2001, the court ruled that the state was required to furnish specialized services sufficient to ensure "active treatment." The court found that, if the services furnished by a nursing facility did not meet the active treatment standard, the Department of Mental Retardation was obliged to furnish supplementary services. In May 2002, the court granted the plaintiffs injunctive relief and ordered that all class members receive services that meet the "active treatment" standard. The state then appealed this ruling to the 1st Circuit on 11th Amendment sovereign immunity and other grounds.

In January 2003, the Circuit rejected the state's appeal.⁶³ In a nutshell, the court held that, under federal law, specialized services, including "active treatment" must be furnished to all individuals who need them. The state also had argued that the nursing home reform provisions did not confer a private right to action. The court rejected this argument, holding that the legisla-

⁶³ The decision is at laws.findlaw.com/1st/021697.htm and discussed in greater depth in a Bazelon Center for Mental Health Law release (bazelon.org/newsroom/2-3-03rolland.htm.)

tion in fact did confer a private right to action, enforceable through the federal courts.

Since 2003, the court has determined that the Commonwealth has generally complied with the settlement's community placement provisions. However, in April 2007, the court ruled that the specialized services furnished to class members did not meet the "active treatment" standard and ordered additional remedial actions.⁶⁴ The Commonwealth has appealed elements of this order to the 1st Circuit Court of Appeals.

10. Michigan: *Olesky et al. v. Haveman et al.*

In September 1999, Michigan's P&A agency filed a complaint in state court on behalf of six individuals with developmental disabilities and/or mental illnesses served in nursing facilities but who wanted services in the community. In June 2000, this litigation was referred to the U.S. District Court for Western Michigan. The plaintiffs' counsel estimated that there were 500 individuals with cognitive disabilities in nursing facilities who could be served in the community. The plaintiffs alleged that Michigan was violating the "Nursing Home Reform Act of 1987" and the ADA. This complaint was similar to *Rolland v. Romney* (see above) except that it included persons with a wider range of cognitive impairments. The Court turned down the state's motion to dismiss the suit on sovereign immunity grounds. The parties then settled. The state agreed to "assure the appropriate and timely community placement of individuals determined to not require nursing facility care. (Priaux, 2005).

11. New Jersey: *New Jersey Protection & Advocacy v. Davy*

In April 2005, New Jersey Protection & Advocacy (NJPA) filed a lawsuit (05-1784) in the U.S. District Court for the District of New Jersey against the Department of Human Services (DHS) alleging that the state has unnecessarily confined individuals with mental illnesses in state psychiatric hospitals by failing to develop suitable community services to meet their needs.⁶⁵ The lawsuit charges the state with violating the ADA and §504, the due process provisions of the U.S. and New Jersey Constitutions, and other provisions of state law. The Bazelon Center is co-counsel.

New Jersey state law provides that individuals committed to state psychiatric hospitals may continue to be held in such facilities even if they do not require inpatient services when community services are not

available to meet their needs. Reportedly, more than 40% of 2,300 persons served in state facilities are in continuing placement status due to the lack of community services. The lawsuit charges that New Jersey has failed to develop a comprehensive, effective working plan to provide for the transition of individuals who are unnecessarily confined in state facilities to the community.

In July 2005, the state moved to dismiss the complaint, arguing that NJPA lacked standing to file the suit and that New Jersey is immune from lawsuits under the ADA. In September 2005, the court denied the motion.

12. New Jersey: *New Jersey Protection & Advocacy et al. v. Davy*

In September 2005, New Jersey Protection and Advocacy filed a complaint (05-04723) in the U.S. District Court for the District of New Jersey, alleging that New Jersey unnecessarily confines individuals with developmental disabilities in its state Developmental Centers.⁶⁶ At present, 3,100 individuals reside in the centers. By report, state officials have acknowledged that one-half of these individuals could be supported in the community.

The complaint claims that the state is violating Title II of the ADA, §504 of the Rehabilitation Act, and the Medicaid Act by not assessing whether developmental center residents could be supported in the community and failing to inform them of the availability of community services. The complaint further alleges that New Jersey lacks a comprehensive integration plan that ensures the movement of individuals to the most integrated setting.

In December 2005, the state answered the complaint. In its answer, the state indicated that its defense would include a claim of sovereign immunity, a claim that the court did not have jurisdiction over the matters in dispute, and a claim that granting plaintiffs the relief that they seek would entail a fundamental alteration in New Jersey's programs for persons with developmental disabilities.

In August 2006, the New Jersey legislature instructed DHS to develop a plan that would ensure that institutionalized individuals could live in the community if they wished within eight years. In May 2007, the New Jersey Division of Developmental Disabilities released "Path to Progress," an *Olmstead* plan that provides for transitioning 1,850 developmental center residents to the community over an eight-year period.⁶⁷

⁶⁴ Order at: centerforpublicrep.org/uploads/NI/By/NIByhA-22Xui52rIA0dUOw/Rolland_non-compliance.pdf

⁶⁵ Information about this lawsuit is located at: njpanda.org/litigation.htm, including the original complaint and other motions and materials.

⁶⁶ The complaint and the state's subsequent response are located at: njpanda.org/litigation.htm.

⁶⁷ More information at: state.nj.us/humanservices/ddd/nofa.htm

13. New York: Disability Advocates, Inc. v. Pataki et al.

In July 2003, Disability Advocates, Inc.⁶⁸ filed a complaint⁶⁹ (03cv03209) in the U.S. District Court for Eastern New York against Governor Pataki, the Department of Health and Office of Mental Health claiming that the placement of individuals with mental illnesses in large “adult homes” violates Title II of the Americans with Disabilities Act and §504 of the Rehabilitation Act by causing their needless institutionalization in substandard facilities when their needs could be more appropriately and effectively met in integrated residential settings. In part, this lawsuit was prompted by the revelations of substandard care in adult homes in a 2002 series of *N.Y. Times* articles.

“Adult homes” are facilities intended to provide room and board, housekeeping, personal care and supervision to residents. The costs of these facilities are underwritten by resident funds, including state SSI supplement payments. Residents of such facilities include individuals with physical disabilities. In New York, there also are a large number of facilities where a high percentage of residents are persons with serious mental illnesses. Facilities are labeled “impacted homes” when 75% or more of the residents have a mental illness. The lawsuit targets 26 such large facilities in New York City where an estimated 4,000 persons with mental illnesses reside. Statewide, it is estimated that 12,000 individuals with mental illnesses are served in such facilities. While adult homes nominally provide limited services to residents and are not classified as mental health facilities, residents of these facilities also receive Medicaid-funded health and mental health services from other vendors. The plaintiffs charge that these services do not adequately or appropriately meet the needs of adult care home residents.

The plaintiffs charge that impacted adult homes are segregated institutional settings and as such fall under the purview of the ADA, §504 and the *Olmstead* decision. The plaintiffs point out that New York State also funds integrated “supported housing” living arrangements that are better geared to meeting the needs of people with serious mental illnesses. However, supported housing is in short supply. Citing studies conducted by the state, the plaintiffs allege that the costs of supporting individuals in supported housing arrangements are no greater than the overall costs of

adult care homes (taking into account resident payments and other Medicaid services). Since residents could be served in a more integrated setting, the plaintiffs are asking the court to order the state to expand the availability of supported housing as well as order the state to improve conditions in adult homes.

In October 2003, New York Attorney General Spitzer replied to the complaint, disputing nearly all the allegations made in the complaint. The state argued that the plaintiffs lack standing to bring the complaint and also argued that the plaintiffs who reside in adult homes have not been determined by the state’s treating professionals as appropriate for a more integrated community setting and, thus, do not fall under the ambit of the *Olmstead* decision. Also, the state argued that the relief sought by the plaintiffs would lead to a fundamental alteration. Next, the state asserted an 11th Amendment sovereign immunity defense. Lastly, the state argued that the complaint is barred – in whole or in part – because the alleged violations fell outside the statute of limitations. Therefore, the state urged the court to dismiss the complaint but has not yet filed a formal motion for dismissal. Since the lawsuit was filed, proceedings have been dominated by disputes concerning discovery. No trial date has been set.

14. New York: Jobe O et al. v. Pataki et al.

In October 2003, a class action complaint (03-cv-08331) was filed in the United States District Court for Southern New York alleging that New York State is violating Title II of the ADA and §504 of the Rehabilitation Act by failing to furnish treatment services that would permit individuals with serious and persistent mental illnesses who also have a chemical addiction to be released from New York City jails.⁷⁰ The plaintiffs allege that they have been discriminated against because other similarly situated individuals who have a chemical addiction but no or minor mental illness are released to community treatment programs more quickly. This complaint was brought on behalf of the plaintiffs by a coalition of organizations, including the Bazelon Center for Mental Health Law, the New York Legal Aid Society and the Urban Justice Center.

The plaintiffs are persons charged with violating the conditions of their parole or post-release supervision. Typically, they committed technical parole violations. The complaint alleges that these individuals have been recommended for placement in a residential treatment program in lieu of incarceration. However, a dearth of available community treatment placements causes them to be needlessly incarcerated. The complaint charges that the lack of residential treatment programs

⁶⁸ Disability Advocates, Inc. is an agency under the Protection and Advocacy for Individuals with Mental Illness Act. Co-counsel include New York Lawyers for the Public Interest, Inc., the Bazelon Center for Mental Health Law, MFY Legal Services and Urban Justice Center.

⁶⁹ bazelon.org/issues/disabilityrights/nycomplaint/index.htm has the complaint and additional information.

⁷⁰ The complaint and a discussion of the lawsuit are at: bazelon.org/newsroom/10-21-03rikers.htm.

results in these individuals languishing in jail, being sent to prison and fated to being trapped in a “vicious cycle between jail and the streets.” The plaintiffs are seeking relief in the form of New York State’s expanding supervised housing programs that serve and treat individuals with co-occurring disorders, either in the form of community residences or supported housing programs. The plaintiffs allege that the costs of needlessly confining these individuals are substantial and the dollars spent on incarceration should be redirected to underwriting community services for them.

In August 2005, the court denied the state’s motion to dismiss the complaint. In September, the state filed its answer to the complaint, denying all the plaintiffs’ claims. Proceedings are bogged down by disputes about discovery.

15. New York: Edwin T et al. v. Carpinello et al.

In March 2006⁷¹, Disability Advocates, Inc. filed a complaint (06-1042) in U.S. District Court for the Eastern District of New York against the New York Office of Mental Health, the Department of Health and Governor Pataki. The lawsuit alleges that New York has improperly placed potentially hundreds and possibly thousands of individuals with mental illnesses from its state psychiatric facilities to nursing homes in New Jersey and New York where they are confined to locked wards and receive inadequate treatment and care. The lawsuit asserts that New York is violating the ADA, the Rehabilitation Act, and the federal Medicaid Nursing Home Reform Act by failing to support these individuals in the most integrated setting or furnish necessary specialized services to them in the nursing facility.

The federal Medicaid Nursing Home Reform Act was enacted by Congress as part of the Omnibus Budget Reconciliation Act of 1987. Among its other provisions (located in §1919 of the Social Security Act), the Act required that states establish pre-admission screening (PAS) procedures to scrutinize the appropriateness of nursing facility admission of persons with mental illnesses (and developmental disabilities) and furnish necessary specialized services to individuals who are admitted to such facilities. This complaint alleges that New York has not properly complied with these requirements since people are being admitted to nursing facilities who do not require that type of service and nursing facility residents with mental illnesses are not receiving necessary specialized services to address their mental illness and thereby progress toward a more integrated living arrangement.

⁷¹ See press release at: nylpi.org/pub/03.08.06_Press_Release_Nursing_homes_case.pdf

In May 2006, the state answered the complaint. In its answer, the state indicated that it would challenge the standing of Disability Advocates to bring the complaint and assert sovereign immunity and fundamental alteration defenses. In October 2006, the parties agreed to try to reach a mediated settlement. But, in April 2007, the parties reported to the court that they were at an impasse in mediation.

16. Oregon: Miranda B. et al. v. Kulongoski et al.

In December 2000, the Oregon Legal Center filed suit (CV-00-01753) in the U.S. District Court for the District of Oregon on behalf of ten state psychiatric institution residents, contending that the state’s own treating professionals had found these individuals to be ready for community discharge but they continued to be institutionalized due to the lack of suitable community placements. The plaintiffs alleged that the state is violating Title II of the ADA, §504 of the Rehabilitation Act and the 14th Amendment’s Due Process Clause. In the plaintiffs’ view, the issues at play were analogous to those addressed by the *Olmstead* decision. The plaintiffs sought class certification.

The state moved for dismissal on various grounds, including 11th Amendment sovereign immunity. In September 2001, the court denied the state’s motion. The state then appealed to the 9th Circuit Court of Appeals (01-35950). In May 2003, the Circuit rejected the state’s appeal and remanded the case back to the district court for further action.⁷²

In December 2003, the parties agreed to settle. In March 2004, the court approved the settlement agreement and dismissed the case but retained jurisdiction to enforce compliance with the agreement. The agreement applies to the class as individuals who were civilly committed to an Oregon psychiatric hospital as of December 1, 2003, had not been discharged within 90-days of a “ready-to-place” determination by a treatment team, and had consented to community treatment. The agreement provides that the state will create 75 new community placements by June 2005 and establish a special \$1.5 million fund to provide supplemental resources to facilitate the placement of individuals who have conditions that are barriers to community reintegration. At least 31 individuals were expected to be placed in the community by June 2005.⁷³

⁷² The decision is at: caselaw.findlaw.com/data2/circs/9th/0135950P.pdf.

⁷³ The agreement is described in more detail in the Oregon Advocacy Center’s newsletter, available at: oradvocacy.org/news/OAC2004Winter.pdf

17. Pennsylvania: Frederick L., et al. v. Department of Public Welfare et al.

In September 2002, the U.S. District Court for Eastern Pennsylvania ruled against the plaintiffs in the *Frederick L. v. Department of Public Welfare* class action complaint. The plaintiffs are residents of Norristown State Hospital (a state mental health facility) who claim that their continued institutionalization at a state facility – despite recommendations for community placement – violates the ADA and § 504 of the Rehabilitation Act. This lawsuit (00-4510) was filed in 2000. The Court ruled that the plaintiffs’ circumstances fell within the criteria spelled out in the *Olmstead* decision. However, the Court decided that accelerating the pace of community placement would lead to increased expenditures and thereby potentially result in reductions in services to other individuals. The Court decided that this would constitute a “fundamental alteration” and thus ruled that it could not grant relief under the ADA. In reaching its decision, the Court relied in part on the decision in the Maryland *Wasserman v. Williams* litigation (see above).

In October 2002, the plaintiffs appealed this decision to the 3rd Circuit of Appeals (02-3721). In December 2002, fourteen former state mental health directors submitted an *amicus* brief on behalf of the plaintiffs. They argued that the district court had adopted too narrow a view concerning the financial implications of accelerated community placement by failing to take into account the potential to offset costs by employing Medicaid funds to hold down the state’s costs of supporting individuals in the community. They pointed out that the hospital was funded with state dollars (federal law prohibits Medicaid funding of “Institutions for Mental Disease”) but Medicaid funding could be used to underwrite the costs of community services. The Circuit heard oral arguments in October 2003.

In April 2004, the Circuit Court handed down its opinion.⁷⁴ In what it characterized as a “precedential” opinion, the court vacated the district court’s judgment and remanded the case back to the district for further proceedings. The Circuit decided that, in order to establish a “fundamental alteration” defense under *Olmstead*, a state had to demonstrate that it had a comprehensive working plan in effect to assure that going forward individuals would be served in the most integrated setting. The Court expressed the view that budgetary and cost considerations alone were an insufficient to support a fundamental alteration defense. While acknowledging Pennsylvania’s prior efforts to reduce reliance on institutional settings and expand

community services, the court pointed out that “past progress is not necessarily probative of future plans to continue deinstitutionalizing.” The court observed:

“After all, what is at issue is compliance with two federal statutes enacted to protect disabled persons. The courts have held states throughout the country responsible for finding the manner to integrate schools, improve prison conditions, and equalize funding to schools within the respective states, notwithstanding the states’ protestations about the cost of remedial actions. The plaintiffs in this case are perhaps the most vulnerable. It is gross injustice to keep these disabled persons in an institution notwithstanding the agreement of all relevant parties that they no longer require institutionalization. We must reflect that on that more than a passing moment. It is not enough for DPW to give passing acknowledgment of that fact. It must be prepared to make a commitment to action in a manner for which it can be held accountable by the courts.”

While not disagreeing with many of the district court findings, the Circuit directed the district court to request Pennsylvania to make “a submission that the district court can evaluate to determine whether it complies with this opinion.”

In September 2004, the District Court entered a judgment in favor of the state and dismissed the case.⁷⁵ The court found that the state’s deinstitutionalization plan and planning process “deserve the protection of the fundamental alteration defense.” The court rejected the plaintiffs’ contention that the state’s plan was not sufficiently concrete. The plaintiffs then appealed this decision to the 3rd Circuit (04-3859).

In September 2005, the Circuit handed down another ruling.⁷⁶ It decided that the district court had erred in dismissing the complaint because the state’s integration plan was not sufficiently concrete to establish a fundamental alteration defense. The court found that the plan lacked measurable benchmarks, noting that a “viable integration plan at a bare minimum should specify the time-frame or target date for patient discharge, the approximate number of patients to be discharged each time period, the eligibility for discharge, and a general description of the collaboration required between the local authorities and the housing, transportation, care, and education agencies to effectuate integration into the community.” The court remanded the complaint back to the district court for further proceedings after turning down the state’s petition for a rehearing.

In November 2005, the plaintiffs moved that the district court enter a judgment in their favor and

⁷⁴ The opinion is available at: caselaw.lp.findlaw.com/data2/circs/3rd/023721p.pdf.

⁷⁵ This decision is available at: paed.uscourts.gov/documents/opinions/04D0294P.pdf

⁷⁶ Located at ca3.uscourts.gov/opinarch/043859p.pdf

proceed to consideration of remedies. The court rejected this motion. In February 2006, the court ordered the state to submit a "viable integration plan" for Norristown State Hospital that would be consistent with the 3rd Circuit's September 2005 ruling.

In April 2006, the state submitted an 85-page four-year plan concerning community placement of Norristown residents. In May 2006, the plaintiffs informed the court that they believed that the plan complied with the 3rd Circuit decision and recommended that the court incorporate the plan into an order, require that the state comply with the plan and retain jurisdiction over the case to ensure compliance. In September 2006, the court entered an order to dismiss the lawsuit.

18. Pennsylvania: Pennsylvania Protection & Advocacy v. Dept. of Public Welfare et al.

In September 2000, Pennsylvania Protection and Advocacy (PPA) filed suit (00cv1582) in the U.S. District Court for Middle Pennsylvania on behalf of the residents of the South Mountain Restoration Center (SMRC), a state nursing facility that serves elderly individuals with severe mental disabilities, many of whom have experienced long-term institutionalization. PPA contended that SMRC residents could be served in more integrated community settings and, hence, their continued institutionalization violated Title II of the ADA and §504 of the Rehabilitation Act. PPA asked the court to appoint an independent expert to identify SMRC residents who could be placed in the community and direct the Department of Public Welfare to commence a program of community placement.

In January 2003, the court ruled in the state's favor and dismissed the lawsuit. In its ruling, the court noted that both parties agreed that many SMRC residents could be served in the community. The state, however, argued that the costs involved in serving these individuals in the community would require a "fundamental alteration" in its programs for persons with mental disabilities because community placement would lead to net increased spending and, thereby, require shifting dollars from services provided to other individuals with mental disabilities to accommodate the placement of SMRC residents.

The court was swayed by the testimony of a defense expert who calculated that the average costs of community placement would exceed average costs at SMRC and, further, that costs of community placement would not be completely offset by reduced expenditures at SMRC. Based on its reading of the *Olmstead* decision, the court decided that the predicted increase in expenditures necessary to pay for community placements but continue to operate SMRC, in fact, would cause a fundamental alteration. PPA had

urged the court to take a broader view of the fundamental alteration question by considering not only the budget for services for persons with mental disabilities but also take into account the overall state budget and other spending within the Department of Public Welfare. The Court rejected this approach, again relying on its interpretation of the *Olmstead* decision that it should confine itself to the effects on the dollars allocated for services for persons with mental disabilities.

In February 2003, PPA appealed the decision to the 3rd Circuit (03-1461). In November 2003, the Circuit Court agreed to a PPA request to hold this appeal in abeyance pending the outcome of the *Frederick L.* appeal (see above). Following the decision in the *Frederick L.* appeal, the court lifted the stay on proceedings. PPA then filed its appellant brief in June 2004. Oral arguments were heard in October 2004.

In March 2005, the Circuit Court handed down its decision.⁷⁷ The court ruled that the district court's dismissal of the lawsuit solely based on the state's fundamental alteration defense "lacks sufficient underpinning." Following much the same reasoning it followed in its *Frederick L.* decision, the Circuit ruled that the fundamental alteration defense requires more evidence than the state had presented and that the state had not demonstrated a "commitment to action" to bring the facility into compliance with the ADA and the Rehabilitation Act. As a result, the court vacated the court's grant of summary judgment in favor of the state, ordered the district court to enter summary judgment in favor of the plaintiffs with respect to the "legal insufficiency of the [state's] fundamental alteration defense," and remanded the case back to the district court for further proceedings.

In December 2005, the parties informed the court that they had arrived at a settlement and asked the court to suspend further proceedings unless the implementation of the settlement broke down. The Disability Law Project reported:

"Under the terms of the settlement ... DPW will evaluate whether SMRC residents are appropriate for discharge to community mental health programs by the end of April 2006. A qualified DPW employee (recommended by PP&A) will be in charge of the evaluations and responsible for the final decisions. The evaluators will also assess whether any individuals who are appropriate for discharge are opposed to discharge and, if so, they will take appropriate steps to overcome such opposition. After the evaluations are completed, the parties will meet to discuss a time line for placements."

⁷⁷ Located at: caselaw.lp.findlaw.com/data2/circs/3rd/031461p.pdf

19. Pennsylvania: Alexander et al. v. Rendell et al.

In November 2005, the guardians and parents of 59 individuals served at Altoona Center filed a complaint (05-cv-00419) in the U.S. District Court for the Western Pennsylvania to block the state's plan to close the facility. Altoona Center is a state-operated facility for persons with mental retardation that presently has 89 residents. The state had slated the facility to close in December 2006. One-half of the residents would be placed in the community and the others transferred to Ebensburg Center, another state-operated institution.

The complaint alleges that the state's closure plan violates the ADA, §504 of the Rehabilitation Act, and the Medicaid Act. The plaintiffs contend that Ebensburg Center is a more restrictive setting than Altoona, none of the residents want to leave Altoona, and further their placement from Altoona Center has not been recommended by treating professionals.

In January 2006, the plaintiffs petitioned the court to issue a preliminary injunction and restraining order to prevent the placement of the residents and the closure of Altoona Center. In January 2006, the court rejected this petition. The court found that the plaintiffs were unlikely to prevail on the merits because Pennsylvania had the authority to close the center. However, the court's order specified that an individual could only be placed in the community with the written consent of the person's legal guardian. In the absence of this consent, individuals would be transferred to Ebensburg Center or another similar facility. The court also directed that the state guarantee that persons placed in the community have the right to return to center-based services for a period of 18-months and that the state follow the protocol for monitoring community placements that it had described to the court.

In early March 2006, the state asked the court to clarify its order, expressing concern that the court's order was at odds with the U.S. Supreme Court's *Olmstead* decision and 3rd Circuit rulings in the *Fredrick L* litigation (see above). Specifically, the state disagreed with the court's giving unfettered authority to legal guardians to veto community placement, even though the individual might prefer such placement and placement was appropriate in order to serve the individual in most integrated living arrangement. The state pointed out that the ruling could have the effect of stopping the community placement of many individuals. The court decided to hold to its previous order. In the court's view, the *Olmstead* decision supports the premise that opposition to community placement by a legal guardian is tantamount to opposition by the individual.

This ruling triggered a motion to intervene by individuals who are served in the community and a coalition of organizations, including Speaking for Ourselves (an association of self advocated), the Arc of Pennsylvania, the National Coalition on Self-Determination, the Pennsylvania chapter of TASH, and others. The petitioners objected to the court's finding that legal guardians could veto community placement, pointing to other cases in Pennsylvania and elsewhere where courts had ruled that the views of the affected individual must be considered along with the treatment team.

Both the plaintiffs and the state oppose the petition to intervene. The state contended that consideration of the issues raised by the interveners would delay closure of the facility, which was expected to be completed in May. The state also argued that the petition was not timely. The district court has not acted on these petitions. Also in March, the state filed an appeal (06-2005) with the 3rd Circuit to vacate certain parts of the court's January order. The Circuit turned down the appeal in August 2006. In September 2006, the district court denied the state's motion to dismiss the lawsuit. In January 2007, the court referred the lawsuit for mediation but mediation proved unsuccessful. In March 2007, the court denied the petition to intervene.

20. Other Litigation

Other litigation in this arena has included lawsuits concerning individuals who have a mental illness who are served in state mental health facilities. Some of these lawsuits include the Charles Q v. Houston and Kathleen S v. Department of Public Welfare litigation in Pennsylvania as well as certain California lawsuits. Also in Pennsylvania, the Helen L. v. Dedario litigation raised "Olmstead"-like issues: namely, the access of nursing facility residents to community waiver services (specifically personal assistance/ attendant care). In 1995, the 3rd Circuit Court of Appeals held that the state's failure to provide services in the most integrated setting appropriate to a person's needs violated the ADA.⁷⁸ Additionally, the Court held that the provision of waiver services to the plaintiff would not fundamentally alter the nature of the waiver program because the services the plaintiff needed were already provided in the waiver program.

⁷⁸ This decision is at: ahcuah.com/lawsuit/federal/didario.

IV. Limitations on Medicaid Home and Community Services

A. Overview

“Access to benefits” lawsuits revolve around whether Medicaid beneficiaries can obtain services and supports that they have been approved or are entitled to receive. Litigation in this arena includes lawsuits that argue that low state payment rates prevent beneficiaries from finding a personal assistant or other workers to provide needed services. There have been many cases where the availability and quality of services available through the Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefits for children with disabilities has been at issue.⁷⁹

These lawsuits contend that state policies or practices concerning the operation of community programs constitute barriers to individuals obtaining authorized services. In some cases, these barriers are alleged to violate the ADA, because they force individuals to accept institutional services due to a shortage of community services while there is more generous state funding for institutional services, thereby discriminating against people who want community services. In the Arizona and California lawsuits, the plaintiffs also alleged that state’s funding practices violate §1902(a)(30)(A) of the Social Security Act, which requires states to make payments for Medicaid services sufficient to ensure their availability to Medicaid beneficiaries. In particular, §1902(a)(30)(A) provides that the “State plan for medical assistance must ... provide such methods and procedures relating to the ... the payment for care and services under the plan ... as may be necessary ... to assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area.”

As in other dimensions of Medicaid law, issues have arisen concerning whether §1902(a)(30)(A) confers individually enforceable rights. As discussed below, the district court found in the *Sanchez v. Johnson* litigation that this provision is not enforceable through a §1983 action and dismissed the lawsuit. That decision was appealed to the 9th Circuit which upheld the dis-

⁷⁹ EPSDT benefits are described in: Sarah Knipper (2004): EPSDT: Supporting Children with Disabilities available at: hsri.org/docs/792FinalEPSDTBooklet.PDF. There has been a high volume of litigation in the arena of EPSDT benefits. There is considerable information about this litigation at healthlaw.org/library.cfm?fa=summarize&appView=Topic&id=2548.

trict court. In March 2004, the 1st Circuit Court of Appeals ruled that §1902(a)(30)(A) is not enforceable, based on the U.S. Supreme Court *Gonzaga* decision.⁸⁰ This ruling is noteworthy because the 1st Circuit abandoned its previous position that §1902(a)(30)(A) was enforceable and in light of its other post-*Gonzaga* decisions upholding the enforceability of various other provisions of Medicaid law.

B. Description of Lawsuits

1. Arizona: *Ball et al v. Biedess et al.*

In January 2000, the Arizona Center on Disability Law and the Native American Protection and Advocacy Agency filed a class-action complaint (00-cv-67) in the U. S. District Court for Arizona arguing that Medicaid payment rates for direct service professionals (attendants) in the community are insufficient to attract enough providers to ensure that Medicaid services are available to persons with disabilities.⁸¹ Among its other claims, the lawsuit argued that the state is violating §1902(a)(30)(A) by failing to make payments sufficient to attract enough providers to meet the needs of Medicaid recipients. The plaintiffs also claimed that the state also is violating other Medicaid requirements, including: 1) reasonable promptness; 2) amount, duration and scope; and, 3) freedom of choice. Also, the plaintiffs argue that Arizona violates Title II of the ADA and §504 of the Rehabilitation Act because the lack of sufficient community support workers puts individuals with disabilities at risk of institutionalization. The District Court granted class certification. The bench trial was conducted in October 2003.

In August 2004, the court ruled in favor of the plaintiffs, finding that Arizona violated §1902(a)(30)(A) by not providing enough attendants to meet the needs of Medicaid beneficiaries.⁸² Specifically, the court found that Arizona’s payments were insufficient to assure “equal access” and “quality of care.” The court ordered that the state: must provide each beneficiary attendant care “without gaps in service” and offer a rate of pay that is sufficient to “attract enough health care workers to deliver all of the services for which the individual qualifies.” However, the court stopped short of specifying the amount that the state must pay. The court also ordered the state to

⁸⁰ This ruling concerned the Massachusetts *Long Term Care Pharmacy Alliance v. Ferguson* lawsuit. The ruling is available at: laws.findlaw.com/1st/031895.html.

⁸¹ The complaint and related materials can be found at: acd.com/ball.html.

⁸² The decision also is located at: acd.com/ball.html.

make other improvements in its program. The court ordered the parties to file a schedule to carry out the directives contained in its order by September 2004.

In late August 2004, the state moved to request a new trial and asked for a stay of the district court's order, pending the disposition of its appeal of the decision to the 9th Circuit. In September, the state filed its appeal (04-16963). In May 2005, the Circuit denied the state's request to stay the district court's order but agreed to hear the appeal. Action on the appeal was then stayed pending the Circuit's decision concerning en banc reconsideration of the California *Sanchez v. Johnson* (see below) appeal. The Circuit heard oral arguments in September 2006. In the meantime, the district court's order is being implemented, although there are disputes about how well the implementation is being carried out by the state.

2. Arkansas: Pediatric Specialty Care, Inc. et al. v. Arkansas Department of Human Services et al.

In November 2001, the Arkansas Department of Human Services (ADHS) announced plans to cut back Medicaid benefits due to budget shortfalls. Among other actions, ADHS proposed eliminating distinct state plan coverage of early intervention day treatment and therapy furnished to children with developmental disabilities ages 0-6. These services are furnished as part of the state's Child Health Management Services (CMHS) program by specialized providers. Three of these providers and three affected families filed suit (01-830) in the U.S. District Court for Eastern Arkansas to enjoin ADHS against eliminating these early intervention services. In December 2001, the district court granted a permanent injunction debarring ADHS from removing the listing of these services from the state plan, reasoning that the federal requirements concerning Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandated that these services be provided so long as they had been ordered by a physician and would result in the "maximum reduction of medical and physical disabilities and restoration of the child to his or her best functional level." State officials argued that they had the "legal right to decide whether to include the services" in the state's Medicaid program. They also contended that the services would continue to be available, but not in the form of a distinct program.

ADHS appealed the injunction to the 8th Circuit. In June 2002, the Circuit ruled that Medicaid-eligible children have a right to early intervention services and that ADHS "must pay part or all of the cost of treatment discovered by doctors who first diagnose

and evaluate the children."⁸³ The Circuit decided that federal law does not require ADHS to specifically identify the services at issue in its Medicaid state plan. However, so long as the services are determined as necessary by a physician, it must pay for them since federal law mandates that Medicaid-eligible children receive physician-ordered services whether the state has formerly listed them or not. The Circuit also reminded "the state that it has a duty under §1902(a)(43) of the Social Security Act] to inform recipients about the EPSDT services that are available to them and that it must arrange for the corrective treatments prescribed by physicians. The state may not shirk its responsibilities to Medicaid recipients by burying information about available services in a complex bureaucratic scheme." The Court remanded the case to the district court to revise the injunction and consider the remaining plaintiff claims.

In November 2002, the district court issued a new order. The thrust of this order was to continue a revised injunction to compel the state to continue to furnish the disputed services. In his order, Judge Wilson expressed chagrin concerning state actions, which in his view were attempts to end-run the injunction. The state then filed a motion asking for a modification of the order, arguing that it had secured federal approval for a Medicaid state plan amendment that complied with the 8th Circuit decision and the effect of the new order might be that the state would not receive federal Medicaid funds for day treatment services under the amended state plan. The plaintiffs countered, arguing that the change in the Medicaid plan coupled with other state actions would have the effect of sharply reducing access to the services or putting new obstacles in the way of families' obtaining the services. The plaintiffs also asked that the Court to review changes that the state might propose in the future to ensure that they would not eliminate the disputed services.

In December 2002, the district court modified its order, finding that the latest order was not inconsistent with the 8th Circuit ruling. The court continued the injunction directing the state to continue to provide the services and also applied the order to the federal Centers for Medicare and Medicaid Services (CMS) and ordered CMS to continue to provide federal Medicaid funding for the services. But, the court declined to directly supervise the state's administration of these services, again enjoined the state to continue to provide and pay for early intervention and related services and barred the state from implementing changes

⁸³ Located at:
caselaw.lp.findlaw.com/data2/circs/8th/013971p.pdf

in the provision of these services. In part, the court based its injunction on the provisions of §1902(a)(30)(A) of the Social Security Act, reasoning that the changes that the state had in mind would affect access to services and that the implementation of any changes must be preceded by a study to determine their impact.

ADHS appealed the revised order to the 8th Circuit; CMS filed its own appeal concerning the order. In its appeal, ADHS protested that its removal of the distinct state plan coverage of early intervention services did not in any way mean that children could not obtain them. CMS concurred and also argued that the district court's order was improper on a number of grounds. The plaintiffs have countered that ADHS is engaged in an ongoing effort to "deconstruct" the services that they furnish.

In April 2004, the 8th Circuit ruled on the appeal.⁸⁴ It dismissed CMS as a party to the litigation. It upheld the district court's injunction on procedural due process grounds, concluding that the injunction against the state's making changes in its program was proper "until a full impact study on the effect of terminating the [CMHS] program is completed."

In July 2004, a fourth amended complaint was filed. This complaint alleges that a prior authorization system that ADHS implemented for CMHS has been operated to arbitrarily deny necessary services to children in order to cut state expenditures. The revised complaint names the Arkansas Foundation for Medical Care (the state's Professional Review Organization (PRO)) as a defendant because it operates the prior authorization system. The state moved to dismiss this complaint, arguing that it had the authority to determine the medical necessity of CMHS. In February 2005, the court rejected the state's motion, concluding that the plaintiffs had established a sufficient basis to proceed to trial to determine whether the prior authorization system resulted in the impermissible denial of services to children. In March, the state appealed this ruling to the 8th Circuit (05-1668), seeking to overturn the ruling on procedural grounds. Oral arguments were heard in February 2006.⁸⁵

In April 2006, the 8th Circuit reaffirmed that state officials could be sued in their official capacity for alleged violations of Medicaid law.⁸⁶ The Circuit reaffirmed that the provisions of Medicaid law at issue could be litigated in federal court, the *Gonzaga*

decision notwithstanding. The Circuit then denied the state's motion for a rehearing. In September 2006, the state filed a petition for a writ of certiorari (06-415) at the U.S. Supreme Court to review the Circuit Court decision. To date, the Court has not acted upon this petition.

3. California: Sanchez et al. v. Johnson et al.

Filed in May 2000 in the U.S. District Court for Northern California on behalf of individuals with developmental disabilities, this complaint (00cv01593) alleged that California has "established and maintained highly differential payment and wage and benefit structures between the institutional and community-based components of California's developmental disability services program, which has the effect of subjecting people with developmental disabilities to unnecessary institutionalization and segregation." The plaintiffs – persons with disabilities, provider and advocacy organizations – claimed that the state, in creating payment differentials, violated Title II of the ADA, both with respect to the integration mandate and other regulations "prohibiting a public entity from providing different or separate aids, benefits or services to individuals with disabilities of to any class of individuals with disabilities that is provided to others." Also, the plaintiffs pointed out that ADA regulations prohibit public entities from "utilizing criteria or methods of administration ... that have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability." As a result, they alleged that California discriminated against the plaintiffs by "utilizing criteria and methods of administration that discriminate against people with disabilities by [offering] low wages for direct care and professional staff."

Claims based on Medicaid law included the allegation that state payments for community services were insufficient to assure efficiency, economy, and quality of care and enlist sufficient qualified providers to ensure access to services as required by §1902(a)(30)(A). The plaintiffs petitioned the court to order the state to improve its community services payment and benefit structure and correct other problems that were alleged to lead to unnecessary institutionalization.

In August 2001, the Court certified the lawsuit as a class action. In September 2001, the Court rejected the state's motion for partial summary judgment to dismiss the plaintiffs' claims with respect to §1902(a)(30)(A). The state argued that neither people with disabilities nor providers may bring a lawsuit in federal court to enforce these provisions. In March 2002, the plaintiffs filed a motion for summary

⁸⁴ This ruling is located at:

caselaw.lp.findlaw.com/data2/circs/8th/031015p.pdf.

⁸⁵ Briefs may be found at ca8.uscourts.gov/tmp/051668.html

⁸⁶ Decision located at:

caselaw.lp.findlaw.com/data2/circs/8th/051115p.pdf

judgment. The motion for summary judgment asked the court to issue “an order enjoining defendants at least to double current community direct care wages and benefits, making them substantially equal to institutional direct care wages and benefits and index them to meet defendants’ future, continuing duties under federal statutes.”

In August 2002, the court turned down the plaintiffs’ motion for summary judgment but ruled that the issues raised by the plaintiffs did not constitute violations of the ADA or §504 of the Rehabilitation Act. The court also denied the state’s motion to dismiss the case on sovereign immunity grounds and ordered that the case proceed to trial. The remaining trial issues concerned whether California’s payments are sufficient to enable providers to furnish quality services and individuals to be able to access to necessary services, as required by §1902(a)(30)(A).

In August 2003, the state filed a motion asking the court to reconsider its decision that the plaintiffs could seek relief in federal court for the alleged violations of Medicaid law. In its motion, the state argued that, in light of the *Gonzaga* decision, the court should find that neither individuals nor providers have enforceable rights under the Medicaid Act.

In January 2004, the court dismissed the lawsuit, agreeing with the state’s argument that the federal Medicaid Act does not confer individually enforceable rights but instead has an aggregate focus. This decision was based on the application of the *Gonzaga* decision to the provisions of §1902(a)(30)(A) and decisions in other cases (including the Pennsylvania *Sabree* decision and another Northern District lawsuit concerning the application of §1902(a)(30)(A) (*California Association of Health Facilities v. State Department of Health Services* (03-736))).

Characterizing the court’s decision as “fatally flawed,” the plaintiffs appealed the dismissal to the 9th Circuit in early February 2004 (04-15228). The plaintiffs expected to rely on a December 2003 U.S. District Court for Eastern California decision in lawsuits⁸⁷ that also concerned Medicaid payments. In that litigation, the district court also wrestled the implications of the *Gonzaga* decision for whether §1902(a)(30)(A) conferred individually enforceable rights for which Medicaid recipients and providers could seek federal

⁸⁷ The lawsuits were: *Clayworth et al. v. Bonta et al.* (03-2110) and *California Medical Association et al. v. Bonta et al.* (03-2336). Both lawsuits were filed to prevent California from instituting a 5% across the board rate reduction in Medicaid (Medi-Cal) payments in order to cut its budget deficit. The state appealed both decisions to the 9th Circuit (04-15498 and 04-15532), which has consolidated the appeals.

court intervention under §1983. Based on its reading of legislative history, the court decided that Congress intended to confer individually enforceable rights under §1902(a)(30)(A) for beneficiaries but not Medicaid providers. Based on this conclusion and other 9th Circuit decisions, the court then granted the plaintiffs a preliminary injunction that prevented California from implementing Medicaid rate cuts that were slated to go into effect in January 2004.⁸⁸ The Circuit Court heard oral arguments in the *Sanchez, Clayworth and CMA* appeals in December 2004.

In August 2005, the 9th Circuit upheld the district court decision dismissing the *Sanchez* complaint.⁸⁹ The court decided that §1902(a)(30)(A) did not confer individually enforceable rights for either providers or Medicaid beneficiaries, applying the tests that the U.S. Supreme Court had set out in its *Gonzaga* decision. The court concluded that §1902(a)(30)(A) does “not focus on an individual recipient’s or provider’s right to benefits, nor is the ‘broad and diffuse’ language of the statute amenable to judicial remedy. We conclude, therefore, that Congress has not spoken with an unambiguous, clear voice that would put a State on notice that Medicaid recipients or providers are able to compel state action under §1983.” The court also upheld the district court’s ruling throwing out the ADA claim, agreeing that the state had made progress in deinstitutionalizing individuals and that ordering an increase in payments would cause the state to make fundamental alterations. The *Sanchez* plaintiffs then petitioned for *en banc* review of the decision. In November 2005, the Circuit Court denied this petition.

4. California: *Rodde et al. v. Bonta et al.*

This lawsuit (03-01580) was filed in the U.S. District Court for the District of Central California expressly to halt Los Angeles County’s plan to close Rancho Los Amigos National Rehabilitation Center, a county-operated facility that furnishes specialized inpatient and outpatient services to individuals with disabilities. The plaintiffs sought and obtained from the court a

⁸⁸ This decision is located at:

207.41.18.73/caed/DOCUMENTS/Opinions/Levi/03-2110.pdf.

In the decision, the court noted that interpreting the legislative history surrounding §1902(a)(30)(A) posed some difficulties. Once the court decided that Medicaid beneficiaries could bring a federal action to block rate cuts that might harm them, it relied on the standards set down by the 9th Circuit in its 1997

Orthopaedic Hospital v. Belshe decision (located at: laws.findlaw.com/9th/9555607.html) in deciding that the state’s rate cut was improper.

⁸⁹ This decision may be found at:

[ca9.uscourts.gov/ca9/newopinions.nsf/3A95CF272053DC6E882570510054C594/\\$file/0415228.pdf?openelement](http://ca9.uscourts.gov/ca9/newopinions.nsf/3A95CF272053DC6E882570510054C594/$file/0415228.pdf?openelement). The court also reversed the district court’s rulings in the *Clayworth and CMA* complaints.

preliminary injunction to halt the closure, contending that, if the facility were closed, they would be left without access to medically necessary services. The plaintiffs based their claims on federal Medicaid law (arguing that they would be unable to obtain services covered by California's Medicaid program) and the ADA (arguing that the county's action was discriminatory because it treated people with disabilities differently than other Medicaid recipients who did not face a similar loss of access to services). The county appealed the injunction to the 9th Circuit Court of Appeals (03-55765).

In February 2004, the Circuit upheld the preliminary injunction, concluding that the plaintiffs were likely to succeed on the merits of their ADA claim.⁹⁰ The court agreed that, absent the injunction, the plaintiffs faced potential harm. The Circuit also noted that the district court decision did not mean that the county could not ultimately close the facility but, instead, if it were to close the facility, it had to ensure that comparable services would be available to the plaintiffs. In October 2005, the parties settled the case. The county agreed to continue operating the facility until at least 2009.⁹¹

5. California: Katie A et al v. Bonta et al.

Filed in 2002, this lawsuit (02-5662) alleges that California's failure to furnish therapeutic foster care and "wrap-around" services to children with serious emotional disturbances violates federal Medicaid law which dictates that a state furnish all medically necessary services to eligible children. The lawsuit charged that the state's failure to address the mental health needs of foster children in its care led to their placement in institutional settings. This lawsuit was filed in the U.S. District Court for the Central District of California against county and state health, social services and mental health agencies by a coalition of advocacy organizations.⁹²

The plaintiffs and Los Angeles County reached a settlement in 2003 wherein the county agreed to make changes in its system to address issues raised in the complaint. However, the settlement did not address other parts of the state nor systemic issues that only could be addressed by the state. In March 2006, the court issued a preliminary injunction against the state to compel it to furnish therapeutic foster care and

wrap-around services through its Medicaid program as Early & Periodic Screening Treatment and Diagnosis (EPSDT) services.⁹³ This order could affect upwards of 85,000 California children who are in foster care.

In April 2006, the state filed motions to stay the injunction. The court denied these motions. The state then appealed (06-55559) the preliminary injunction to the 9th Circuit. In March 2007, the Circuit Court affirmed that the state was obliged under the EPSDT mandate to furnish necessary services to foster children, turning down the state's argument that its only obligation was to make services available. However, the Circuit reversed the preliminary injunction and remanded the case back to the district court. The Circuit determined that the district court had too broadly interpreted the EPSDT mandate with respect to the exact types of services that the state must furnish.⁹⁴

6. Connecticut: Pravano et al. v. Wilson-Coker

In November 2002, three Medicaid beneficiaries with disabilities filed a lawsuit (02-CV-1968) against the Connecticut Department of Social Services (DSS, the state's Medicaid agency) alleging that the state was refusing to pay for durable medical equipment they need to improve their health and live independently. The plaintiffs argue that the state has adopted "an unwritten and unpublished policy of denying Medicaid payment for any equipment not covered by the federal Medicare program," thereby impermissibly restricting access to necessary equipment. The plaintiffs sought a preliminary injunction and class certification. The plaintiffs are represented by New Haven Legal Assistance Association and Connecticut Legal Services.

In 1997, the New Haven Legal Assistance Association filed a similar lawsuit (*DeSario v. Thomas*) challenging Connecticut's practice of limiting payment for medical equipment to items included on a list established by DSS. Ultimately, this case was settled by the state's agreeing to periodically update its list of covered items and allow individuals to obtain unlisted items when necessary. This litigation also prompted the Health Care Financing Administration (now CMS) to clarify its policies concerning the coverage of medical equipment, including requiring states to provide individuals "a meaningful opportunity for seeking modifications of or exceptions to a State's pre-

⁹⁰ Decision located at: caselaw.lp.findlaw.com/data2/circa/9th/0355765p.pdf

⁹¹ The settlement agreement is located at: www.pai-ca.org/BulletinBoard/Index.htm#CPF

⁹² See bazelon.org/newsroom/archive/2003/3-17-03katiea.htm for a discussion of this litigation, a copy of the complaint and other related materials.

⁹³ See bazelon.org/issues/children/incourt/KatieA/KatieA.htm for a discussion of the order and to obtain a copy of the March 14, 2006 order.

⁹⁴ Opinion located at: [ca9.uscourts.gov/ca9/newopinions.nsf/6370802B473DC4D6882572A6008183A3/\\$file/0655559.pdf?openelement](http://ca9.uscourts.gov/ca9/newopinions.nsf/6370802B473DC4D6882572A6008183A3/$file/0655559.pdf?openelement). Additional information located at: bazelon.org/newsroom/2007/KATIE040307.html

approved list.” This policy was promulgated via a September 1998 State Medicaid Director letter.⁹⁵

In this lawsuit, the plaintiffs alleged that the Department was once again employing an arbitrary list to deny individuals of equipment that is necessary for them to function in the community and thereby increase their risk of institutionalization. In particular, the plaintiffs alleged that Connecticut’s policies violated: (a) §1902(a)(17)(A) of the Social Security Act which requires that the state apply reasonable standards in determining eligibility for services; (b) the goals of the Medicaid by denying payment for DME necessary for individuals to attain and maintain independence and self-care; and, (c) Medicaid requirements that bar limiting the scope of coverage based on a person’s specific medical condition. In March 2003, the Court turned down the plaintiffs’ request for a preliminary injunction. The parties arrived at a tentative settlement in September 2003. In December 2003, the court approved the agreement. Under the agreement, the Department of Social Services has issued a revised provider bulletin concerning DME and beneficiary rights to appeal adverse determinations.

7. Illinois: Jackson et al. v. Maram

In January 2004, three individuals residents filed a class action complaint (04-0174) against the Illinois Department of Public Aid in the U.S. District Court for the Northern Illinois contending that the agency impermissibly denies motorized wheelchairs to nursing facility residents in violation of federal Medicaid law, the ADA and §504 of the Rehabilitation Act. The plaintiffs have been denied motorized wheelchairs even though rehabilitation hospitals have determined that the plaintiffs would benefit from them. As a consequence, the plaintiffs contend that they are unnecessarily confined to the nursing homes in which they reside. In contrast, the plaintiffs point out that individuals who are not in nursing facilities are authorized to receive Medicaid-funded motorized wheelchairs. The lawsuit was filed on the plaintiffs’ behalf by Access Living of Metropolitan Chicago, an Independent Living Center.

The plaintiffs contend that the state’s policy to not provide motorized wheelchairs to nursing home residents violates the requirements of the federal 1987 Nursing Home Reform Act, §1902(a)(10)(B) by not making Medicaid services available to all beneficiaries who require them, the ADA (by virtue of discriminatory treatment of individuals with disabilities and encouraging unnecessary segregation of nursing facility residents), and §504 because the state’s policies discriminate on the basis of disability.

⁹⁵ Located at: cms.hhs.gov/smdl/downloads/SMD090498.pdf

The state moved to dismiss and in opposition to class certification. Both motions adopted the position that Medicaid law, the ADA, and the Rehabilitation Act do not give the plaintiffs enforceable rights that may be pursued through a §1983 action. In August 2004, the court granted the motion for class certification.

In October 2006, the parties submitted a proposed consent decree to the court. The decree provides for an evaluation of nursing facility residents to determine whether they require a wheelchair. The state agreed to purchase motorized wheelchairs for residents who require them. The nursing facility would furnish non-motorized wheelchairs when required. In December 2006, the Illinois Health Care Association (IHCA) objected to the consent decree, arguing that the decree mandated nursing facilities to incur costs for which they would not be compensated. In February 2007, the court approved the settlement. The court turned away the IHCA objection, ruling that the organization did not have standing.⁹⁶

8. Illinois: Bertrand et al. v. Maram et al.

Filed in January 2005 in the U.S. District Court for the Northern District of Illinois, this lawsuit (05-0544) charges that Illinois impermissibly restricts the access to Community-Integrated Living Arrangement (CILA) residential services in its HCBS waiver program for persons with developmental disabilities. This is a class action complaint. It follows on the heels of a non-class action complaint (*Drzewicki v. Maram et al.* (04-CV-7164) that raised the same issue but which the state agreed to settle.

Like the predecessor complaint, the lawsuit contends that Illinois violates the reasonable promptness requirement at §1902(a)(8) of the Social Security Act and is at odds with the policies set forth in CMS *Olmstead Letter #4*, which provides that a state may not deny covered waiver services to waiver participants who require them. Plaintiffs contend that Illinois’ policy of limiting the availability of CILA services to persons who satisfy the state’s emergency or priority placement criteria is an impermissible limitation on access to services.

In February 2005, the state answered the complaint. The state argued that Medicaid law does not confer individually enforceable rights and, consequently, the plaintiffs do not have standing to bring an action in federal court. The state also advanced the defense that the criteria it uses to regulate access to CILA services were contained in its waiver application to CMS and,

⁹⁶ For more information, see: stevegoldada.com/stevegoldada/archive.php?mode=A&id=200;&sort=D

because CMS had approved the application, the criteria were allowable. Both the plaintiffs and the state filed motions for summary judgment. The state also filed a motion opposing class certification.

In September 2006, the court approved the state's motion for summary judgment and thereby ruled against the plaintiffs. The court agreed, based on other decisions, that §1902(a)(8) confers individually enforceable rights. The court also acknowledged that CMS *Olmstead Letter #4* (as well as decisions in other cases such as the Massachusetts *Boulet* litigation) does not permit a state to deny access by waiver participants to necessary services offered in a waiver. However, the court decided that, since CMS had approved Illinois' waiver request (including its scheme to regulate access to residential services based on a prioritization scheme) after it issued *Olmstead Letter #4*, CMS must have concluded that the Illinois scheme complied with the policies contained in the letter. The court decided to defer to CMS' own interpretation of its policy.

In October 2006, the plaintiffs appealed the district court's decision to the 7th Circuit (06-3705).⁹⁷ The Circuit heard oral arguments in May 2007. The plaintiffs contend that the district court erred in interpreting the CMS approval of the waiver application as permitting the state to deny CILA services to waiver participants.

9. Indiana: Collins et al. v. Hamilton et al.

In 2001, the Indiana Civil Liberties Union filed a class action lawsuit against state officials for failing to provide child and youth long-term residential treatment in psychiatric residential treatment facilities (PRTF). The plaintiffs argued that Indiana's refusal to provide such services violated federal Medicaid law because PRTF services are a recognized Medicaid benefit and, hence, must be furnished to all eligible children and youth when "medically necessary" under the federal Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate. The district court ruled in plaintiffs favor, deciding that the provision of PRTF services was mandatory when medically necessary. The court permanently enjoined Indiana from denying these services.

In 2002, the state appealed this decision to the 7th Circuit Court of Appeals (02-3935), arguing that it had decided to exclude such services for various reasons. In November 2003, the Circuit Court rejected the state's appeal and upheld the district court decision.⁹⁸ The court found that the EPSDT mandate requires that

a state must furnish any Medicaid coverable service that is medically necessary.

10. Kansas: Interhab, Inc. et al. v. Schalansky et al.

In October 2002, Interhab and five other community service providers filed a class action lawsuit in Shawnee County District Court (02C001335) against the Kansas Department of Social and Rehabilitation Services (SRS) claiming that the state's payments are insufficient to meet the needs of people with developmental disabilities and thereby violate Kansas and federal law. Interhab is an association of Kansas community service providers. The plaintiffs assert that community services were underfunded by \$88 million. The lawsuit also seeks damages for alleged underfunding in previous years; such damages might total \$300 million, according to the plaintiffs.

The lawsuit claims that the state has violated the state's 1996 Developmental Disabilities Reform Act (DDRA), which the plaintiffs argue mandates that the state provide "adequate and reasonable" funding for community services. In particular, the plaintiffs point out that the DDRA made it Kansas policy that:

"...this state ...assist persons who have a developmental disability to have: (a) Services and supports which allow persons opportunities of choice to increase their independence and productivity and integration and inclusion into the community; (b) access to a range of services and supports appropriate to such persons; and (c) the same dignity and respect as persons who do not have a developmental disability." (K.S.A. 39-1802).

The DDRA also provides that SRS establish "a system of adequate and reasonable funding or reimbursement for the delivery of community services that:

"requires an independent, professional review of the rate structures on a biennial basis resulting in a recommendation to the legislature regarding rate adjustments. Such recommendations shall be adequate to support: (A) a system of employee compensation competitive with local conditions; (B) training and technical support to attract and retain qualified employees; (C) a quality assurance process which is responsive to consumers' needs and which maintains the standards of quality service (D) risk management and insurance costs; and (E) program management and coordination responsibilities." (K.S.A. 39-1806)

The plaintiffs charge that the required rate review was not conducted and the wage rates upon which SRS bases payments are inadequate. As a result, provider agencies are unable to recruit and retain qualified staff to meet the needs of individuals. In addition to violating the DDRA, the plaintiffs also charge that SRS has

⁹⁷ Briefs are located at: ca7.uscourts.gov/briefs.htm Enter the case number to view the briefs.

⁹⁸ The decision is at:

<http://caselaw.findlaw.com/data2/circs/7th/023935P.pdf>

violated §1902(a)(30)(A) of the Social Security Act by not making payments sufficient to ensure that “consumers of community programs and services have access to high quality care.” The plaintiffs also are advancing an equal protection claim under both the U.S. and Kansas Constitutions by contending that the state discriminates between community providers and its own institutions by funding similar services differently. The plaintiffs also allege breach of contract.

The plaintiffs are asking the court to: (a) review all payment rates for the period 1996 – 2003; (b) order the state to pay for all “underfunding” during that period; (c) enjoin the state to pay “adequate and reasonable reimbursement rates”; (d) enjoin the state to establish a rate setting methodology that complies with federal and state law; and (e) enter a judgment directing SRS to reimburse all costs incurred by the plaintiffs in delivering services, including hourly wages and benefits that reflect the amounts paid to other workers in each locality. In December 2002, the state filed motions to dismiss the federal and state law claims.

In January 2003, the plaintiffs amended the complaint and asked the court to issue a temporary restraining order to block payment and other funding cuts ordered in August and November 2002 by outgoing Governor Bill Graves to address the state’s mounting budget deficit.

In February 2003, the court turned down the plaintiff’s request for a temporary restraining order. The Court ruled that there was no evidence that the state acted “arbitrarily, capriciously or unreasonably in [its] choices of program reductions.” While acknowledging that the budget cuts “appear potentially harmful,” the “court could not conclude that its interference would not do more harm than good to the public interest if it issued a temporary restraining order.” With the rejection of the request for a temporary restraining order, activity in this litigation has returned to the issues raised in the original complaint. The court has heard oral arguments concerning various motions over the past few months.

At a September 2003 hearing, the court observed that it was struggling to understand the issues in the case, including the complexities of the funding of community services in Kansas and whether the plaintiffs had the right to make the claims they had. The court allowed two individuals with developmental disabilities who receive services to be added as plaintiffs. The court decided to allow the lawsuit to go forward, rejecting the state’s motion to dismiss except for the claims for retrospective recovery of funds under federal law. In January 2004, the plaintiffs once again asked the court for a temporary restraining order,

temporary and permanent injunctions and the appointment of a special master. The court turned down these requests. Over the past several months, the plaintiffs and the state have filed numerous motions, including motions by the state to dismiss plaintiff claims. The litigation is ongoing.

11. Louisiana: Malen v. Hood

This class action complaint was filed in December 2000 against the Louisiana Department of Health and Hospitals in the U.S. District Court for the Eastern District of Louisiana. At issue was the state’s proposed method of implementing a new “Children’s Choices” HCBS waiver for children with severe disabilities. The new waiver program offers a dollar-capped set of benefits that is less broad than that offered under Louisiana’s pre-existing HCBS waiver program. The state had proposed that, if a child were on the waiting list for Louisiana’s existing HCB waiver program for people with developmental disabilities, the family would have to agree to give up the child’s place on that waiting list if they accepted enrollment in the new waiver program. Families objected to this proviso because it meant that their children would be disadvantaged if they needed more intensive services. Plaintiffs contended that this requirement was impermissible under federal law.

When the lawsuit was filed, federal officials had not yet decided whether to approve the new program. Subsequently, CMS determined that the state’s proposal concerning the waiting-list proviso could not be approved. The state then removed the proviso and CMS approved the waiver request. The Children’s Choices program has since been implemented and the lawsuit has been settled.

12. Maine: Risinger et al. v. Concannon et al.

Filed in June 2000, this complaint (00-116-B-C) alleged that Maine violated federal Medicaid law by failing to furnish medically necessary EPSDT services to children with mental disabilities. The lawsuit was filed by private attorneys in collaboration with Maine Equal Justice Partners, Inc. Maine’s Disability Rights Center joined the lawsuit as a named plaintiff. The lawsuit argued that federal law requires the state to arrange for medically necessary EPSDT services – including in-home mental health services – in a reasonably prompt manner. Consequently, at issue was Maine’s assuring access to non-waiver Medicaid services for children. Under federal law, a state may not limit the availability of medically necessary EPSDT services. The lawsuit also contended that Maine’s payments for services were insufficient to ensure their availability when and as needed and thereby the state is violating §1902(a)(30)(A). As a

consequence, the plaintiffs argued that 600 Maine children with mental disabilities had been wait listed for services or could not obtain entitled services.

In July 2001, the District Court granted the plaintiff's motion for class action certification.⁹⁹ In May 2002, the parties reached a settlement. Reportedly, the settlement provides that children who need services will be evaluated more quickly and no child will wait more than six months to receive approved services.

13. Massachusetts: Rosie D et al. v. Romney et al.

This class action complaint (01-30199) was filed in October 2001 in the U.S. District Court for the District of Massachusetts. The complaint alleged that Massachusetts violated the Medicaid Act by failing to provide medically necessary Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) with reasonable promptness to children who have serious emotional disturbances and children with autism. The complaint alleged violations of §1902(a)(8), §1905(r) (EPSDT) and other provisions of the Social Security Act. In 2002, the state appealed the district court's dismissal of its motion to dismiss the complaint on sovereign immunity grounds. This appeal was rebuffed by the 1st Circuit Court of Appeals.¹⁰⁰ Trial was held during April – June 2005.

In January 2006, the district court ruled¹⁰¹ that Massachusetts was not complying with Medicaid EPSDT requirements to perform necessary assessments and coordination of services for children with serious emotional disturbances and was furnishing inadequate in-home behavioral supports to such children. The court was especially critical of the state's heavy reliance on short-term interventions to respond to the needs of these children, pointing out that short-term programs cannot "treat children with chronic conditions, who usually require carefully planned and flexible services for months or years. The absence of these long-term services too often leaves SED children with only one option: expensive, clinically unnecessary and damaging confinement in a long-term residential program or hospital, far from home and family." As a result, the court found that SED children experience recurring crises and excessive out-of-home placements.

The court ordered the parties to develop proposed

remedies to present to the court. In February 2006, the parties proposed a process and timetable for developing remedies over a six-month period, including enlisting a facilitator if need be. In August 2006, the parties reported to the court that they had been unable to agree on a remedial plan. Each side submitted its own remedial plan to the court for consideration.

In February 2007, the court accepted the state's remedial plan with certain provisos. The plaintiffs have filed some objections to the remedial plan.

14. Minnesota: Association for Residential Resources in Minnesota et al. v. Goodno et al. and Masterman et al. v. Goodno

Both of these lawsuits seek to halt Minnesota's "rebasings" the amount of funds it allocates to counties for HCBS waiver services for persons with mental retardation and related conditions. In each case, the concern is that rebasing will result in a reduction of funds to individuals. The Association for Residential Resources in Minnesota (ARRM) filed its lawsuit (03-cv-2438) in the U.S. District Court for the District of Minnesota in March 2003. ARRM asked the court to issue a temporary restraining order (TRO) to halt the rebasing until the court could decide the issues in the lawsuit. In March 2003, the court issued the TRO. In April 2003, the court held a hearing concerning the ARRM motion for a preliminary injunction to halt the rebasing and issued the requested TRO. In August, the Court dissolved the TRO and denied an ARRM motion for a new TRO. However, in September 2003, the court agreed to the *Masterman* plaintiffs' petition to issue a new TRO. This TRO did not halt the method of rebasing but simply provided that no reduction to the budgets of individual waiver participants could take place because of rebasing until the Court could hear the merits of the ARRM motion for a temporary injunction. With respect to this lawsuit, the parties are in preliminary settlement discussions before the discovery phase begins. The ARRM lawsuit was dismissed in November 2004 after the parties arrived at a settlement agreement.

In April 2003, four individuals and Arc Minnesota filed a similar lawsuit (03cv2939) asking for a preliminary injunction to halt the rebasing. The Minnesota Disability Law Center (the state's P&A agency) filed this lawsuit on behalf of the plaintiffs. The plaintiffs contend that the payment rebasing will result in "irreparable harm." It appears that the plaintiffs also argue that rebasing will adversely affect their choice between HCBS waiver and institutional services as well as undermine meeting the essential needs through the waiver program. This lawsuit was transferred to the judge hearing the ARRM lawsuit.

⁹⁹ At med.uscourts.gov/opinions/carter/2001/GC_07022001_1-00cv116_Risinger_v_Concannon.pdf

¹⁰⁰ At

caselaw.lp.findlaw.com/scripts/getcase.pl?court=1st&navby=cas&no=021604

¹⁰¹ Decision is located at:

centerforpublicrep.org/docs/2796_RosieD.pdf. See also: arcmass.org/rosied.html for a summary of the decision.

The state filed a motion to dismiss the lawsuit. In its motion to dismiss, the state argued that: (a) the plaintiffs have no right of private action under §1983 to pursue their Medicaid claims under §1902(a)(10)(B) (comparability), §1915(c)(2)(A) (assurance of the health and welfare of HCBS waiver participants), and §1902(a)(1) statewideness of the Social Security Act; (b) plaintiffs lack standing because they cannot show that concrete or imminent injury has resulted from rebasing; and, (c) the plaintiffs' ADA claim fails because it attempts to expand the ADA's integration mandate beyond its basic parameters by arguing that the lack of identical funding between institutional and community services is discriminatory.

In October 2003, the Court heard arguments concerning the plaintiffs' request that the court issue a preliminary injunction to halt the rebasing. The state opposed this motion, contending that sufficient funds were now available in the waiver program to ensure that no deep cuts would be made and that the administrative appeals process afforded individuals sufficient protection should their services be reduced.

In January 2004, the court turned down the plaintiffs' motion for a preliminary injunction and dissolved the temporary restraining order against implementation except in the case of the individual plaintiffs.¹⁰² The court decided that it could not continue to block the rebasing, especially because the lawsuit was not a class action. At the same time, however, the court denied the state's motion to dismiss, except for one claim. The court rejected the state's contention that the *Gonzaga* decision undermined the plaintiffs' standing to bring suit. The Court also rejected the state's request to dismiss the ADA and §504 claims. The Court also expressed the view that the rebasing decision might be at odds with Medicaid statutory provisions concerning the operation of HCBS waiver programs, noting "That Congress has allowed states to limit the number of people served by waivers does not mean that Congress meant to allow states to under serve those actually on the waiver, or treat waiver recipients differently, or excuse states from assuring the health and safety of waiver recipients. Most importantly, it does not evidence that Congress did not intend Medicaid recipients to benefit from the Medicaid program."

In June 2004, the state and the *Masterman* plaintiffs filed a joint motion asking the court to dismiss this litigation, based on a settlement agreement that they had reached.¹⁰³ Under the settlement agreement, the

state agreed to increase county allocations over the next two years and issue new guidelines to counties in establishing individual budgets. The state also agreed to contract with an independent consultant to establish a new funding methodology for the waiver program.

15. Ohio: Nickolaus Thompson and Ohio Private Resource Association et al. v. Hayes et al.

Filed in June 2003 in the Franklin County Court of Common Pleas, this lawsuit charges that Ohio is violating federal Medicaid law by interfering with the right of individuals to choose their service provider and does not administer Medicaid services for people with developmental disabilities uniformly in all parts of the state.¹⁰⁴ The lawsuit was filed by the Ohio Private Resource Association (OPRA) and individual provider agencies against the Departments of Job and Family Services (Ohio's Medicaid agency) and Mental Retardation and Developmental Disabilities (ODMRDD, which administers the state's HCBS waivers for people with developmental disabilities) along with several county boards of mental retardation and developmental disabilities that administer services locally and the Ohio Association of County Boards of Mental Retardation and Developmental Disabilities. At issue in this litigation is the legitimacy of Ohio counties operating Medicaid-funded community services in a fashion that varies county-to-county and, hence, potentially results in disparate treatment of individuals and providers across counties.

In a press release concerning this lawsuit, the provider association executive director said:

"Federal law is very clear on this point. Medicaid must be administered uniformly across the state. The fact that the State of Ohio has abdicated its responsibility to write uniform administrative rules does not mean that county boards, which also are substantial service providers in addition to their Medicaid administration roles, can assume powers that are not properly theirs. What we have here is an attempt by county boards and their associations to hijack state law for their own purposes, even though the result will be that individuals with mental retardation and developmental disabilities will not get the same quality of services from county to county."

The plaintiffs asked the court to grant injunctive relief to prevent the county boards from forcing them to sign county service agreements that they do not regard as legal or withhold payments.

Since the lawsuit was filed, Ohio has made many changes in how it operates its HCBS waivers for people with developmental disabilities, partly in response to problems identified by CMS regarding the

¹⁰² The decision is at:

nysd.uscourts.gov/courtweb/pdf/D08MNXC/04-00195.PDF

¹⁰³ The settlement is described in more detail at:

arcminnesota.com/Rebasing_Settlement.htm.

¹⁰⁴ See: opra.org/pdf/Lawsuit-MemoranduminSupport.PDF

impermissible delegation of authority by the state to county boards regarding waiver operations. In particular, CMS has made it clear that providers cannot be required to enter into county board service agreements that have the effect of imposing additional requirements over and above those established by the state. In a September 2005 brief, the state affirmed that federal Medicaid requirements override provisions in Ohio state law concerning the authority of counties to require that private providers enter into county service agreements in addition to a Medicaid provider agreement.¹⁰⁵

16. Oklahoma: Fisher et al. v. Oklahoma Health Care Authority et al.

In 2002, Oklahoma decided that it would limit to five the number of prescribed medications that participants in the state's "Advantage" HCBS waiver program for people with disabilities and older persons could receive in order to reduce spending to address the state state's budget deficit. Previously, there was no limit on the number of medications that Advantage participants could receive, a policy that also was in effect for nursing facility residents. Medicaid beneficiaries not served in nursing facilities or participating in the waiver program are subject to a three-prescription limit. Oklahoma's Advantage program covered prescribed drugs over and above this limit as an additional "extended pharmacy" benefit. In limiting prescribed drugs to five per month, the state amended its waiver program to curtail the number of medications provided under the extended pharmacy benefit.

The Oklahoma Disability Law Center immediately filed suit (02-cv-762) in the U.S. District Court for the Northern District of Oklahoma, arguing that limiting the number of medications violated the ADA and §504 because the state continued to allow nursing facility residents an unlimited number of medications. The plaintiffs argued that the state's policy was discriminatory. The district court, however, granted summary judgment to the state, deciding that the plaintiffs could not maintain a claim under the ADA because they were not institutionalized or at risk of institutionalization. The plaintiffs appealed this decision to the 10th Circuit Court of Appeals. In July 2003, the Circuit reversed the summary judgment and remanded the complaint to the district court.¹⁰⁶

The Circuit ruled that the district court erred in interpreting the ADA and the Olmstead decision as only apply to institutionalized persons or individuals at risk of institutionalization. The Circuit pointed out that Title II applied to all publicly-operated programs that

serve people with disabilities. The Circuit also questioned the district court's reasoning that requiring the state to reinstate unlimited prescribed medications would constitute a fundamental alternation. The Circuit noted that, if the effect of the limit were to force individuals to seek care in nursing facilities, the state would incur higher costs because such services are more expensive than waiver services. Since the plaintiffs had not based their original claims on Medicaid law, the Circuit refused to rule on alleged violations of Medicaid requirements that they raised on appeal. These claims revolved around the effect of the waiver of comparability that states receive when they operate an HCBS waiver program and their argument that such a waiver does not extend to other non-waiver Medicaid services. The Circuit noted that these issues would have to be addressed by the district court.

In November 2003, the lawsuit was settled by the parties and dismissed. The Oklahoma Health Care Authority revised its policies concerning prescribed drugs, increasing the prescription limit to six per month for all adult Medicaid beneficiaries. In the case of HCBS waiver participants, in addition to the six prescriptions, they also may have up to seven additional generic prescriptions. Persons who require additional medications may request them through a prior authorization process that will include a clinical review of all the individual's prescribed drugs.

17. Tennessee: Newberry et al. v. Goetz et al.

In December 1998, the Tennessee Justice Center (TJC) filed a class action complaint in the U.S. District Court for the Middle District of Tennessee against the state of Tennessee alleging that the state was in violation of federal Medicaid law by impermissibility denying home health benefits to individuals under its TennCare waiver program and, thereby, causing them to be needlessly institutionalized in nursing facilities. Specifically, the complaint claimed violations of federal Medicaid law and the ADA.¹⁰⁷

When Tennessee obtained federal approval of its §1115 health care demonstration waiver, it included home health services in the package of benefits that would be furnished by managed care organizations (MCOs) under a capitated payment arrangement. Under the terms of its federally-approved waiver, the state agreed to furnish home health care as "medically necessary" and further agreed not to limit the number of home health visits that a person could receive or restrict the provision of home health services to "homebound" individuals. Nursing facility services were "carved out" of the waiver (i.e., they were ex-

¹⁰⁵ Available at: opra.org/pdf/jlentry_statereply.pdf

¹⁰⁶ Decision located at: laws.findlaw.com/10th/025192.html.

¹⁰⁷ The complaint is at: tnjustice.org/TennCare/Newberry/Newberry.html

cluded from the services that MCOs provide and would continue to be furnished under pre-existing arrangements).

TJC charged that MCOs impermissibly denied home health services in order to hold down their costs and that the state had de facto adopted policies to restrict home health in violation of the terms of the approved waiver. The outcome was the unnecessary institutionalization of individuals who could have remained in the community had they had access to medically necessary home health services. When the lawsuit was filed, the state had set in motion steps to explicitly limit in the waiver the allowable number of home health visits and impose a co-pay requirement as well as eliminate the coverage of private duty nursing. TJC pointed out that the state's policies led to higher overall expenditures because nursing facility costs were higher than home health costs.

In August 2003, the parties arrived at a settlement agreement. Under the terms of the agreement, the state agreed not to implement its planned restrictions on home health benefits and committed to provide such benefits in accordance with applicable federal regulations (e.g., not condition the provision of home health on a person's being "homebound" or deny the benefits because they might be required for an extended period of time). In addition, the state agreed to develop HCBS waiver alternatives to nursing facility services.

18. Texas: Frew et al. v. Hawkins et al.

Filed in 1993, this lawsuit alleged that Texas was not meeting its obligations in furnishing EPDST services to children. In 1996, the state entered into a voluntary consent decree that would be enforceable by the court. The decree required the state to institute detailed procedures to comply with the decree. In 1998, the plaintiffs returned to court, arguing that the state was not living up to the decree. The court agreed and then moved to enforce the decree, prescribing detailed requirements that the state would have to meet. This prompted the state to appeal the district court's enforcement of the decree to the 5th Circuit Court of Appeals. In particular, Texas claimed that it should not be held to the decree because its requirements went well beyond those contained in federal Medicaid law and the decree was not enforceable under the 11th Amendment. The 5th Circuit ruled in the state's favor, deciding that the decree could not be enforced unless the state voluntarily waived its 11th Amendment immunity.

The plaintiffs then petitioned the U.S. Supreme Court to reverse the 5th Circuit's decision. The plaintiffs contend that the state's agreeing to the consent decree amounted to a waiver of sovereign immunity and,

therefore, the state could not back out of the decree. This litigation raised significant concerns about the enforceability of consent decrees and settlement agreements and thereby their role in resolving litigation.¹⁰⁸

The Supreme Court granted the petition (02-628) and heard oral arguments on October 7, 2003. During the oral arguments, several Justices expressed serious reservations concerning the 5th Circuit's decision.

In January 2004, the Court handed a unanimous decision reversing the 5th Circuit decision.¹⁰⁹ Writing for the Court, Justice Kennedy wrote: "Federal courts are not reduced to approving consent decrees and hoping for compliance. Once entered, a consent decree must be enforced."

In January 2007, the Supreme Court turned down another petition by Texas to review the case. In April 2007, the state agreed to settle the case. In the settlement, the state agreed to increase payment rates to attract more providers and hire additional case managers to help families and children access services. The Texas Legislature is boosting funding to accommodate the settlement.

19. Wisconsin: Nelson et al. v. Milwaukee County et al.

Filed in 2004 in the U.S. District court for Eastern Wisconsin, this lawsuit (04-cv-00193) claims that the manner in which the Medicaid Family Care program operates in Milwaukee County has a discriminatory impact on individuals with disabilities. The lawsuit was filed by several Family Care recipients who claim that they have been adversely affected by the implementation of family care in Milwaukee County.

The Wisconsin Family Care program operates under federal waivers under §1915(b) and §1915(c) of the Social Security Act. These waivers permit the state to implement managed care service delivery methods for Medicaid long-term services, including home and community services. Family Care operates in some but not all Wisconsin counties. In Milwaukee County, the operation of Family Care is confined to individuals age 60 and older. Persons under age 60 are served through regular HCBS waiver programs for people with developmental and other disabilities.

The plaintiffs claim that when individuals transition to Family Care in Milwaukee County that they suffer a reduction in benefits and that their services are changed in a fashion that erodes their ability to live in the most integrated setting. In addition, plaintiffs

¹⁰⁸ More information at:

medill.northwestern.edu/~secure/docket/mt/archives/000721.ph

p.

¹⁰⁹ The decision is at: laws.findlaw.com/us/000/02-628.html

contend that Milwaukee County pays providers less to serve Family Care recipients than it does HCBS waiver participants even though their needs are similar. As a consequence, plaintiffs allege that Milwaukee County along with the state are operating Medicaid services in a fashion that violates the ADA and §504 of the Rehabilitation Act by discriminating based on age and disability and §1902(a)(30)(A) of the Social Security Act by not making payments that are adequate to meet the needs of Medicaid beneficiaries. In March 2005, the plaintiffs filed their fourth amended complaint. In June 2005, the state responded to the complaint, arguing that the plaintiffs lacked standing to bring the action and further arguing that the plaintiffs had adopted an overly broad interpretation of both the ADA and §504.

In February 2006, the district court ruled on the state's motion to dismiss the plaintiffs' claims. The court dismissed claims for damages for past violations. However, the court refused to dismiss the plaintiffs' other claims concerning alleged violations of the ADA and the Rehabilitation Act as well as §1902(a)(30)(A) of the Social Security Act. The court decided that the remaining claims have potential merit and, thereby, should be tried. The state then filed a motion to stay the proceedings in anticipation that it would file an interlocutory appeal to the 7th Circuit Court of Appeals. In its motion, the state indicated that it would contest the court's finding that individuals have standing to bring suit under §1983 and that §1902(a)(30)(A) creates individually-enforceable rights. The court denied the motion to stay.

In October 2006, the court certified the lawsuit as a class action complaint. The court instructed the parties to explore the potential for a mediated settlement. The parties appear to have worked out a settlement.

References

Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services (2000). Understanding Medicaid Home and Community Services: A Primer. Washington DC. Also available at: aspe.hhs.gov/daltcp/reports/primer.htm.

Elizabeth Priaulx (September 2005). "P&A Docket of Cases Related to Community Integration" Washington DC: National Disability Rights Network, Training and Advocacy Support Center.

Robert Prouty, Gary Smith and K. Charlie Lakin (eds.) (2006). Residential Services for Persons with Intellectual and Developmental Disabilities: Status and Trends Through 2005. Minneapolis: University of Minnesota, Research and Training Center on Community Living. Available at: rtc.umn.edu/residential/pub1.asp

Gary Smith (1999). Closing the Gap: Addressing the Needs of People with Developmental Disabilities Waiting for Supports. Alexandria VA: National Association of State Directors of Developmental Disabilities Services.

Resources

The National Health Law Project provides a wealth of information concerning litigation in this arena. This information may be accessed at: healthlaw.org/

APP D

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ANTI-SUBORDINATION ABOVE ALL:
A DISABILITY PERSPECTIVE

*Ruth Colker**

INTRODUCTION

The field of disability discrimination is undertheorized; it conflates “separate” and “unequal.” Theories of justice typically do not consider the example of disability,¹ or if they do, they proceed from a

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¹ John Rawls’s theory of justice, for example, presumes that society consists of “free and equal persons . . . who can play the role of fully cooperating members.” JOHN RAWLS, *JUSTICE AS FAIRNESS: A RESTATEMENT* 24 (Erwin Kelly ed., 2001). Further, “we must add to these concepts those used to formulate the powers of reason, inference, and judgment.” *Id.* As Martha Nussbaum points out, Rawls excludes individuals with disabilities from consideration when designing basic political principles. MARTHA NUSSBAUM, *FRONTIERS OF JUSTICE* 111 (2006). Similarly, Ravi Malhotra argues that Rawls’s theory suffers from several problems which make it difficult to apply to the disability area. See Ravi A. Malhotra, *Justice as Fairness in Accommodating Workers with Disabilities and Critical Theory: The Limitations of a Rawlsian Framework for Empowering People with Disabilities in Canada*, in *CRITICAL DISABILITY THEORY* 70, 74–83 (Dianne Pothier & Richard Devlin eds., 2006). Norman Daniels applies Rawls’s theory of justice to the disability arena by finding a justification for reasonable accommodations so that we can keep “people with disabilities functioning as close to normally as possi-

pure “integrationist” perspective.² Although an integrationist perspective played an important historical and structural role in helping to close some horrendous disability-only institutions, it fails to recognize that the government may need to retain some disability-only services and institutions for those who need or want them while

ble.” Norman Daniels, *Mental Disabilities, Equal Opportunity, and the ADA*, in MENTAL DISORDER, WORK DISABILITY AND THE LAW 281, 287 (Richard J. Bonnie & John Monahan eds., 1997). Daniels’s work expands the group of individuals with disabilities who can take advantage of Rawls’s original position but also presupposes an integrationist perspective in measuring equality. Daniels makes a passing reference to the illegitimacy of “Jim Crow or other caste-enforcing laws,” saying they “should be given no moral weight in arguments about social policy.” NORMAN DANIELS, JUST HEALTH CARE 124 (1985). That argument is consistent with my anti-subordination perspective but does not address the integration/segregation dichotomy of this Article.

Douglas Rae mentions individuals with disabilities in passing as part of his “need-based person-regarding” equality theory, but the examples are degrading. See DOUGLAS RAE, EQUALITIES 99 (1981). He says, for example,

Perhaps *no* service could make a crippled child as happy as her healthy friends, but her special needs may nonetheless require special services equal to and different from those of her playmates. Even if a mentally retarded boy will never derive the same utility from schooling that his bright brothers derive from it, schooling equally suited to his needs should still be provided (even if it is more costly than ordinary schooling).

Id.

2 For an excellent overview of disability theory, see David Wasserman, *Philosophical Issues in the Definition and Social Response to Disability*, in HANDBOOK OF DISABILITY STUDIES 219 (Gary L. Albrecht et al. eds., 2001). William and Susan Stainback are typical of researchers who justify integrated (or what is often called “inclusive”) education for all children with disabilities. Susan Stainback & William Stainback, *Inclusive Schooling*, in SUPPORT NETWORKS FOR INCLUSIVE SCHOOLING 6–7 (William Stainback & Susan Stainback eds., 1990). They argue: “When a single person, who has not broken any laws, is excluded from the mainstream of school and community life, all of society becomes vulnerable.” *Id.* at 7. This last argument is a conversation stopper because it makes the act of separation evil in itself and requires no justification for integration. In this Article, however, I will argue that it is too simplistic to equate separation and harm; such a claim must be made on a more individualized basis. For similar arguments, see Harold Hongju Koh & Lawrence O. Gostin, *Introduction to THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES* 1, 5 (Stanley S. Herr et al. eds., 2003) (presenting a collection of papers arguing that the core elements of an international civil rights standard on disability should include “such rights as *access* to tools for exercising individual agency; *participation* and *inclusion* in critical decisions that affect the disabled person’s life and future; and freedom for disabled individuals proactively to exercise their rights, both personally and through agents”); ANITA SILVERS ET AL., DISABILITY, DIFFERENCE, DISCRIMINATION 5 (1998) (presenting arguments for the full social participation of individuals with disabilities in society). An exception to this trend is the work of Carlos Ball which proceeds from a communitarian perspective. See Carlos A. Ball, *Looking for Theory in All the Right Places: Feminist and Communitarian Elements of Disability Discrimination Law*, 66 OHIO ST. L.J. 105 (2005).

protecting others from coercively being required to accept such services or being placed in such institutions. An absolutist integrationist perspective disserves the disability community by supporting an inappropriately high threshold for the development and retention of disability-only services and institutions. An anti-subordination perspective³ should replace it.

An important figure in the development of the integrationist approach was Jacobus tenBroek who in a 1966 article calling for tort reform argued for individuals with disabilities to have “the right to live in the world.”⁴ tenBroek penned his passionate plea for “integration-

3 Twenty years ago, I argued for an anti-subordination perspective for analyzing sex- or race-based claims of discrimination. See Ruth Colker, *Anti-Subordination Above All: Sex, Race, and Equal Protection*, 61 N.Y.U. L. REV. 1003, 1007–08 (1986) (“Under the anti-subordination perspective, it is inappropriate for certain groups in society to have subordinated status because of their lack of power in society as a whole. This approach seeks to eliminate the power disparities between men and women, and between whites and non-whites, through the development of laws and policies that directly redress those disparities. From an anti-subordination perspective, both facially differentiating and facially neutral policies are invidious only if they perpetuate racial or sexual hierarchy.”). In that article, I did not consider the example of individuals with disabilities. This Article seeks to apply that framework to individuals with disabilities.

For a thoughtful article that seeks to apply an anti-subordination perspective to the law of disability discrimination, see Samuel R. Bagenstos, *Subordination, Stigma, and “Disability,”* 86 VA. L. REV. 397 (2000) (connecting the concept of disability-based subordination to “stigma,” which he thinks best explains how subordination operates in the lives of individuals with disabilities). Bagenstos considers the concept of subordination to help define the class covered by disability or civil rights legislation and does not address the integration and remedy issue which is central to this Article.

4 See Jacobus tenBroek, *The Right To Live in the World: The Disabled in the Law of Torts*, 54 CAL. L. REV. 841, 917 (1966). tenBroek declares that “integrationism,” which he describes as “a policy entitling the disabled to full participation in the life of the community and encouraging and enabling them to do so,” should guide the decisions of legislatures and courts. *Id.* at 843. tenBroek’s passionate argument for integrationism is necessary, in part, because of the failure of basic political principles to include individuals with disabilities. In tenBroek’s words:

However much the courts may instruct juries that the reasonably prudent man is an idealized mortal, possessing human, not superhuman virtues, but no human or subhuman weaknesses or depravities; however often they may repeat that he is an abstraction not to be confused with any identifiable individual, and especially not with a judge or a juror; and however much they may emphasize that he acts in the light of all of the circumstances and that he is physically disabled when the plaintiff is, the jurors are almost entirely able-bodied (blind people are excluded from jury service), and the judge has sound if somewhat aging limbs, fair enough eyesight, and, according to counsel, can hear everything but a good argument. The abstraction they conceive is unavoidably in their image and, in any event, will be applied

ism" at a time when individuals with disabilities were excluded from juries, had few educational opportunities, were disenfranchised, were often housed in inhumane warehouses and had little "right to live in the world."⁵ Separation was synonymous with inequality.

Although tenBroek is primarily remembered in the disability field for his integrationist perspective,⁶ he also recognized the importance of values other than integrationism. At the end of his path-breaking torts article, he noted that the disability community wanted the

same right to privacy that others do; not only the right to rent a home or an apartment, public or private housing, but the right to live in it; the right to determine their living arrangements, the conduct of their lives; the right to select their mates, raise their families, and receive due protection in the safe and secure exercise of these rights.⁷

"The right to live in the world consists in part of the right to live out of it."⁸ He argued for integrationism at a time when forced segregation was the dominant social existence for most individuals with disabilities, but he also recognized the positive role that separation by choice can have in the lives of individuals with disabilities.

through the filter of their experiences and make-up. Standing on good feet and legs, erect through the strength of taut muscles, peering through eyes approaching or receding from 20/20 visual acuity, the judge or juror, or their personified image, provide the blind, the deaf, the lame, and the otherwise physically disabled with a standard of reasonableness and prudence in the light of all of their circumstances, including some often quite erroneous imaginings about the nature of the particular disability.

Id. at 917.

⁵ *Id.* Another key early figure in fashioning the integrationist approach was Stanley Herr. He argued many of the early cases which sought to provide access to the public school system for children with mental disabilities. *See, e.g.,* *Mills v. Bd. of Educ.*, 348 F. Supp. 866, 878 (D.D.C. 1972) (requiring that public schools in the District of Columbia cease denying retarded children a "regular public school assignment"). His work is often credited as being a precursor to the standards found in the Education for All Handicapped Children Act of 1975, § 612(5)(B), Pub. L. No. 94-142, 89 Stat. 773, 781 (codified as amended at 20 U.S.C. § 1412(a)(5)(A) (2000)) (requiring children with disabilities to be taught in the regular classroom wherever possible).

⁶ Jacobus tenBroek was also a noted Fourteenth Amendment scholar. *See* JACOBUS TENBROEK, *THE ANTISLAVERY ORIGINS OF THE FOURTEENTH AMENDMENT* (1951); Joseph Tussman & Jacobus tenBroek, *The Equal Protection of the Laws*, 37 CAL. L. REV. 341 (1949).

⁷ tenBroek, *supra* note 4, at 918.

⁸ *Id.*

Since 1966, at the urging of disability advocates, the law of disability discrimination has developed under the integrationist rubric⁹ with insufficient attention to how separateness can have positive benefits. It has conflated inequality and separation by borrowing the race mantra that “[s]eparate . . . [is] inherently unequal.”¹⁰ Hence, special education is considered intrinsically degrading and is disfavored as the mechanism for delivering educational services to children with disabilities.¹¹ Disability-based institutionalization is considered an inhumane way to deliver health care services.¹² Segregated voting practices for individuals with disabilities are considered to be a denial of basic citizenship rights.¹³

From a historical perspective, the connection between separation and inequality makes sense. Special education was a “dead end” academically that did not seek to prepare children for higher education or well paying careers.¹⁴ Disability institutionalization was a way to hide and degrade individuals with disabilities rather than provide them with treatment.¹⁵ Segregation served to suppress voting behavior by individuals with disabilities in at least two ways: (1) by requiring them to use absentee ballots rather than vote at regular polling places and (2) by disenfranchising them based on their residency at a state facility for mental retardation or insanity.¹⁶ Together, these segregating practices contributed to the subordination of individuals with disabilities in society.

Modern disability legal policy developed as a response to these historical practices of invidious segregation. Federal education law dictated that children with disabilities “to the maximum extent appro-

9 Mark Weber describes the Americans with Disabilities Act as “a classic integrationist measure.” Mark C. Weber, *Home and Community-Based Services, Olmstead, and Positive Rights: A Preliminary Discussion*, 39 WAKE FOREST L. REV. 269, 279 (2004).

10 *Brown v. Bd. of Educ.*, 347 U.S. 483, 495 (1954). See generally RICHARD KLUGER, *SIMPLE JUSTICE* (rev. & expanded ed. 2004) (tracing the evolution of the *Brown* strategy from a case by case demonstration of inequality stemming from segregation to a critique of segregation itself).

11 See *infra* notes 61–72 and accompanying text.

12 See *infra* Part II.A.

13 See *infra* Part III.B.

14 See *infra* Part I.A.

15 See *infra* notes 97–101 and accompanying text.

16 See *infra* Part III.A. Today, we would not use the terms “mental retardation” or “insanity.” Instead, we refer to categories such as intellectual and developmental disabilities. This Article, however, uses these terms as they reflect the language of the legislatures and courts who have considered these issues.

prate” should be educated “with children who are not disabled.”¹⁷ The Supreme Court interpreted federal antidiscrimination law to require states to seek to provide living assistance to individuals with severe disabilities in a home rather than disability-only institution.¹⁸ Federal voting law required each state to have at least one accessible machine in each polling place by 2006 so that individuals with disabilities could vote independently and privately with the rest of the public.¹⁹

Although each of these policies can be justified historically as a necessary structural remedy to protect against invidious discrimination, they also reflect an unsophisticated connection between separation and inequality. Separation need not result in inequality if it is accompanied by adequate services and positive recognition; it need not be the equivalent of invidious segregation. Hence, today, some parents are *seeking* to have their children labeled as “learning disabled” to obtain special education resources.²⁰ Other parents are *criticizing* state attempts to close disability-only institutions because they believe those institutions may be the most appropriate place for their children to receive needed health care services.²¹ Some voting rights advocates are encouraging states to develop mechanisms so that *all voters* can vote in the privacy of their homes rather than consider voting to be a public act of citizenship where accessible polling places would be required.²² An anti-subordination theory of equality could recognize the validity of these claims as well as the continued possibility of invidious segregation. Anti-subordination²³ rather than integration should be the measure of equality.

17 Individuals with Disabilities Education Improvement Act of 2004, § 101, 20 U.S.C. § 1412(a)(5)(A) (Supp. IV 2004). For further discussion, see *infra* Part I.B.

18 *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 607 (1999). For further discussion, see *infra* notes 156–65 and accompanying text.

19 Help America Vote Act of 2002, 42 U.S.C. §§ 15301–15545 (Supp. IV 2004). For further discussion, see *infra* Part III.B.

20 See *infra* text accompanying notes 256–60.

21 See *infra* Part IV.B.

22 See *infra* Part IV.C.

23 This Article does not seek to provide a universalistic definition of “anti-subordination” that can be applied to all claims of inequality by groups in society. Rather, this Article presumes that under any definition of subordination, individuals with disabilities qualify as having experienced subordination by the dominant power structure in society. As Parts I.A, II.A, and III.A will recount, individuals with disabilities have been coercively institutionalized, denied an opportunity to receive an education, and denied the right to vote. They are among the poorest members of society with an estimated unemployment rate of eighty percent. Whether we define subordination on the basis of economic inequality, stigma, or a basic denial of the right to participate in political institutions, individuals with disabilities would meet those criteria.

This Article will examine the connection between separation and inequality in the disability context with special emphasis on how the racial civil rights movement influenced the development of disability theory and practice. Part I will discuss special education, Part II will discuss health care institutionalization and Part III will discuss voting. It will demonstrate that governmental entities created and funded disability-only educational and health care institutions in the late eighteenth century, in part, out of a humane desire to provide assistance to individuals with severe disabilities. Nonetheless, these institutions became severely overcrowded, underfunded and inhumane by the middle of the nineteenth century as public attitudes towards individuals with disabilities became more negative. The disenfranchisement of individuals with disabilities was connected to the increasingly negative attitude towards individuals with disabilities that emerged as compulsory public education and an emphasis on literacy increased during the early nineteenth century. The disability rights movement arose in response to these deplorable conditions with the argument that separation is inherently unequal. The borrowing of the *Brown v. Board of Education*²⁴ formulation of equality²⁵ made sense because of the historical connection between invidious race and disability segregation. Disability segregation was a mechanism to degrade disfavored groups in society including individuals with disabilities, immigrants and racial minorities. Part IV will conclude that policy makers need to develop an approach that recognizes the history of overt disability-

Others can seek to develop universalistic criteria for determining which groups in society have faced subordination and are therefore entitled to protective legal measures to redress their history of subordination. See generally NUSSBAUM, *supra* note 1, at 111–19 (2006) (criticizing Rawls for excluding the disabled from playing any role in his social contract theory); JOHN RAWLS, A THEORY OF JUSTICE 65–73 (rev. ed. 1999) (proposing principles of justice to benefit the least well-off members of society); AMARTYA SEN, COMMODITIES AND CAPABILITIES 10 (1985) (arguing that the characteristics of goods are independent of the characteristics—“able-bodied or crippled”—of their owner); Ronald Dworkin, *What is Equality?*, 10 PHIL. & PUB. AFF. 283, 296–99 (1981) (discussing the response to disability in the insurance industry).

²⁴ 347 U.S. 483 (1954).

²⁵ In *Brown*, the Supreme Court held that “[s]eparate educational facilities are inherently unequal.” The Court then followed the *Brown* decision with a series of summary opinions which extended its holding beyond the context of education. See, e.g., *Mayor & City Council of Baltimore City v. Dawson*, 350 U.S. 877 (1955) (public bathhouses and beaches); *Holmes v. Atlanta*, 350 U.S. 879 (1955) (municipal golf course); *Gayle v. Browder*, 352 U.S. 903 (1956) (city buses); *New Orleans City Park Improvement Ass’n v. Detiege*, 358 U.S. 54 (1958) (municipal parks and golf courses). The Court offered no explanation for these decisions but, implicitly, it extended the concept that separate “educational” facilities are inherently unequal to the concept that any separate facility or service is inherently unequal.

based discrimination through invidious segregation while also leaving room for modern approaches to the delivery of separate services and maintenance of some disability-only institutions for individuals with disabilities that are not premised on an intention to demean and degrade. The concept that “separate is inherently unequal” has outlived its usefulness in the disability context.

Moving beyond the mantra “separate is inherently unequal” is challenging because a tension exists between using broad structural remedies to eliminate degrading disability-only services and institutions while also retaining effective disability-only services and institutions for those who need or desire them. States do not want to retain expensive disability-only institutions if they are going to be underpopulated.²⁶ It is hard to strike a balance between a state’s fiscal concerns—which may result in coercive overpopulation and overuse of disability-only institutions and services—and the needs of some individuals for such institutions and services.

In trying to resolve this tension, history can offer some important lessons. States initially offered no services for individuals with disabilities and, during times of fiscal austerity, tried to eliminate the few special programs and institutions that existed for individuals with disabilities. The movement towards integration on the part of the states was motivated, in part, by a desire to save money rather than a desire to improve the lives of individuals with disabilities.²⁷ Support

²⁶ On a per person basis, it is considered less expensive to educate children in mainstream classrooms or provide health care services to people in community settings than to maintain disability-only institutions. If *some* people need disability-only institutions, then states are faced with high fixed costs to retain those institutions. Hence, the integrationist perspective puts pressure on the states to close all disability-only institutions, leaving no safety net for those who need or desire such institutions. See *infra* note 63 and accompanying text.

²⁷ Even today, arguments for integration (or community placement) often contain subtle suggestions that integration would be cheaper for the state than institutionalization. See, e.g., JAMES W. CONROY ET AL., CTR. FOR OUTCOME ANALYSIS, INITIAL OUTCOMES OF COMMUNITY PLACEMENT FOR THE PEOPLE WHO MOVED FROM THE STOCKLEY CENTER 47–48 (2003), available at <http://www.dhss.delaware.gov/dhss/ddds/files/conroyrep.pdf> (“In practically all prior studies, including more than 200 ‘independent assessments’ of Medicaid Waivers, community costs have been found to be lower than public institutional costs, even for the same or comparable people. . . . Only through proper tracking of costs will the State be aware of the money that could possibly be saved, and spent more wisely, in the community. This kind of evidence will become crucial for development of public policy, as the pressures for full implementation of Olmstead mandates increase.”); Michael J. Head & James W. Conroy, *Outcomes of Self-Determination in Michigan: Quality and Costs*, in COSTS AND OUTCOMES OF COMMUNITY SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITIES 219, 232–34 (Roger J. Stancliffe & K. Charlie Lakin eds., 2005) (concluding that public costs do not

for integration has not always accompanied support for genuine equality as measured by the principle of anti-subordination. Disability rights advocates need to recognize that integration is not inherently beneficial, as separation is not inherently degrading. They need to support disability-only services and institutions that are available to those who need or desire them²⁸ while also creating safeguards to prevent some people from being inappropriately coerced into entering disability-only institutions, particularly residential institutions, for the sole purpose of making them financially viable for others. If tenBroek were alive today, he might be willing to measure progress towards equality through the principle of anti-subordination rather than integration.²⁹

I. SPECIAL EDUCATION

A. History

Until the nineteenth century, most individuals with disabilities received no education whatsoever, because they were feared and

increase when service recipients obtain control over resources and move towards community placements).

28 Some parents have argued that the integration movement threatens the special education programs that have benefited their children. See, e.g., Margaret N. Carr, *A Mother's Thoughts on Inclusion*, in *THE ILLUSION OF FULL INCLUSION* 263, 265–57 (James M. Kauffman & Daniel P. Hallahan eds., 1995).

29 To be clear, I am *not* suggesting that we should develop an anti-integration perspective. Integration is frequently a useful remedy for individuals with disabilities who face claims of discrimination. For example, children with vision or mobility impairments have historically been excluded from the regular classroom. See *infra* Part I.A. In most cases, there is no justification for such exclusion. They should be educated with typically developing children. But we do not need an integration presumption to attain that result because there are few, if any, arguments for why these children would not do better in a mainstream rather than special education classroom. By contrast, the evidence with respect to children with cognitive and mental impairments is more mixed. I argue that we can only determine the most appropriate classroom configuration for those children on an individual basis, taking into account their specific needs and abilities. An integration presumption inappropriately tips the balance towards a mainstream classroom for such children. I simply suggest that we should be more agnostic about the correct remedy as we examine the information available for any specific child. I discuss the available empirical data for children with cognitive and mental impairments in a prior article, and do not repeat those arguments in this Article. See Ruth Colker, *The Disability Integration Presumption: Thirty Years Later*, 154 U. PA. L. REV. 789, 825–35 (2006). In this Article, I simply attempt to expose the widespread use of the integration presumption and how it causes parents, policymakers, and courts to reach conclusions that might not be supported by the evidence of what practices are most likely to redress a history of subordinating practices.

shunned by society.³⁰ Thomas Hopkins Gallaudet was among the earliest American reformers to argue for the education of individuals who are deaf. He helped found the Connecticut Asylum for the Education and Instruction of Deaf and Dumb Persons in Hartford, Connecticut in 1817.³¹ Samuel Gridley Howe played a similar role in Massachusetts, helping to found the Massachusetts Asylum for the Blind in 1832 and the Massachusetts Asylum for Idiotic and Feeble-Minded Youth in 1848.³² Howe argued that such institutions should be considered part of the public school system.³³ Both Gallaudet and Howe had to overcome enormous barriers even to suggest that individuals with disabilities should be educated.³⁴ These schools were residential facilities which did not seek to educate children who used wheelchairs, who were not toilet-trained or who were considered uneducable.³⁵ Thus, they served a small subsection of the disability community.

Gallaudet and Howe had humanitarian reasons for seeking to create separate residential facilities for individuals who were deaf, blind or mentally disabled. By the early 1900s, however, such institutions became much more problematic. Attitudes towards disability became more negative "with the disabled facing near as much ostracism, contempt, and misunderstanding as ever."³⁶

30 ROBERT L. OSGOOD, *THE HISTORY OF INCLUSION IN THE UNITED STATES* 18 (2005) ("patterns of response grounded in fear, suspicion, contempt, and cruelty"). One of the earliest cases affirming this principle is *Watson v. City of Cambridge*, 32 N.E. 864, 864-65 (Mass. 1893) (permitting exclusion of a child who is "weak in mind" from public schools). That principle was approved as recently as 1958. See *Dep't of Pub. Welfare v. Haas*, 154 N.E.2d 265, 270 (Ill. 1958) (finding no right to public education for the "feeble minded").

31 See SCOTT B. SIGMON, *RADICAL ANALYSIS OF SPECIAL EDUCATION* 21 (1987).

32 *Id.* at 23.

33 OSGOOD, *supra* note 30, at 21.

34 See generally *id.* at 21 (indicating that educational institutions for the disabled came "into being amid intense scrutiny and skepticism on the part of the public").

35 SIGMON, *supra* note 31, at 22.

36 OSGOOD, *supra* note 30, at 22. A case from 1919 reflects this ostracism. *State ex rel. Beattie v. Bd. of Educ.*, 172 N.W. 153 (Wis. 1919). Merritt Beattie, who was paralyzed at birth, was educated in the public schools until the fifth grade. The record indicates that he was "normal mentally" and "kept pace with the other pupils." *Id.* at 153. Nonetheless, after a visit to the school by a representative of the state department of public instruction, he was excluded from the regular public schools. The school district's rationale for the exclusion was that

[H]is physical condition and ailment produces a depressing and nauseating effect upon the teachers and school children; that by reason of his physical condition he takes up an undue portion of the teacher's time and attention,

In addition to separate residential facilities for children with hearing, sight or intellectual disabilities, states also began to experience children with disabilities in nonresidential public school classrooms beginning in the late 1800s.³⁷ They began to develop segregated education classrooms at this time. The development of special education classrooms must be understood in relationship to the development of compulsory education³⁸ and hostility to immigrants.³⁹

The compulsory education movement increased class size in regular public school classes and put pressure on the public school system to discard the undesirables (which included the disabled and immigrants) by dumping them into special education classrooms. Large public schools began to exist in urban areas in the United States in the early 1800s. These classes often had eighty or ninety students. In the second half of the century, schools instituted grade placement where students were assigned according to their chronological age but differed dramatically with respect to background, interests, skills, abilities, and preparation.⁴⁰ Faced with broad discrepancies among students in the classroom, teachers began to request "segregated settings for children who were different, uncooperative, or unsuccessful in school."⁴¹ School districts developed generic ungraded classes for these children which were "dumping grounds."⁴² The primary population for these generic ungraded classes was immigrants, although the developing interest in intelligence testing also gave rise to the classification of many of these immigrants as in the "moron" range of intelligence.⁴³ Thus, educational segregation was a mechanism to remove undesirables from the regular classroom rather than offer them high quality education.

Meanwhile, school districts also began to open some day schools for subcategories of individuals with disabilities—primarily students who were deaf or mentally retarded.⁴⁴ By 1932, 75,000 children with

distracts the attention of other pupils, and interferes generally with the discipline and progress of the school.

Id.

³⁷ SIGMON, *supra* note 31, at 22.

³⁸ Compulsory education laws were enacted in each state between 1852 and 1918. *See id.* at 20.

³⁹ *Id.*

⁴⁰ OSGOOD, *supra* note 30, at 22–25.

⁴¹ *Id.* at 24.

⁴² *Id.*

⁴³ *Id.* at 25.

⁴⁴ SIGMON, *supra* note 31, at 21.

mental retardation were being educated in special classes. Ironically, the category of mental retardation received little attention until compulsory education raised the literacy rate; children who had trouble learning to read then became more apparent.⁴⁵ The rise of the mental retardation category put pressure on the need to create a formal identification process. Students classified as mentally retarded were typically male immigrants of all races.⁴⁶

Justifications for segregation of these various populations in the late nineteenth and early twentieth centuries into separate schools in urban school districts were: (1) that separate schools benefited "normal" students by removing disruptive elements and (2) that segregated settings benefited children with disabilities because they would be surrounded by "mutual understanding, helpfulness and sympathy."⁴⁷ Special schools arose from a mixture of bureaucratic interest in controlling the classroom and a humanitarian interest in developing appropriate educational programs for children with a wide variety of disabilities.⁴⁸ Special schools were largely an urban phenomenon; rural school districts with one room schoolhouses typically sought to exclude or expel children who were problematic.⁴⁹

The movement towards special classes in public day schools or separate disability-only institutions, however, declined from 1930 to 1940 due to financial pressures.⁵⁰ Children with mental retardation returned to the regular classrooms where little learning took place. Parents pushed for the resurrection of special classes after World War II and were pleased with the return to that educational alternative.⁵¹ By 1948, more than 439,000 children were educated in special settings; those numbers increased by forty-seven percent between 1948 and 1953.⁵² Although separation was the primary method of educating children with disabilities, some parents and practitioners began expressing concern about separation in the 1940s and 1950s. As early as 1945, the International Council for Exceptional Children held a panel entitled "Segregation versus Non-Segregation of Exceptional

45 *Id.* Similarly, a focus on "intelligence" has been historically a mechanism to limit the franchise. See *Dunn v. Blumstein*, 405 U.S. 330, 356 (1972) ("[T]he criterion of 'intelligent' voting is an elusive one, and susceptible of abuse.").

46 OSGOOD, *supra* note 30, at 26-27.

47 *Id.* at 28 (quoting J.E. WALLACE WALLIN, *THE EDUCATION OF HANDICAPPED CHILDREN* 94-97 (1924)).

48 *Id.* at 31.

49 *Id.* at 32-33.

50 *Id.* at 37-38.

51 See SIGMON, *supra* note 31, at 22.

52 OSGOOD, *supra* note 30, at 42.

Children.”⁵³ Efficacy studies were conducted to determine which educational configuration made the most sense for children with mild mental retardation.⁵⁴ The dominant view continued to support segregation. Studies suggested that disabled children suffered rejection and isolation in mainstream classrooms. “Such rejection, it was thought, underscored the judgment that physical proximity did not necessarily lead to true integration, nor did a primarily separate setting condemn an exceptional child to permanent isolation.”⁵⁵ Arthur S. Hill, education director of United Cerebral Palsy and an associate editor of the journal *Exceptional Children*, criticized the pursuit of integration as the “pursuit of a ‘cliché’ for its own sake.”⁵⁶ His sharp critique of integration responded to an emerging mainstreaming movement.

In addition to separate schooling for children with disabilities, more residential institutions began to emerge during the 1950s. In fact, seventy-five percent of the residential institutions that served individuals with disabilities that existed in 1970 had been built since 1950.⁵⁷ These institutions varied widely with respect to how much education occurred within their walls. “[T]he wide range of ages and severity of disabilities made provision of formal schooling problematic, and the educational functions of each became clouded by the institutions’ multiple roles as school, hospital, penal institution, and warehouse.”⁵⁸ Although this construction boom was supposed to alleviate serious overcrowding problems, those problems persisted in the 1970s.⁵⁹

Until 1967, state and federal legislation did not focus on placing children with disabilities in the regular classroom.⁶⁰ The focus was on creating universal and compulsory educational opportunities for children with disabilities. Disability advocates considered integration to be a less expensive and less satisfactory option than special schools or classrooms.

In the 1960s and 1970s, educators began to publish articles questioning the effectiveness of self-contained schools and special educa-

53 *Id.* at 44.

54 *Id.* at 47.

55 *Id.* at 51.

56 *Id.* at 53.

57 *Id.* at 54–55.

58 *Id.* at 55.

59 *Id.*

60 SIGMON, *supra* note 31, at 24.

tion classes.⁶¹ Their work laid the foundation for the concept of "least restrictive alternative"—that children should be educated in the most integrated setting possible.⁶² The proponents of integration presented evidence that special schools and separate classrooms did not necessarily achieve better outcomes than regular classrooms with appropriate support. Further, as one proponent of integration has noted:

[N]ot all of those jumping on the mainstreaming bandwagon are doing so for solely egalitarian reasons. The total per capita annual expenditure is considerably less for a nonclassified student, and in this sense, mainstreaming saves money. So in this political era of fiscal austerity, the concept of mainstreaming is welcomed by many.⁶³

The disability rights movement, in some sense, became strange bedfellows with school districts that sought a less expensive way to educate children with disabilities. Motivations other than anti-subordination spurred some school districts to adopt integration for children with disabilities.

The racial civil rights movement also influenced the disability movement towards integration. Educators began to argue that there were parallels between the treatment of African-Americans and individuals with disabilities, and that integration was necessary to eliminate negative stereotypes.⁶⁴ Increased attention to disability, especially mental retardation, arose during John F. Kennedy's presidency, particularly because of his personal family experience with

61 *Id.* at 27–28; *see also* OSGOOD, *supra* note 30, at 78–84 (discussing critiques of special education).

62 *See* *Welsch v. Likins*, 550 F.2d 1122, 1125 (8th Cir. 1977) (at the time, the concept was referred to as "least restrictive environment").

63 SIGMON, *supra* note 31, at 32. In fact, one of the most well known critiques of the effectiveness of special education identified monetary concerns as one problem with special education. G. Orville Johnson argued:

It is indeed paradoxical that mentally handicapped children having teachers especially trained, having more money (per capita) spent on their education, and being enrolled in classes with fewer children and a program designed to provide for their unique needs, should be accomplishing the objectives of their education at the same or at a lower level than similar mentally handicapped children who have not had these advantages and have been forced to remain in the regular grades.

OSGOOD, *supra* note 30, at 80 (quoting Orville Johnson, *Special Education for the Mentally Handicapped—A Paradox*, 29 EXCEPTONAL CHILD. 62, 65–66 (1962)).

64 OSGOOD, *supra* note 30, at 60–61.

mental retardation.⁶⁵ Federal funding became available to the states to support special education.

Further, disability advocates began to identify the horrific nature of many of the residential institutions for school-age children with disabilities. The number of children enrolled in such institutions rose from 40,000 in 1958 to 127,000 in 1966.⁶⁶ Investigations during the 1960s revealed that many of these institutions were deplorable and offered little or no education to children.⁶⁷ The "normalization" or deinstitutionalization movement sought to move these individuals out of disability-only institutions.⁶⁸

Although the movement toward normalization and deinstitutionalization reached its initial impetus on behalf of individuals who were mentally retarded and who lived in institutional settings, it soon spread to concerns about other categories of disability and to children who received special education outside of the residential institutional setting. In the 1970s, the prevailing view, even among those who ardently argued for integration of children with mild mental retardation, was that children with severe disabilities should be educated in nonresidential special education programs.⁶⁹ The National Association for Retarded Citizens supported a continuum approach under which nonresidential separate education would play an important role.⁷⁰ Nonetheless, the continuum approach took a backseat to a presumption that children should be educated in the most integrated environment possible. Lloyd Dunn's article on the benefits of integrated education for children with mild mental retardation⁷¹ was used to support an integration presumption for all children with disabilities, although Dunn himself supported special education for children with more severe disabilities.⁷²

65 *Id.* at 64–66 (noting that Kennedy's sister Rosemary was identified as mentally retarded).

66 *Id.* at 67.

67 *Id.*

68 "[T]he normalization principle means making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society." *Id.* at 94 (quoting Doug Fuchs & Lynne Fuchs, *Evaluation of the Adaptive Learning Environments Model*, 55 *EXCEPTIONAL CHILD*. 155 (1988)).

69 *Id.* at 96–97.

70 *Id.* at 98.

71 See Lloyd Dunn, *Special Education for the Mildly Retarded: Is Much of It Justifiable?*, 35 *EXCEPTIONAL CHILD*. 5 (1968).

72 *Id.* at 6 ("We are not arguing that we do away with our special education programs for the moderately and severely retarded, for other types of more handicapped children, or for the multiply handicapped. The emphasis is on doing something bet-

This brief history of special education reflects that it went through many stages of development. Initially, children with disabilities were excluded entirely from the school system. Then, humanitarian reformers supported the creation of residential institutions for subcategories of individuals with disabilities. These humanitarian impulses were soon co-opted by those who wanted to separate out the "undesirables," including immigrants as well as individuals with disabilities. These institutions became dumping grounds or warehouses for society's outcasts. During a period of fiscal austerity in the 1930s, some children with mental retardation were returned to the regular classroom with negative results. Parents then pushed for the development of well funded disability institutions in the 1950s as the United States recovered financially. Parallel to the development of disability-only institutions was the development of special education classes. This mode of education for children with disabilities was popular until the 1970s when the separate nature of these programs was called into question. The legal discourse soon moved to an integration presumption even though many educators, in fact, called for a continuum of programs and services for individuals with disabilities.

Advocates for children with disabilities have been able to find many examples of abuse during this period. Many disability-only institutions were substandard warehouses. Many special classrooms for individuals with disabilities did not do an effective job. Nonetheless, children with disabilities who were integrated into the regular classroom did not always fare well due to negative attitudes and inadequate support. Every alternative has been problematic. As we will see in the next subpart, success in the education area has been measured by the extent to which children are educated in the most integrated setting possible rather than by whether they have received the most effective education possible.

B. Legal Developments

The law of special education and race discrimination in education have been closely connected, strengthening the tendency for the disability rights movement to focus on the "separate is inherently une-

ter for slow learning children who live in slum conditions, although much of what is said should also have relevance for those children who are labeling [sic] emotionally disturbed, perceptually impaired, brain injured, and learning disordered. Furthermore, the emphasis of the article is on children, in that no attempt is made to suggest an adequate high school environment for adolescents still functioning as slow learners."'). For further discussion, see Osgood, *supra* note 30, at 80-84, 96-98; Colker, *supra* note 29, at 825-35.

qual” argument. This is particularly true for students who are labeled as “mentally retarded” and placed in special education rather than the regular classroom. In 1967, Judge Skelly Wright authored an opinion for the United States District Court for the District of Columbia in which he concluded that ability tracking was a mechanism to maintain de facto segregation after de jure segregation was ended in D.C. public schools.⁷³ He concluded that the tracking system was “tainted” by race discrimination because “of all the possible forms of ability grouping, the one that won acceptance in the District was the one that—with the exception of completely separate schools—involves the greatest amount of physical separation by grouping students in wholly distinct, homogeneous curriculum levels.”⁷⁴ Throughout the opinion, Judge Wright refers to “retarded” students who are assigned to the lowest tracking level so that they can be placed with a curriculum that they can understand.⁷⁵ This track was called “special academic” and was for students who had “emotionally disturbed behavior, an IQ of 75 or below, and substandard performance on achievement tests.”⁷⁶ Originally, placement in this track was mandatory for qualifying students; over time, it became possible only with parental consent. Judge Wright was very critical of the implementation of this tracking system. He found that the methodology used to place children in the lowest track was culturally biased and that assignments in early grades tended to be permanent and offered students no opportunity to take classes outside of their track. Further, the special academic track was supposed to offer students remedial education, yet he found that little remedial education was available in that track. Hence, the effect of being subjectively placed in the lowest track was to consign poor and African-American students to a low-skill vocational track.⁷⁷ His hundred page opinion was a ringing indictment of the relationship between ability tracking and racial segregation.⁷⁸

73 *Hobson v. Hansen*, 269 F. Supp. 401, 513 (D.D.C. 1967).

74 *Id.* at 443.

75 *See, e.g., id.* at 444.

76 *Id.* at 448.

77 *Id.* at 512–13.

78 Similar litigation was brought in Georgia, but the court did not find that the disproportionate placement of African-American children in the educable mentally retarded category violated federal law. *See Ga. State Conference of Branches of NAACP v. Georgia*, 775 F.2d 1403, 1412–13 (11th Cir. 1985). Similarly, in more recent litigation, a Georgia district court found that ability tracking, even though it resulted in racially disparate results, did not violate federal law or the Constitution. *See Thomas County Branch of the NAACP v. City of Thomasville Sch. Dist.*, 299 F. Supp. 2d 1340, 1358–59 (M.D. Ga. 2004), *aff'd in part, rev'd in part sub nom. Holton v. City of Thomasville Sch. Dist.*, 425 F.3d 1325 (11th Cir. 2005). On appeal, however,

Subsequent litigation in D.C. focused on the failure of the public schools to provide any education to a subclass of children with disabilities—those with mental or cognitive impairments.⁷⁹ Some of these children were never allowed to enroll in the public school system; others were suspended or expelled after they enrolled. Each of the named plaintiffs was African-American.⁸⁰ Hence, disability status and race were commingled, as with the lawsuit challenging tracking.⁸¹

Lawsuits in other states challenged both exclusion and tracking. One of the earliest lawsuits challenging exclusion was brought in Pennsylvania.⁸² The lawsuit was brought by the parents of thirteen children with mental retardation, alleging that they were excluded from the educational system. Under Pennsylvania law, children could be excluded from the state's compulsory education law if they were deemed "uneducable and untrainable" or had not attained a mental age of five years.⁸³ The case resulted in a consent decree under which the state agreed to provide all mentally retarded children with a free public education.⁸⁴ The parents wanted their children to receive a free public education; some of these parents had paid for their children to attend a private residential school during the pendency of the litigation. The focus of this litigation was ending the practice of exclusion rather than creating integrated education within the regular classroom⁸⁵ yet the consent decree included the presumption that "placement in a regular public school class is preferable to placement in a special public school class."⁸⁶

the Eleventh Circuit reversed, finding that the district court had failed to determine whether the placements were "based on present results of past segregation." *Holton*, 425 F.3d at 1346.

⁷⁹ See *Mills v. Bd. of Educ.*, 348 F. Supp. 866, 874 (D.D.C. 1972).

⁸⁰ *Id.* at 870.

⁸¹ From a social science perspective, Lloyd Dunn's important critique of special education also recognized the relationship between race and special education tracking. See Dunn, *supra* note 71, at 6 ("In my best judgment, about 60 to 80 percent of the pupils taught by these teachers are children from low status backgrounds This expensive proliferation of self contained special schools and classes raises serious educational and civil rights issues which must be squarely faced. It is my thesis that we must stop labeling these deprived children as mentally retarded. Furthermore, we must stop segregating them by placing them into our allegedly special programs.")

⁸² See *Pa. Ass'n for Retarded Children v. Pennsylvania (PARC)*, 343 F. Supp. 279 (E.D. Pa. 1972).

⁸³ *Id.* at 282-83.

⁸⁴ *Id.* at 288.

⁸⁵ *Id.* at 297 ("Plaintiffs do not challenge the separation of special classes for retarded children from regular classes or the proper assignment of retarded children to special classes.")

⁸⁶ *Id.* at 307.

Similar lawsuits were brought elsewhere. Unlike the Pennsylvania case, these cases also alleged racial bias in the placement of children in the mentally retarded category.⁸⁷ In 1971, six African-American children in California filed suit challenging as unconstitutional the use of standardized intelligence tests for the placement of children in classes for the “educable mentally retarded.”⁸⁸ Although their case began as one brought under the Constitution, it soon expanded to include allegations of violations of race-based and disability-based federal statutes.⁸⁹

As in the earlier D.C. litigation, the case provided strong evidence of how the separate, special education program was used to remove African-Americans from the regular classroom through the mentally retarded label. There were three categories of children in this school system: typical children, the “educable mentally retarded” and the “trainable mentally retarded.”⁹⁰ African-Americans were statistically overrepresented in the “educable mentally retarded” category but not in the “trainable mentally retarded” category. If genetic or socio-economic factors caused African-Americans, in general, to have lower IQ scores than whites, then one would have expected African-Americans

87 Overrepresentation of African-Americans in special education continues today. See generally Robert A. Garda, Jr., *The New IDEA: Shifting Educational Paradigms To Achieve Racial Equality in Special Education*, 56 ALA. L. REV. 1071 (2005) (arguing that the Individuals with Disabilities Education Improvement Act of 2004 is a necessary, though not sufficient, step in addressing the overrepresentation of African-Americans in special education programs); Daniel J. Losen & Kevin G. Welner, *Disabling Discrimination in Our Public Schools: Comprehensive Legal Challenges to Inappropriate and Inadequate Special Education Services for Minority Children*, 36 HARV. C.R.-C.L. L. REV. 407 (2001) (advocating a combination of Title VI and disability law to combat overrepresentation of African-Americans in special education programs).

88 *Larry P. v. Riles*, 343 F. Supp. 1306, 1307 (N.D. Cal. 1972), *aff'd*, 502 F.2d 963 (9th Cir. 1974); see also *Larry P. v. Riles*, 495 F. Supp. 926 (N.D. Cal. 1979), *aff'd in part, rev'd in part*, 793 F.2d 969 (9th Cir. 1984) (expanding claims in earlier litigation and reaching a decision on the merits in favor of Larry P.). Similar litigation was brought in Chicago. *Parents in Action on Special Educ. v. Hannon*, 506 F. Supp. 831, 833 (N.D. Ill. 1980). This litigation was unsuccessful; disagreeing with the result in *Larry P.*, 495 F. Supp. 926, the court concluded that the tests were not culturally biased and did not discriminate against African-American children. *Hannon*, 506 F. Supp. at 882.

89 See *Larry P.*, 495 F. Supp. at 978–79. The intervening Supreme Court decision in *Washington v. Davis*, 426 U.S. 229, 239 (1976), in which the Court concluded that disparate impact alone did not demonstrate a constitutional violation, put pressure on statutory approaches to disparate impact arguments in the special education context. Ultimately, the *Larry P.* court concluded that federal law, but not the Fourteenth Amendment, was violated by the disproportionate enrollment of African-American children in classes for the “educable mentally retarded.” See *Larry P.*, 793 F.2d at 984.

90 See CAL. EDUC. CODE § 56515 (West 1978) (repealed 1980).

to be disproportionately represented in *both* of the below average IQ categories.⁹¹ Instead, the evidence strongly suggested that the educable mentally retarded category was used to take African-Americans out of the regular classroom. The separate classrooms for the educable mentally retarded were described as “dead-end” classes which did *not* try to teach these children the regular curriculum or prepare them to re-enter mainstream classes.⁹²

These cases brought attention to two problems: (1) the misidentification of some children as mentally retarded and (2) the inadequate education made available to those who were identified as mentally retarded. Initially, the courts focused on the first problem. Schools that had a racial disparity in placement in the classes for children with mental retardation were required to devise a remedial plan to equalize placements.⁹³ So long as the appropriate racial balance existed, California could maintain its system of “dead-end” classes for children with mental retardation.

This misidentification focus continues today.⁹⁴ Schools are required to keep program data by race, ethnicity and limited English proficiency status, gender, and disability categories⁹⁵ so that the government, as well as plaintiffs, can ascertain whether certain groups are disproportionately represented in certain disability categories or certain types of education programs. The assumption underlying this misidentification problem is that special education programs are inferior programs where children should not be educated unless they are genuinely mentally retarded. Separation is equated with invidious segregation. The concept that “separate is inherently unequal” has passed back and forth between disability and race-based civil rights cases because of the historical connection between special education and racial segregation in the mental retardation context.⁹⁶

91 See *Larry P.*, 793 F.2d at 976.

92 *Id.* at 980.

93 *Id.* at 984.

94 For a recent case involving this issue, see *Lee v. Butler County Board of Education*, No. CIV.A.70-T-3099-N, 2000 WL 33680483, at *3 (M.D. Ala. Aug. 30, 2000) (continuing to monitor overrepresentation of African-American children in the mental retardation and emotional disturbance categories and underrepresentation in the specific learning disabilities and gifted and talented special education classifications).

95 20 U.S.C. § 1418 (Supp. IV 2004).

96 There is far less litigation under the IDEA involving other disability categories on the integration issue, although the IDEA covers all children with a disability that affects their ability to learn. The integration/segregation issue mostly arises in the context of children with mental retardation or emotional impairments including autism. Neither schools nor parents will typically disagree about whether a child with a mobility impairment or visual impairment should be educated outside the regular

II. HEALTH CARE INSTITUTIONALIZATION

A. History

Although disability-only institutions for the mentally ill were horrific by the 1950s, their origins were more benign. In the late eighteenth and early nineteenth centuries, some disability rights advocates were pleased to persuade lawmakers to allocate funds for the construction of public psychiatric hospitals.⁹⁷ They considered these institutions to be a better option than the streets, almshouses, or jails.⁹⁸ But others sought to create these institutions as a way to confine and reform a “defective” population. “The physical design of the asylum was shaped by the portrayal of lunacy as inconvenient at best, and contagious at worst.”⁹⁹

Until 1880, some of these institutions emphasized humane care and were not overcrowded. Between 1880 and 1955, however, the psychiatric population grew thirteenfold. “Hospitals that had originally been built as humane asylums had become on the best of days merely human warehouses. On the difficult days, they became much worse than that.”¹⁰⁰ These institutions began to emphasize incarceration rather than treatment. The philosophy underlying these institutions also became more racist. “By the late nineteenth century, the educational optimism of the founding era succumbed to racial and ethnic mythology, spearheaded by a nativistic fear of the ‘menace of the feeble-minded’ and a professional turn to eugenic control.”¹⁰¹

Conscientious objectors who had been assigned to work in public hospitals in the 1940s brought the deplorable conditions of these institutions to the public’s attention.¹⁰² A grand jury was convened in Cleveland in 1944 to investigate the conditions at Cleveland State Hospital and reported that it was “shocked beyond words that a so-called civilized society would allow fellow human beings to be mistreated as

classroom. Children with hearing impairments raise separate issues which will be discussed in Part IV.A.3.

97 See generally E. FULLER TORREY, *OUT OF THE SHADOWS* 81–90 (1997) (describing the difficulties the mentally ill have faced securing adequate treatment in the United States).

98 See *id.* at 81.

99 JOHN G. RICHARDSON, *COMMON, DELINQUENT, AND SPECIAL* 30 (1999).

100 TORREY, *supra* note 97, at 82.

101 RICHARDSON, *supra* note 99, at 33.

102 See TORREY, *supra* note 97, at 82. The 1946 publication of *The Snake Pit* and its 1948 movie version (starring Olivia DeHaviland) stunned many people into learning about the inhumanness and coerciveness of lunatic asylums. See MARY JANE WARD, *THE SNAKE PIT* (1946).

they are at the Cleveland State Hospital.”¹⁰³ This kind of evidence spurred the creation of the deinstitutionalization movement. Consequently, the number of patients at Cleveland State Hospital declined from 2200 in 1944 to 140 in 1994.¹⁰⁴

But deinstitutionalization has not been an overwhelming success. A 1994 report by a Cleveland newspaper found that many mentally ill people were living within the prison system rather than in state mental hospitals—there was an “explosion in the number of mentally ill inmates” because of “repetitive incarceration of nonviolent offenders on scant mental health services in the home counties.”¹⁰⁵ Rather than ending institutionalization, the deinstitutionalization movement resulted in many people being housed in jails rather than state mental institutions. One study found that forty percent of the patients in state hospitals cannot be cared for in the community irrespective of the range of services offered.¹⁰⁶ Nonetheless, public psychiatric hospitals have deinstitutionalized ninety-two percent of their patients. Some strong proponents of the deinstitutionalization movement acknowledge that disability rights advocates have gone too far in expounding deinstitutionalization as the remedy.¹⁰⁷

Nonetheless, the deinstitutionalization movement did benefit many individuals who had been living in state mental institutions. A study of individuals discharged from a Rhode Island state hospital into well-structured community settings found that “94 percent expressed a preference for life in the community” even though fifty-five percent of people in the study required rehospitalization at least once.¹⁰⁸ A Delaware study which followed the results of individuals moved from an institution for the developmentally disabled into the community noted that the movement of people with developmental disabilities from institution to community has been generally more successful than the movement from institution to community for people with mental illness.¹⁰⁹ The challenge, as described in a 1989 report by the National Institute of Mental Health, is to find the “appropriate balance between liberty and paternalism that will maximize individual

103 TORREY, *supra* note 97, at 83 (quoting ALEX SAREYAN, *THE TURNING POINT* 67 (1994)).

104 *Id.* at 85.

105 *Id.*

106 *Id.* at 87.

107 *See id.* at 86–87.

108 *Id.* at 85.

109 CONROY ET AL., *supra* note 27, at 5–6.

and societal rights to physical safety and well-being.’”¹¹⁰ An integrationist perspective has measured success on the basis of integration rather than safety and well-being.

Authors who chronicle the deinstitutionalization movement frequently only describe it from an integrationist perspective. For example, David Braddock and Susan Parish provide an excellent description of the deinstitutionalization movement in the *Handbook of Disability Studies*.¹¹¹ Yet, they conclude that that movement has not been a complete success because approximately forty-six percent of the funds allocated for disability services and long-term care support individuals in segregated settings.¹¹² Further, they are critical of the fact that sixty-one percent of students with intellectual disabilities were served in segregated settings in 1996.¹¹³ Similarly, they report the sharp decline in the number of deaf and blind children being educated in residential or special schools.¹¹⁴ But nowhere do they provide data as to whether individuals receiving services in *modern* disability-only institutions are worse off than individuals receiving services in more integrated settings.¹¹⁵ An integrationist perspective has shaped research methodology, thereby precluding researchers from asking whether the integration movement has sufficiently protected individuals’ well-being and safety.

B. Legal Developments

The health care and education desegregation stories have many parallels. In each context, the courts developed case law requiring individuals to be in the most integrated setting possible, as a response to litigation about the horrific nature of disability-only institutions. But, as E. Fuller Torrey has argued, “deinstitutionalization has been a psychiatric *Titanic*” for a “substantial minority. . . . [t]he ‘least restrictive setting’ frequently turns out to be a cardboard box, a jail cell, or a terror-filled existence plagued by both real and imaginary enemies.”¹¹⁶

110 TORREY, *supra* note 97, at 87 (quoting C. Attkisson et al., *Clinical Services Research*, 8 SCHIZOPHRENIA BULL. 561, 605 (1992)).

111 David L. Braddock & Susan L. Parish, *An Institutional History of Disability*, in HANDBOOK OF DISABILITY STUDIES, *supra* note 2, at 11, 45–51.

112 *Id.* at 51.

113 *Id.*

114 *Id.* at 48.

115 They cite one study from England in which women self-reported that education in special schools was detrimental to their growth and independence. *Id.*

116 TORREY, *supra* note 97, at 11.

Ironically, one of the early legal opinions that formed the basis for the deinstitutionalization movement foresaw the problems that might arise under this movement. In *Lake v. Cameron*,¹¹⁷ the United States Court of Appeals for the District of Columbia Circuit granted habeas corpus relief to plaintiff Catherine Lake, who appeared to suffer from dementia, to determine if an alternative existed to her forced confinement at Saint Elizabeths Hospital.¹¹⁸ Writing for the majority in an en banc panel, Judge Bazelon remanded the case to the district court for an inquiry into "other alternative courses of treatment"¹¹⁹ for the plaintiff, such as whether she could be required

to carry an identification card on her person so that the police or others would take her home if she should wander, or whether she should be required to accept public health nursing care, community mental health and day care services, foster care, home health aide services, or whether available welfare payments might finance adequate private care.¹²⁰

In dissent, three judges argued that that kind of inquiry was beyond a court's remedial authority in a habeas corpus proceeding and that a court can merely order her release from the state institution. They then argued that "it would be a piece of unmitigated folly to turn this appellant loose on the streets with or without an identity tag."¹²¹ Nonetheless, Torrey argues that there were 2.2 million Americans with untreated severe mental illnesses in 1995, with 150,000 of them being "homeless, living on the streets or in public shelters" and 159,000 being incarcerated "mostly for crimes committed because they were not being treated."¹²²

The challenge for courts in these cases was that the option of keeping people in these institutions was unfathomable. For example, in *Wyatt v. Stickney*,¹²³ the district court describes the conditions in an Alabama state mental institution six months after defendants were

117 364 F.2d 657 (D.C. Cir. 1966).

118 *Id.* at 661.

119 *Id.*

120 *Id.*

121 *Id.* at 664 (Burger, Danaher & Tamm, JJ., dissenting).

122 TORREY, *supra* note 97, at 3. Interestingly, one of the early institutionalization cases involved the relationship between the prison system and state mental hospitals. At age eighteen, Charles Rouse was acquitted by reason of insanity of the misdemeanor charge of carrying a weapon without a license. Five years later, he brought a successful habeas corpus action in which he argued that he had never consented to the insanity defense and should be released from the state mental hospital. He prevailed on this argument. *Rouse v. Cameron*, 387 F.2d 241, 245 (D.C. Cir. 1967).

123 334 F. Supp. 1341 (M.D. Ala. 1971), *aff'd in part, rev'd in part*, 503 F.2d 1305 (5th Cir. 1974).

required to institute improvements, and those conditions were unquestionably inhumane. The plaintiffs were housed in unsanitary, dangerous living conditions where fifty cents per day was spent on their food, and virtually no medical treatment was offered to the patients.¹²⁴ On appeal, Judge Wisdom recounts the conditions in graphic terms. "The patients suffered brutality, both at the hands of the aides and at the hands of their fellow patients; testimony established that four Partlow residents died due to understaffing, lack of supervision, and brutality."¹²⁵

One of the four died after a garden hose had been inserted in his rectum for five minutes by a working patient who was cleaning him; one died when a fellow patient hosed him with scalding water; another died when soapy water was forced into his mouth; and a fourth died from a self-administered overdose of drugs which had been inadequately secured.¹²⁶

The most challenging issue in the *Wyatt* litigation was the appropriate remedy. Unlike the *Lake* case, the plaintiffs did not seek relief under habeas corpus—the right to be released from the facility. Instead, they sought to require the state to establish a "constitutionally acceptable minimum treatment program."¹²⁷ The state's obligation to provide that basic level of service apparently stemmed from the fact that "the state has involuntarily confined" the plaintiffs in mental hospitals.¹²⁸ Governor Wallace argued that compliance with the court order would "entail the expenditure annually of a sum equal to sixty per cent of the state budget excluding school financing, and a capital improvements outlay of \$75,000,000."¹²⁹ It is not hard to predict from the budget forecasts in this litigation that the state would choose deinstitutionalization as a means of avoiding such significant expenditures of money. The number of patients in Alabama in public mental hospitals declined from 7197 in December 1955 to 1649 in December 1994.¹³⁰ The deinstitutionalization movement could claim victory given the horrific nature of the state institutions in the early 1970s.¹³¹

124 *Id.* at 1343.

125 *Wyatt*, 503 F.2d at 1311.

126 *Id.* at 1311 n.6.

127 *Id.* at 1316.

128 *Id.* at 1315.

129 *Id.* at 1317.

130 TORREY, *supra* note 97, at 207.

131 These problems were not limited to Alabama. In *Lessard v. Schmidt*, 349 F. Supp. 1078, 1089–90 (E.D. Wis. 1972), *vacated*, 414 U.S. 473 (1974) (per curiam), the court discusses the high mortality rate and poor conditions at mental institutions in Wisconsin.

But how many of those thousands of people were getting adequate treatment and living conditions?

One impetus for the deinstitutionalization movement was that many people were unnecessarily institutionalized. For example, an Illinois statute "allowed married women and infants to be committed on the request of a husband or guardian."¹³² These loose commitment standards resulted in 679,000 persons being confined in mental institutions in 1963 as contrasted with 250,000 persons who were involuntarily incarcerated.¹³³ The legal response to this evidence of unnecessary institutionalization was to craft a rigorous institutionalization standard which focused on whether the state has "a compelling interest in emergency detention of persons who threaten violence to themselves or others for the purpose of protecting society and the individual."¹³⁴ The Supreme Court hastened this development when it held in 1975 that "a State cannot constitutionally confine without more a nondangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends."¹³⁵

The problem of relief was complicated in these cases and caused some courts to hesitate in providing the release of all individuals held in state institutions. In 1973, for example, Judge Judd concluded that the conditions at Willowbrook State School for the Mentally Retarded were inhumane.

Testimony of ten parents, plus affidavits of others, showed failure to protect the physical safety of their children, and deterioration rather than improvement after they were placed in Willowbrook School. The loss of an eye, the breaking of teeth, the loss of part of an ear bitten off by another resident, and frequent bruises and scalp wounds were typical of the testimony.¹³⁶

132 See *id.* at 1086 (describing the situation in Illinois). The court's order in *Lessard* was vacated on appeal. See *Lessard*, 414 U.S. at 477 (vacating the order of the lower court as insufficiently specific and presenting an inadequate foundation for review).

133 *Lessard*, 349 F. Supp. at 1090.

134 *Id.* at 1091; *cf.* *Boddie v. Connecticut*, 401 U.S. 371, 377-79 (1971) (describing the fundamental right of procedural due process guaranteed by the Fourteenth Amendment and the standard the state must meet to infringe upon it).

135 *O'Connor v. Donaldson*, 422 U.S. 563, 576 (1975). The Court claimed that it did not decide "whether mentally ill persons dangerous to themselves or to others have a right to treatment upon compulsory confinement by the State, or whether the State may compulsorily confine a nondangerous, mentally ill individual for the purpose of treatment." *Id.* at 573.

136 *N.Y. State Ass'n for Retarded Children v. Rockefeller*, 357 F. Supp. 752, 756 (E.D.N.Y. 1973).

Nonetheless, the court concluded that it could not “in fairness direct that any of the residents be released before they have been habilitated so far as possible. . . . Nor can the court direct the closing of Willowbrook. . . . ‘The State has no realistic option open to it to discontinue its mental hospitals and training schools forthwith.’”¹³⁷

The concept of “least restrictive alternative” developed during this litigation in the 1970s. In *Welsch v. Likins*,¹³⁸ a case involving the institutionalization of individuals with mental retardation, the district court held as a matter of law “that retardees are constitutionally entitled to the benefit of the least restrictive environment consistent with their needs and conditions.”¹³⁹ The plaintiffs in *Welsch*, like the plaintiffs in the Willowbrook litigation, did not seek to be released immediately from state institutions. Instead, they sought meaningful habilitation so that they could learn to live more independently. The *Welsch* court, however, was more explicit in recognizing a goal of living in a less “restrictive environment” than the rigid institutionalization offered by the state facility.¹⁴⁰ Two years later, in adopting the “least restrictive alternative approach,” the Third Circuit in the *Halderman v. Pennhurst State School and Hospital*¹⁴¹ litigation noted that it did not include “a shutdown of all institutions.”¹⁴² In fact, it overturned the district court’s “blanket prohibition against institutionalization” as inconsistent with the concept of least restrictive alternative because it would preclude “institutionalization of patients for whom life in an institution has been found to be the least restrictive environment in which they can survive.”¹⁴³

Today, the situation has become more complicated as people complain that it is too difficult to get treatment for mentally ill family or friends. Torrey begins his book by describing the story of a man

137 *Id.* at 768 (quoting *Employees of Dep’t of Pub. Health & Welfare v. Dep’t of Pub. Health & Welfare*, 452 F.2d 820, 827 (8th Cir. 1971), *aff’d*, 411 U.S. 279 (1973)). For a follow-up on the Willowbrook litigation, see DAVID J. ROTHMAN & SHEILA M. ROTHMAN, *THE WILLOWBROOK WARS* (2005). The Rothman book is written from a pure integration perspective; it assumes that every resident of Willowbrook should ultimately attain a community placement.

138 550 F.2d 1122 (8th Cir. 1977).

139 *Id.* at 1125 (describing the district court opinion).

140 *Id.*; *see id.* at 1132.

141 612 F.2d 84 (3rd Cir. 1979), *rev’d*, 451 U.S. 1 (1981).

142 *Id.* at 114. The court quoted the sponsor of the relevant Pennsylvania legislation, who had said: “The object of this legislation is to make it possible for every mentally disabled person to receive the kind of treatment he needs, when and where he needs it.” *Id.* at 114–15 (quoting 1966 PA. LEGIS. J., 3d Spec. Secc., No. 33, 76 (Sept. 27, 1966) (remarks of Senator Peacham)).

143 *Id.* at 115.

whom he calls Thomas McGuire.¹⁴⁴ When McGuire suffered chest pains and shortness of breath, he was readily admitted to the hospital and treated for his heart problem. He also benefited from a follow-up program to reduce his cholesterol. But when he went to the emergency room because of suicidal symptoms, he was released from the emergency room without being given any medication because the senior psychiatrist found "there were no issues of danger to self [or] others."¹⁴⁵ Nonetheless, his wife found him hanging from a rope in their basement a few hours after discharge.

McGuire's situation is not a direct result of the deinstitutionalization movement. He was not released from an institution as a result of that movement. But he could not be involuntarily admitted to a hospital, upon his wife's request, without meeting a high standard of potential danger to himself or others. The senior psychiatrist in the hospital's waiting room was not able to correctly assess that McGuire was in imminent danger of committing suicide. Had the legal standard been lower, McGuire may have received treatment and, in the short term, avoided suicide.

McGuire's case poses an odd equality problem. The standard for admission for his physical condition (risk of heart attack) was lower than for his mental condition (risk of suicide). But his case also presents the legacy of concerns about the quality of institutionalization, and whether psychiatric wards or hospitals offer care that is below what we consider basic to human dignity. Torrey reports that McGuire lived in a state that had closed over eighty percent of its public psychiatric beds and had a long history of promoting "mental health" issues; his wife had sought treatment for her husband "in a prestigious university hospital in a city reputed to be a regional medical Mecca."¹⁴⁶

The problem here is one that we will see in the educational context as well—the move towards structural reforms (deinstitutionalization) comes at the price of consideration of what is best for the individual patient. By closing most public psychiatric beds and creating a very high standard for institutionalization, certain important structural reforms were achieved. Moreover, the evidence suggests that most individuals do benefit from deinstitutionalization.¹⁴⁷ At the

144 TORREY, *supra* note 97, at 2.

145 *Id.*

146 *Id.* at 3.

147 See generally S. KIM ET AL., RESEARCH & TRAINING CTR. ON CMTY. LIVING, UNIV. OF MINN., POLICY RESEARCH BRIEF—BEHAVIORAL OUTCOMES OF DEINSTITUTIONALIZATION FOR PEOPLE WITH INTELLECTUAL DISABILITIES: A REVIEW OF STUDIES CONDUCTED BETWEEN 1980 AND 1999, at 1 (1999), available at <http://ici.umn.edu/products/prb/>

individual level, however, there is no safety net for the McGuires of our society. As one proponent of deinstitutionalization has noted: “[T]he problem that has proved most vexing—the treatment of the new generation that has grown up since deinstitutionalization—was almost totally unforeseen by the advocates of deinstitutionalization.”¹⁴⁸ Torrey estimates there are 2.2 million Americans with untreated severe mental illnesses and that 150,000 of them are homeless and 159,000 are incarcerated in jails and prisons.¹⁴⁹ Torrey argues that “even one Thomas McGuire is too many; hundreds of thousands are a disgrace.”¹⁵⁰ Yet, our legal system has remained relatively unchanged since Torrey described McGuire’s case in 1997. Deinstitutionalization has continued to move forward, state laws for involuntary commitment have gone unchanged, and our health insurance crisis (for nearly everyone) remains unchanged. The integrationist perspective is so strong that it is difficult to put cases like McGuire’s on center stage to achieve law reform.

The pre-1990 cases were usually decided on the basis of a combination of state law and federal constitutional right. Since the passage of the Americans with Disabilities Act of 1990 (ADA),¹⁵¹ many of these cases have been litigated under federal law. The federal courts have been seeking to find a balance between integration and appropriate services in interpreting modern federal antidiscrimination law. Although they have struck the balance on the side of integration, they have recognized that separate services may play a proper role in the delivery of health care for individuals with disabilities.

Under Section 504 and Title II of the ADA, Congress has not clearly imposed an integration requirement. Nonetheless, both the enforcement agencies and the courts have interpreted the nondiscrimination rule imposed by ADA Title II¹⁵² and Section 504 of the

101/101.pdf (reporting the results of a review of thirty-eight studies of deinstitutionalizing people with mental disabilities).

148 H. Richard Lamb, *Deinstitutionalization at the Beginning of the New Millennium*, in *DEINSTITUTIONALIZATION* 3, 4 (H. Richard Lamb & Linda E. Weinberger eds., 2001).

149 TORREY, *supra* note 97, at 3. Similarly, Steven Raphael concludes that deinstitutionalization of state and county mental hospitals has resulted in an increase of between 48,000 to 148,000 inmates in state prisons in 1996. See Steven Raphael, *The Deinstitutionalization of the Mentally Ill and Growth in the U.S. Prison Population: 1971 to 1996*, at 12 (Sept. 2000), <http://socrates.berkeley.edu/~raphael/raphael2000.pdf>.

150 TORREY, *supra* note 97, at 11.

151 Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101–12213 (2000)).

152 ADA Title II provides: “Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from

Rehabilitation Act¹⁵³ to include an integration requirement. Regulations promulgated to interpret Section 504 of the Rehabilitation Act require recipients of federal funds to “administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.”¹⁵⁴ Similarly, the regulations promulgated to enforce ADA Title II state that “[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”¹⁵⁵

In *Olmstead v. L.C. ex rel. Zimring*,¹⁵⁶ the Supreme Court was faced with the question of whether the nondiscrimination rule found in ADA Title II mandated that the plaintiffs live in the most integrated setting possible which, in this case, would be at home rather than in an institutionalized setting. The Court concluded that this requirement is imposed by ADA Title II’s nondiscrimination language and offered these two justifications for that conclusion:

First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.¹⁵⁷

Nonetheless, in *Olmstead*, the Court was careful to limit its holding to cases involving individuals with disabilities who live in institutional settings and prefer to live in the community.¹⁵⁸ It expressly did not

participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.” 42 U.S.C. § 12132.

153 Section 504 provides: “No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.” Rehabilitation Act of 1973 § 504, Pub. L. No. 93-112, 87 Stat. 355, 394 (codified as amended at 29 U.S.C. § 794(a) (2000)).

154 28 C.F.R. § 41.51(d) (2006).

155 28 C.F.R. § 35.130(d) (2006).

156 527 U.S. 581 (1999).

157 *Id.* at 600–01 (citations omitted).

158 The court required states to provide community-based services and support for individuals with disabilities when (1) the state’s treatment professionals determine that community placement is appropriate for the individual, (2) the individual does not oppose treatment in the community, and (3) the placement can be reasonably accommodated, taking into account the state’s available resources and the needs of others with disabilities. *Id.* at 596–602.

determine the validity of the general pro-integration regulations, cited above.¹⁵⁹

In dissent, Justice Thomas disputes this expansive interpretation of the word “discriminate” under ADA Title II. He argues that Congress could have specifically outlawed unnecessary segregation in the provision of public services under ADA Title II if it had so desired, since it used such language elsewhere in the ADA under Title I.¹⁶⁰ Yet Congress chose not to use such specific language.

Although Thomas disagrees with the majority’s statutory interpretation of ADA Title II, he does not disagree with the majority’s normative assertions about the deleterious effects of institutional isolation. He characterizes the majority’s assertions on this point as “unremarkable,”¹⁶¹ by which I assume he means “obvious.” The fact that such a position could be normatively justified, however, does not mean that Congress intended to impose that requirement on the states. Returning to the statutory language and its proximate causation requirement, he therefore concludes that it is wrong to interpret the statute to preclude “[c]ontinued institutional treatment of persons who, though now deemed treatable in a community placement, must wait their turn for placement.”¹⁶²

Implicit in Thomas’s response to the majority is the sense that one cannot dispute the normative claim underlying a pro-integration argument. His hesitation is similar to the hesitation found in the special education context. Researchers are cautious even to ask the question of whether the most integrated setting is presumptively the most appropriate for children with disabilities. Underlying this hesitation is the sense that integration *must* be a highly desirable moral imperative.

Nonetheless, even the majority seems to understand that the argument for integration must have some nuances. Hence, Justice Ginsburg’s opinion for the Court observes that “nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.”¹⁶³ Justice Kennedy’s concurrence (which was joined by Justice Breyer) is mindful of the fact that deinstitutionalization is not the right answer for everyone with severe mental illness and observes that it would be “tragic” if the *Olmstead* decision scared states into provid-

159 *Id.* at 592.

160 *Id.* at 622 (Thomas, J., dissenting).

161 *Id.* at 625.

162 *Id.* at 626.

163 *Id.* at 601 (majority opinion).

ing services for individuals with disabilities in "settings with too little assistance and supervision."¹⁶⁴

Carlos Ball justifies the Ginsburg and Kennedy approaches from a communitarian perspective. He defends the district court result in *Williams v. Wasserman*,¹⁶⁵ in which the court held that the state did not violate ADA Title II by retaining some state institutions so that it would have viable options for those who could not benefit from community settings.¹⁶⁶ The *Williams* litigation reflects how hard it is to create structural remedies by closing many disability-only institutions while still maintaining sufficient disability-only institutions to provide a safety net for those who need such institutions.

The plaintiffs in the *Williams* litigation suffered significant harm during the course of their institutionalization. Ms. Lentz received the drug Thorazine for seventeen years and thereby developed tardive dyskinesia; the evidence suggested that she should not have been administered the drug for this entire time period.¹⁶⁷ She was also "assaulted after stealing belongings from other patients."¹⁶⁸ Mr. Polard may have received inappropriate treatment with neuroleptics and benzodiazepines for his seizure disorders.¹⁶⁹ Ms. Kemble and Ms. Jackson engaged in self-destructive behavior which might have been avoided with more effective supervision.¹⁷⁰ The plaintiffs were also subjected to physical restraints. Six of the plaintiffs were subjected to two- or four-point restraints at times during their tenures in the state hospitals. Two plaintiffs were restrained using a geri-chair and posey bed to prevent them from harming themselves. Nearly all the plaintiffs faced seclusion from time to time "as a form of behavior modification."¹⁷¹ The most inappropriate use of restraints related to Ms. Lentz. She was placed in mitten or wrist restraints between 1986 and 1988 to control her compulsive stealing but the restraints were "discontinued more than six years before this lawsuit was filed."¹⁷²

Despite these myriad of problems, the court declined to find statutory or constitutional violations in this case. Medication was administered based on sound medical advice. The use of restraints was for patient safety and did not deviate from accepted medical standards.

164 *Id.* at 610 (Kennedy, J., concurring).

165 164 F. Supp. 2d 591, 636-38 (D. Md. 2001).

166 *See* Ball, *supra* note 2, at 161-64.

167 *Williams*, 164 F. Supp. 2d at 616.

168 *Id.* at 618.

169 *Id.* at 616-17.

170 *Id.* at 618-19.

171 *Id.* at 620.

172 *Id.*

They “were used as necessary to calm or protect the patients or other residents.”¹⁷³

The court also emphasized the aspect of *Olmstead* that permitted it to consider the effect on other individuals with disabilities if the plaintiffs were accorded their desired remedy. The court found that Maryland’s pace of attaining deinstitutionalization was appropriate because a faster pace might be costly and jeopardize the well-being of those who needed institutionalized care.¹⁷⁴ Carlos Ball describes this approach as “communitarian” rather than integrationist because it considers the impact on others in devising a remedy.¹⁷⁵

Ball’s justification, however, is problematic because it does not explain why individuals with mild disabilities should have to bear the burden of finding financial resources to assist those with severe disabilities who need to live in residential institutions. Why is their liberty less valuable than the liberty of any other individuals in society? While it may be true from a communitarian perspective that *everyone* in society should bear the financial burden of funding humane institutions for individuals with severe disabilities, it seems inappropriate for those with mild disabilities to sacrifice their liberty interest of living in the community so that others can live in institutions. An anti-subordination perspective would impose those costs on the entire society rather than balance one group of individuals with disabilities against another group.¹⁷⁶ It would also closely track the well-being of all groups of individuals with disabilities to see if they are benefiting from the remedies imposed by the courts.

173 *Id.* at 622.

174 *Id.* at 638.

175 Ball, *supra* note 2, at 162–64.

176 Admittedly, there are subtle issues in these kinds of contexts that cannot be readily resolved by an anti-subordination perspective. An anti-subordination perspective tells us that we should devote economic and social resources to remedying a group’s history of subordination. Individuals with health care needs that make it difficult for them to live independently are one group that qualifies for such resources from an anti-subordination perspective. Nonetheless, the individuals within that class may have competing claims for resources within a limited economic pot. Assuming society has devoted sufficient economic resources to remedying that historic problem, we still need to establish how to allocate those resources. An anti-subordination perspective is not particularly helpful at resolving those competing claims. It merely establishes that we cannot expect those with disabilities to bear the most extreme sacrifices that are necessary to remedy this historical problem. Keeping some individuals with more mild disabilities *institutionalized* as a way to ensure that sufficient resources are devoted to those with more severe disabilities therefore seems inappropriate from an anti-subordination perspective. It is not appropriate to expect those with mild disabilities to bear the primary burden of ensuring that those with severe disabilities have adequate and appropriate housing.

The hesitation to impose immediate integration in the *Williams* litigation, however, cannot necessarily be attributed to the court's questioning of the pure integration perspective. Instead, it could be attributed to the court's interest in avoiding a political backlash from imposing integration too quickly.¹⁷⁷

The deinstitutionalization case law is muddled. States have been given the opportunity to move through their waiting lists at a "reasonable pace," sacrificing the liberty interests of those who are mildly disabled and could live in the community so that the state can afford to maintain its disability-only institutions for those with more severe disabilities. Further, success is measured by the rate of deinstitutionalization rather than by the quality of life for those who are deinstitutionalized. Even if states are allowed to proceed toward integration at a "reasonable pace," they should be required to account for the quality of life of both those who are institutionalized and those who are placed in community settings under an anti-subordination perspective. An exclusive focus on integration creates an insufficient safety net for the plaintiffs who are supposedly assisted by the courts' decisions.

III. VOTING

A. *History*

The disenfranchisement of individuals with disabilities was the result of two different kinds of mechanisms. For individuals with intellectual or developmental disabilities, disenfranchisement occurred as the result of explicit denial of the vote. For individuals with various physical disabilities, disenfranchisement occurred as the result of unconscious barriers, such as the need to see or walk, that impeded access to the polling place or ballot itself.

¹⁷⁷ See Samuel R. Bagenstos, *Justice Ginsburg and the Judicial Role in Expanding "We the People": The Disability Rights Cases*, 104 COLUM. L. REV. 49, 58 (2004) (noting that such cases reflect a "recognition of the limited capacity of courts to shoulder the burden of significant social change on their own"). Nonetheless, some commentators have praised *Olmstead* and its progeny as providing important safeguards for individuals with disabilities. See Jefferson D.E. Smith & Steve P. Calandrillo, *Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits After Olmstead v. L.C.*, 24 HARV. J.L. & PUB. POL'Y 695, 721-22 (2001) (arguing that "unchecked deinstitutionalization" could put "people into communities where they are unable to cope, and where they lack the structured environment and monitoring of an institution").

1. Intellectual and Developmental Disabilities

The story of the disenfranchisement of individuals with intellectual or developmental disabilities is connected to the history of institutionalization, recounted above.¹⁷⁸ As states began to develop special schools and asylums for subcategories of individuals with disabilities, they also began to create constitutional and statutory rules that excluded the “idiot and insane” from voting.¹⁷⁹

Vermont and Maine were the first two states to exclude individuals from voting based on intellectual or developmental disabilities. Vermont’s Constitution of 1793 required voters to have “quiet and peaceable behaviour.”¹⁸⁰ Maine’s Constitution of 1819 excluded “persons under guardianship” from voting.¹⁸¹ The explicit disenfranchisement of those who are “idiot[s]” or “insane” began in 1831 in Delaware¹⁸² and soon spread to Rhode Island,¹⁸³ New Jersey,¹⁸⁴ Iowa,¹⁸⁵ Wisconsin,¹⁸⁶ California,¹⁸⁷ Ohio,¹⁸⁸ Maryland,¹⁸⁹ Minne-

178 See *supra* Parts I.A, II.A. It is also connected to the disqualification of individuals with various mental disabilities from entering a contract of marriage. See, e.g., *Inhabitants of St. George v. City of Biddeford*, 76 Me. 593, 598–99 (1885) (upholding lower court decision to void marriage on the grounds that the man did not have sufficient mental capacity to enable him to undertake the responsibilities of marriage).

179 See generally Kay Schriener et al., *Democratic Dilemmas: Notes on the ADA and Voting Rights of People with Cognitive and Emotional Impairments*, 21 BERKELEY J. EMP. & LAB. L. 437, 439 (2000) (“States use terms such as ‘idiot,’ ‘insane,’ ‘lunatic,’ ‘mental incompetent,’ ‘mentally incapacitated,’ ‘unsound mind,’ and ‘not quiet and peaceable’ to characterize persons who will not be allowed to vote.”).

180 VT. CONST. of 1793, ch. II, § 21, reprinted in 6 THE FEDERAL AND STATE CONSTITUTIONS, COLONIAL CHARTERS, AND OTHER ORGANIC LAWS OF THE STATES, TERRITORIES, AND COLONIES NOW OR HERETOFORE FORMING THE UNITED STATES OF AMERICA 3762, 3768 (Francis Newton Thorpe ed., 1909) [hereinafter LAWS OF THE STATES].

181 ME. CONST. of 1819, art. II, § 1, reprinted in 3 LAWS OF THE STATES, *supra* note 180, at 1646, 1649.

182 DEL. CONST. of 1831, art. IV, § 1, reprinted in 1 LAWS OF THE STATES, *supra* note 180, at 582, 589.

183 R.I. CONST. of 1842, art. II, § 4 (“[No] lunatic, person *non compos mentis*, [or] person under guardianship . . . shall be permitted to be registered or to vote.”), reprinted in 6 LAWS OF THE STATES, *supra* note 180, at 3222, 3226.

184 N.J. CONST. of 1844, art. II, para. 1, reprinted in 5 LAWS OF THE STATES, *supra* note 180, at 2599, 2601.

185 IOWA CONST. of 1846, art. II, § 5, reprinted in 2 LAWS OF THE STATES, *supra* note 180, at 1123, 1125.

186 WIS. CONST. of 1848, art. III, § 2, reprinted in 7 LAWS OF THE STATES, *supra* note 180, at 4077, 4080.

187 CAL. CONST. of 1849, art. II, § 5, reprinted in 1 LAWS OF THE STATES, *supra* note 180, at 391, 393.

sota,¹⁹⁰ and Oregon.¹⁹¹ Other states achieved similar results in this period without direct reference to idiots or the insane.¹⁹² Initially, most of the states that excluded idiots or the insane were northern states, but many of the southern states created such exclusions between 1860 and 1880 when they wrote new state constitutions following the Civil War.¹⁹³

As with the special education and institutionalization movements, this development can be traced to evolving views of individuals with disabilities. The initial disenfranchisement movement excluded “persons under guardianship” and favored those “of a quiet and peaceable behavior.”¹⁹⁴ The guardianship reference could be thought of as a reference to dependency rather than as a moral statement about one’s worth as a citizen. The evolving references to idiots or the insane, however, reflected “intellectual and moral incompetency due to disability, not dependency.”¹⁹⁵ In addition, the disenfranchisement of individuals with intellectual or developmental disabilities is parallel to the disenfranchisement of African-Americans. As with the special education movement, a disability-specific term may have achieved disability, class-based, and racial discrimination.¹⁹⁶ As property classifications began to develop for voting, idiots and the insane were excluded from voting, in part, because they were perceived to be financially dependent (as well as deviant).¹⁹⁷ Further, the focus on cognitive aptitude was a relatively recent phenomenon

188 OHIO CONST. of 1851, art. V, § 6, *reprinted in* 5 LAWS OF THE STATES, *supra* note 180, at 2913, 2924.

189 MD. CONST. of 1851, art. I, § 5 (“[N]o person under guardianship as a lunatic, or as a person *non compos mentis*, shall be entitled to vote.”), *reprinted in* 3 LAWS OF THE STATES, *supra* note 180, at 1712, 1718.

190 MINN. CONST. of 1857, art. VII, § 2, *reprinted in* 4 LAWS OF THE STATES, *supra* note 180, at 1991, 2007.

191 OR. CONST. of 1857, art. II, § 3, *reprinted in* 5 LAWS OF THE STATES, *supra* note 180, at 2998, 3001.

192 Massachusetts excluded “persons under guardianship.” MASS. CONST. of 1780, amend. art. III (1821), *reprinted in* 3 LAWS OF THE STATES, *supra* note 180, at 1888, 1912. Louisiana excluded any “person under interdiction.” LA. CONST. of 1845, tit. II, art. 12, *reprinted in* 3 LAWS OF THE STATES, *supra* note 180, at 1392, 1394.

193 See Kay Schriener & Lisa A. Ochs, *Creating the Disabled Citizen: How Massachusetts Disenfranchised People Under Guardianship*, 62 OHIO ST. L.J. 481, 489–90 (2001).

194 *Id.* at 489 n.42 (quoting ME. CONST. of 1819, art. II, § 1; VT. CONST. of 1793, ch. II, § 21).

195 *Id.* at 490.

196 I have not seen any data on this connection but it is interesting to note that the disability disenfranchisement category was created in the southern states at the same time as Jim Crow laws and other vehicles of racial segregation.

197 Schriener & Ochs, *supra* note 193, at 507.

because "intellectual impairments did not have the economic significance that they would later acquire when work became more individualized and routinized."¹⁹⁸

The exclusion of individuals from voting on the basis of a cognitive or emotional impairment continues today.¹⁹⁹

Only ten states permit citizens to vote irrespective of mental disability. Twenty-six states proscribe voting by persons labeled idiotic, insane or non compos mentis Twenty-four states and the District of Columbia disenfranchise persons adjudicated incompetent or placed under guardianship Four states disqualify from voting persons committed to mental institutions . . . , but other laws in three of those states provide that commitment alone does not justify disenfranchisement.²⁰⁰

Today, states are sometimes required to make more individualized assessments of voter qualifications rather than assume that all the idiots or the insane are unqualified to vote. Nonetheless, informal barriers still persist even in those states to such persons being able to vote. One of the biggest challenges is for individuals who reside in institutional settings. They rarely have private transportation and are dependent on others to vote. If transportation is provided for them to travel to the polling place, will they feel comfortable voting independently and privately in accordance with their own political beliefs?

The institutional segregation of individuals with intellectual or developmental disabilities has also been a mechanism to screen them for exclusion. For example, one of the important voting rights cases for individuals with such disabilities involved a group of twenty-eight residents of a state facility (the New Lisbon State School) who traveled by bus to the clerk's office in Burlington County to register to vote on October 3, 1974.²⁰¹ The clerk refused to register them to vote, making that determination based on their residence.²⁰² The trial court judge concluded that they were excluded from voting not because of

198 *Id.* at 506.

199 For an excellent recent survey of voting rights law as it applies to individuals with intellectual and developmental disabilities, see Kay Schriener & Lisa Ochs, "No Right is More Precious": *Voting Rights and People with Intellectual and Developmental Disabilities*, POL'Y RES. BRIEF, May 2000, at 1, 7-15, available at <http://ici.umn.edu/products/prb/111/111.pdf>.

200 Note, *Mental Disability and the Right To Vote*, 88 YALE L.J. 1644, 1645-47 (1979) (footnotes omitted).

201 See *Carroll v. Cobb*, 354 A.2d 355, 356-57 (N.J. Super. Ct. App. Div. 1976).

202 Barbara Armstrong, *The Mentally Disabled and the Right To Vote*, 27 HOSP. & COMMUNITY PSYCHIATRY 577, 578 (1976). Similarly, in a case from Massachusetts, *Boyd v. Board of Registrars of Voters*, 334 N.E.2d 629 (Mass. 1975), residents of Belchertown State School who were "adjudicated incompetent or placed by the court under guard-

“their idiocy or their insanity” but because they were “confined to such a school.”²⁰³

Their transportation needs can also serve as a method to identify them for disenfranchisement. For example, Karl Peters took twenty-five trainees at a local workshop for individuals with mental retardation by bus to register to vote, in part, so that they could vote in favor of building “a new mental retardation facility and workshop” on the next primary ballot.²⁰⁴ Had these individuals not arrived together by bus, they would probably not have been singled out for unfavorable treatment. Residential segregation can therefore be tied to disenfranchisement because it creates an easy method to identify disabled individuals, and then deny the franchise.

2. Physical Impairments

In general, two different kinds of barriers impede voting by people with disabilities—access to the polling place itself or access to the ballot. A 2001 report by the General Accounting Office found that twenty-eight percent of polling places had “potential impediments” and did not provide curbside voting in the 2000 presidential election.²⁰⁵ Barriers can include inaccessible parking, architectural barriers such as curbs, narrow doorways, poor signage, and stairs. In addition, eighty-four percent of polling places had at least one barrier that could have impeded individuals with disabilities from voting.²⁰⁶

Even if voters can enter the polling place, they have historically not been able to vote privately and independently if they have a visual impairment or an impairment that affects their ability to use the regular ballot. Voters with visual impairments cannot read the text of the ballot, voters with hand or arm impairments cannot operate voting equipment, and many individuals who use wheelchairs cannot access the machines from their chairs.²⁰⁷ The National Organization on Disability reported in 2001 that fewer than ten percent of polling places

ianship” were not allowed to register to vote because of their residence in a state facility. *Armstrong, supra*, at 579.

203 *Carroll*, 354 A.2d at 357.

204 *Armstrong, supra* note 202, at 580–81.

205 U.S. GEN. ACCOUNTING OFFICE, *VOTERS WITH DISABILITIES 7* (2001), available at <http://www.gao.gov/new.items/d02107.pdf>.

206 *Id.* at 26.

207 See Michael Waterstone, *Constitutional and Statutory Voting Rights for People with Disabilities*, 14 *STAN. L. & POL'Y REV.* 353, 357 (2003).

used audio output that would allow visually impaired voters to vote privately and independently.²⁰⁸

Voters with visual impairments have historically found that polling places offered *no* opportunity for them to vote privately and independently.²⁰⁹ Voters with visual impairments need to request assistance from others to cast their ballots and often do not feel confident that their actual intentions were recorded.²¹⁰

In theory, voters with mobility or visual impairments are offered the opportunity to vote with the general public. In practice, however, it can be very difficult for them to vote. Thus, there are both *de jure* and *de facto* voting barriers that limit the rights of individuals with disabilities. Disenfranchisement is a way of precluding people from full participation in society as equal citizens.

B. Legal Developments

One of the earliest known cases involving the voting rights of individuals with disabilities occurred in 1878 when E.E. Clark sought to contest an election which he had lost by sixteen votes.²¹¹ He contested the votes of five individuals who were allegedly mentally defective or “idiots.” (For some reason, the plaintiff appears to know how various individuals voted;²¹² the ballot does not appear to have been entirely secret.) The court ruled against the plaintiff with respect to these votes, finding the evidence insufficient to establish them as incompetent to vote.²¹³ These individuals lived as regular members of the community, holding jobs.²¹⁴ Nonetheless, some professionals were willing to characterize them as “idiots” who were not competent to vote.²¹⁵ Similarly, the Arkansas Supreme Court ruled that the lower

208 National Organization on Disability, ALERT: Most Voting Systems Are Inaccessible for People with Disabilities (Aug. 2, 2001), <http://www.nod.org> (type “voting systems” into search field; then follow hyperlink for article title).

209 Both the General Accounting Office report and a separate report by the League of Women Voters found no voting equipment adapted to blind voters as recently as the 2000 presidential election. See Waterstone, *supra* note 207, at 357.

210 See Michael Waterstone, *Civil Rights and the Administration of Elections—Toward Secret Ballots and Polling Place Access*, 8 J. GENDER RACE & JUST. 101, 105 (2004) (“When people with disabilities did vote in polling places, they were often directed to do so in ways that compromised the secrecy and independence of their ballots.”).

211 Clark v. Robinson, 88 Ill. 498, 500 (1878).

212 *Id.* at 501 (stating they voted for the appellee).

213 *Id.* at 502–03 (finding individuals had “peculiarities and eccentricities indicative of mental deficiency to some extent” but not sufficient to be deemed incompetent to vote).

214 *Id.* at 502.

215 *Id.*

court was correct to rule that Elzy Thorn was not an "idiot or insane" for the purposes of determining whether an election was valid.²¹⁶ In those early cases, the plaintiff tried to use the voter's disability status as a mechanism to void an entire election; that strategy was not viewed favorably by the courts even if they were not willing to open up the general problem of the disenfranchisement of individuals with disabilities.²¹⁷ The courts' decisions in these cases, however, can best be understood as reflecting hesitancy to invalidate elections, not reflecting an interest in protecting the rights of voters with disabilities. When voters tried to invalidate elections on the ground that some individuals were disenfranchised, the results were equally unsuccessful.²¹⁸

In the 1970s, voters with disabilities started to bring direct challenges concerning the inaccessibility of polling places under the Equal Protection Clause. These lawsuits were largely unsuccessful because courts found that the availability of an absentee ballot was sufficient access to voting.²¹⁹ Courts rejected arguments that this alternative was unacceptable because it required advanced planning.²²⁰ Segregation of voting was therefore condoned in the 1970s even though judges were able to imagine other alternatives which would have allowed voters with disabilities to make last-minute decisions and vote at regular polling places.²²¹

216 *Youngblood v. Thorn*, 224 S.W. 962, 963 (Ark. 1920).

217 *See also Ruffo v. Margolis*, 401 N.Y.S.2d 900, 902-03 (N.Y. App. Div. 1978) (rejecting attempt to invalidate election because some residents of a mental institution were permitted to vote by absentee ballot).

218 *See Whalen v. Heimann*, 373 F. Supp. 353, 357 (D. Conn. 1974) (refusing to invalidate election on grounds that absentee ballots were not available to those who were unable to appear at polling places for health or business reasons).

219 *See, e.g., Selph v. Council of L.A.*, 390 F. Supp. 58, 61 (C.D. Cal. 1975).

220 *Id.* ("This approach can be seen as a rational alternative to the legitimate state purpose of minimizing the high cost and substantial administrative effort involved in providing more than 3800 accessible polling places.").

221 *Id.* at 62. Similarly, judges were reluctant to second-guess legislative judgments about how to treat voters with visual impairments. Tennessee, for example, amended its state statute that related to voting by individuals with visual impairments, to limit them to choosing a select group of relatives or election officials to assist them with marking a ballot rather than allowing them to continue to use "any reputable person of the voter's selection." *Smith v. Dunn*, 381 F. Supp. 822, 824 (M.D. Tenn. 1974) (quoting TENN. CODE ANN. § 2-1226 (repealed 1973)). Voters unsuccessfully argued that they should not have to reveal their voting decision to persons not of their own choice if they could not bring in a relative for assistance. *Id.* The court permitted this change in policy despite recognizing that although "the court may find the former provision preferable, . . . regulation of the election process is, within constitutional boundaries hereinafter explored, a purely legislative function." *Id.*

Individuals with disabilities also sought to challenge policies which precluded individuals from voting because they resided at a state school for mental retardation. In this instance, residential segregation made it easy to identify a category of individuals who could then be disenfranchised. Courts had varying responses to these cases. Sometimes, they concluded that residence at a state school should not be a *per se* disqualification from voting;²²² other times, they concluded it could be.²²³ Irrespective of the legal outcome, these cases reflect an attempt by the government to connect segregation to subordination by denying the franchise to these individuals who lived in segregated housing arrangements.

The lack of concern for voters with disabilities as recently as the mid-1970s is graphically illustrated by some language from Judge Newman's opinion in *Whalen v. Heimann*.²²⁴ Judge Newman was considering the allegation that an election should be invalidated because of Connecticut's requirement that all voting take place in person at the polls without the availability of absentee balloting. He said:

Is there anything in the Constitution that prohibits a state from requiring that voting be done by physical attendance at the polls? Surely this is not an arbitrary or unreasonable requirement such as would violate the due process or equal protection clauses. A physically incapacitated voter has no more basis to challenge a voting requirement of personal appearance than a blind voter can complain that the ballot is not printed in braille.^[*] Nor is it the province of courts to weigh the relative ease or difficulty with which the state could accommodate its voting procedures to meet the needs of various handicapped voters. These are policy questions to be resolved by legislators.

[*] Though the Constitution does not require special arrangements to facilitate voting by the physically handicapped, legislatures of course have ample discretion to enact remedial measures for this purpose. *See, e.g.*, [CONN. GEN. STAT. ANN. § 9-297 (West 2002)].²²⁵

Judge Newman's comments are striking because they reflect the disconnection between segregation and subordination. The problem in the disability context is the disenfranchisement of individuals with disabilities. Some states achieved that disenfranchisement by insisting that voters with disabilities use absentee ballots because they did not

²²² *See, e.g.*, *Boyd v. Bd. of Registrars of Voters*, 334 N.E.2d 629, 630 (Mass. 1975); *Carroll v. Cobb*, 354 A.2d 355, 359 (N.J. Super. Ct. App. Div. 1975).

²²³ *See, e.g.*, *Town of Lafayette v. City of Chippewa Falls*, 235 N.W.2d 435, 443 (Wis. 1975).

²²⁴ 373 F. Supp. 353 (D. Conn. 1974).

²²⁵ *Id.* at 357 & n.6.

want to bear the expense of making polling places accessible. Other states achieved that disenfranchisement by creating the unrealistic requirement that everyone would vote at polling places even though they knew that some voters with disabilities could not vote at existing polling places. The no-absentee ballot rule could be seen as a rule mandating integration, but in practice, it created disenfranchisement for some voters. Under the low-level rational basis review available at the time, even voters with visual impairments had no recourse to insist that they be provided with a ballot that they could actually use.²²⁶

Until recently, voters with disabilities also had little recourse under federal statutory law.²²⁷ Despite the enactment of the Voting Accessibility for the Elderly and Handicapped Act,²²⁸ section 504 of the Rehabilitation Act of 1973,²²⁹ and Title II of the ADA,²³⁰ the United States Department of Justice has concluded "that Braille ballots are not required for blind voters, assistance of another person of the voter's choice is equivalent, and that curbside voting complies with the ADA's access requirements and does not constitute discriminatory treatment."²³¹ A district court has chosen to require a secret

226 Interestingly, in one of the few successful equal protection challenges to voting practices, a court used a reverse discrimination theory to conclude that it was unconstitutional for a state to allow blind and physically disabled voters to receive assistance in marking their ballot but not to extend that assistance to illiterate voters. *See Garza v. Smith*, 320 F. Supp. 131, 136-37 (W.D. Tex. 1970), *vacated*, 401 U.S. 1006 (1971). In the context of a voting rights challenge by illiterate voters, the court used heightened scrutiny even though other judges had only used rational basis scrutiny in cases involving voters with disabilities. *Id.* at 137 (requiring "compelling state interest" justification). Other courts have rejected this equal protection argument. *See, e.g., State ex rel. Melvin v. Sweeney*, 94 N.E.2d 785, 790 (Ohio 1950) ("The granting to voters handicapped by 'physical infirmities' of aid in marking their ballots, although such privilege is not extended to others, is, in the opinion of this court, not unconstitutional legislation.").

227 Plaintiffs sometimes prevailed under state law. *See, e.g., Carroll*, 354 A.2d at 359 (holding that it is improper under state law to deny individuals the right to register to vote merely because they live at a state school for the "mentally retarded").

228 Pub. L. No. 98-435, 98 Stat. 1678 (codified at 42 U.S.C. § 1973ee (2000)).

229 Pub. L. No. 93-112, 87 Stat. 355 (codified as amended at 29 U.S.C. §§ 701-706 (2000)) (prohibiting disability discrimination by entities receiving federal financial assistance).

230 Pub. L. No. 101-336, 104 Stat. 327 (codified at 42 U.S.C. §§ 12101-12213 (2000)) (finding that discrimination on the basis of disability persists "in such critical areas as voting").

231 Waterstone, *supra* note 207, at 361 (citing Letter from Stewart B. Oneiglia, Chief, Coordination & Review Section, Civil Rights Div., Dep't of Justice (Aug. 25, 1993), available at <http://www.usdoj.gov/crt/foia/lofc018.txt>; Letter from Stewart B. Oneiglia, Chief, Coordination & Review Section, Civil Rights Div., Dep't of Justice (Sept. 10, 1993), available at <http://www.usdoj.gov/crt/foia/lofc021.txt>; Letter from

ballot for visually impaired voters despite the Department of Justice position,²³² but that is an unusual outcome under the ADA.²³³ Nonetheless, some of the guardianship restrictions have been found to violate federal statutory or constitutional law.²³⁴

The lack of success of many of these lawsuits under the ADA, coupled with reports about inaccessible voting in the 2000 presidential election, caused Congress to enact the Help America Vote Act of 2002 (HAVA).²³⁵ States are provided with grants to upgrade voting machines, ensure that polling places are accessible, and meet general standards for voting technology. Certain minimum standards are established by the Act; nonvisual access to equipment for voters with visual impairments, and polling place accessibility for voters with mobility impairments.²³⁶ Enforcement, however, is weak, with states merely having to submit applications for approval by the Secretary of Health and Human Services to be eligible for payments.²³⁷ States did submit these plans by March 2004, although "the plans were often vague and lacked any detailed descriptions of the type of actual standards that would be used to ensure accessibility."²³⁸

The focus of the disability provisions of HAVA is on gaining access to public polling places and allowing visually impaired voters to vote privately and independently.²³⁹ States are able to self-certify compliance and voters with disabilities are not able to bring private causes of action against the state for enforcement.²⁴⁰ The Attorney General

Stewart B. Oneglia, Chief, Coordination & Review Section, Civil Rights Div., Dep't of Justice (Sept. 30, 1993), *available at* <http://www.usdoj.gov/crt/foia/lofc023.txt>.

232 *See* Lightbourn v. County of El Paso, 904 F. Supp. 1429, 1433–34 (W.D. Tex. 1995), *rev'd*, 118 F.3d 421 (5th Cir. 1997).

233 *See, e.g.*, Am. Ass'n of People with Disabilities v. Shelley, 324 F. Supp. 2d 1120, 1127–30 (C.D. Cal. 2004) (ruling against plaintiffs with visual impairments who sought to vote independently and privately); Doe v. Rowe, 156 F. Supp. 2d 35, 59 (D. Me. 2001) (refusing to determine competency for plaintiffs with mental illness); Nelson v. Miller, 950 F. Supp. 201, 204 (W.D. Mich. 1996), *aff'd on other grounds*, 170 F.3d 641 (6th Cir. 1999) (finding that Congress did not intend "to elevate a blind voter's privacy in casting a ballot to a protected right under the ADA or RA").

234 *See, e.g.*, New York *ex rel.* Spitzer v. County of Del., 82 F. Supp. 2d 12, 16–18 (N.D.N.Y. 2000); DiPietra v. City of Philadelphia, 666 A.2d 1132, 1134–36 (Pa. Commw. Ct. 1995), *aff'd*, 673 A.2d 905 (Pa. 1996).

235 Pub. L. No. 107-252, 116 Stat. 1666 (codified at 42 U.S.C. §§ 15301–15545 (Supp. III 2003)).

236 42 U.S.C. § 15421(b).

237 *Id.* § 15423.

238 Christina J. Weis, *Why the Help America Vote Act Fails To Help Disabled Americans Vote*, 8 N.Y.U. J. LEGIS. & PUB. POL'Y 421, 445 (2005).

239 *See* 42 U.S.C. § 15481(a)(3).

240 *See id.* §§ 15511–15512.

is expected to achieve national compliance—an impossible task with each state establishing its own guidelines.²⁴¹ Hence, disability rights advocates call for a uniform set of national standards that can be enforced by the disability community through a private right of action.²⁴² These national standards are premised on the notion that integration is the measure of success. The focus on integration, however, may have caused us to lose sight of the underlying goal of voting rights—increasing voter participation by individuals with disabilities. Despite various federal reforms, voting participation by individuals with disabilities has barely improved;²⁴³ if we measured success by increasing participation rather than by integration, further remedies may become evident.²⁴⁴

IV. ALTERNATIVES TO PURE INTEGRATIONISM

A. *Special Education Alternatives*

Evidence from three different education contexts can show how separate programming for individuals with disabilities can be considered superior rather than invidious: (1) education for children with learning disabilities, (2) private schools for children with various cognitive or emotional impairments, and (3) deaf-only educational environments. This evidence suggests that it is wrong to conflate separate with unequal.

1. Learning Disabled Category

Early critiques of the special education system demonstrated that African-Americans were overrepresented in the “educable mentally retarded” category and shunted into dead-end educational programs. In 1997, Mark Kelman and Gillian Lester made the controversial argument that white upper-class children are now overrepresented in the “learning disabled” category and receive expensive low-stigma

241 *See id.* § 15511.

242 *See Weis, supra* note 238, at 456.

243 *See infra* Part IV.C.

244 An additional problem, which is beyond the scope of this Article, is the problem of voting fraud by individuals who purport to vote on behalf of individuals with disabilities when those individuals are not able to cast independent and private ballots. *See generally* Jason H. Karlawish et al., *Addressing the Ethical, Legal, and Social Issues Raised by Voting by Persons with Dementia*, 292 JAMA 1345, 1348 (2004) (“Further study is needed to determine whether there are ways of reducing the risk of fraud or coercion while fully protecting the voting rights of disabled but capable individuals.”).

resources that are not made available to racial minorities.²⁴⁵ They distinguish between self-contained special education classrooms and part-time resource rooms for providing services to children with disabilities.²⁴⁶ They argue that self-contained special education classrooms are disproportionately used for low-income racial minorities and are both inadequate and stigmatizing, and that resource rooms are comparatively effective and nonstigmatizing.²⁴⁷

Kelman and Lester's work proceeds from two controversial premises: (1) that the "learning disabled" (LD) category is a questionable "soft" disability category with less stigma than the "educable mentally retarded" (EMR) category and (2) that resource rooms and in-class supplementary services are less stigmatizing than self-contained special education classrooms.²⁴⁸ The word "stigma" appears throughout the book, but it is not clear how they decide what categories and settings are "stigmatizing." Is LD less stigmatizing because it is a predominantly white disability category or because it is an inherently less stigmatizing label? Are resource rooms less stigmatizing because they are disproportionately populated by upper middle-class white boys or because they are inherently less stigmatizing?

The data on disability classification is more complicated than described by Kelman and Lester. The United States Department of Education publishes data by race and disability that document who is served under the Individuals with Disabilities Education Act (IDEA).²⁴⁹ As provided below, the most recent data are for the 2000–2001 academic year and do not include New York.

245 See MARK KELMAN & GILLIAN LESTER, *JUMPING THE QUEUE: AN INQUIRY INTO THE LEGAL TREATMENT OF STUDENTS WITH LEARNING DISABILITIES* 79–80 (1997).

246 *Id.* at 75.

247 *Id.*

248 *Id.* at 16, 75.

249 Pub. L. No. 91-230, 84 Stat. 175 (codified as amended at 20 U.S.C. §§ 1400–1482).

TABLE I. PERCENTAGE OF STUDENTS AGES SIX THROUGH TWENTY-ONE SERVED UNDER IDEA BY DISABILITY AND RACE/ETHNICITY (2000-2001 ACADEMIC YEAR)²⁵⁰

Disability	American Indian/Alaska Native	Asian/Pacific Islander	Black (non-Hispanic)	Hispanic	White (non-Hispanic)	All students served
Specific Learning Disabilities	56.3	43.2	45.2	60.3	48.9	50.0
Speech or language Impairments	17.1	25.2	15.1	17.3	20.8	18.9
Mental Retardation	8.5	10.1	18.9	8.6	9.3	10.6
Emotional Disturbance	7.5	5.3	10.7	4.5	8.0	8.2
Multiple Disabilities	2.5	2.3	1.9	1.8	1.8	2.1
Hearing Impairments	1.1	2.9	1.0	1.5	1.2	1.2
Orthopedic Impairments	0.8	2.0	0.9	1.4	1.4	1.3
Other Health Impairments	4.1	3.9	3.7	2.8	5.9	5.1
Visual Impairments	0.4	0.8	0.4	0.5	0.5	0.4
Autism	0.6	3.4	1.2	0.9	1.4	1.4
Deaf-blindness	0.0	0.0	0.0	0.0	0.0	0.0
Traumatic Brain Injury	0.3	0.3	0.2	0.2	0.3	0.3
Developmental Delay	0.7	0.6	0.7	0.2	0.6	0.5
All Disabilities	100.0	100.0	100.0	100.0	100.0	100.0

These data suggest that the connection between race or ethnicity and disability category is complex. While it is true that African-Americans are overrepresented in the mental retardation category and underrepresented in the learning disability category, the same pattern is not evident for other minority groups. American Indian/Alaska Natives are overrepresented in the learning disability category and underrepresented in the mental retardation category. And contrary to Kelman and Lester's assertions,²⁵¹ whites are *not* overrepresented

²⁵⁰ U.S. DEP'T OF EDUC., TWENTY-FOURTH ANNUAL REPORT TO CONGRESS ON THE IMPLEMENTATION OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT, at II-22 tbl.II-5 (2002), available at <http://www.ed.gov/about/reports/annual/osep/2002/index.html> (follow hyperlink under Section II).

²⁵¹ KELMAN & LESTER, *supra* note 245, at 76.

in the learning disability category. The two groups that are overrepresented in this category are American Indian/Alaska Natives and Hispanics. Asian/Pacific Islanders are underrepresented in the learning disability category, overrepresented in the speech or language impairment category and overrepresented in the autism category. The speech or language numbers could be explained by second-language issues, but neither the learning disability nor autism categorizations have an obvious explanation.

The Department of Education data do not indicate where the students received their services—regular classroom, resource room, or self-contained special education classroom. Kelman and Lester assume that children who are diagnosed with learning disabilities are more likely to receive services in a more integrated setting than children who are diagnosed with mental retardation.²⁵² Moreover, they assume that the learning disability diagnosis is less stigmatizing than the mental retardation label.²⁵³ If so, then the children least stigmatized by disability labeling would be Hispanic children, not whites. Possibly, Hispanic children are less stigmatized by disability labeling, but more likely, the connection that Kelman and Lester perceived between disability and stigma was really a racial stigma connection, not a disability stigma connection.

Kelman and Lester's work proceeds from the "separate is inherently unequal" premise. They assume that self-contained special education classrooms are stigmatizing, "dead-end" classes.²⁵⁴ They assume that part-time resource rooms or intervention in the regular classroom—which are more integrated alternatives—are less stigmatizing. Although their work includes a very careful empirical account of much disability literature, they make their assumptions about stigma without investigating the literature on stigma as it relates to disability educational practices. Studies of children with cognitive or mental disabilities report that the children often prefer pull-out programs and special education classrooms because they find them to be "no more embarrassing and stigmatizing than in-class services."²⁵⁵

Kelman and Lester's "separate is inherently unequal" perspective is also contradicted by their own findings. They report that upper-class white parents are seeking to have their children labeled as "learning disabled" so that they can receive the protections of the IDEA and

252 *Id.* at 74.

253 *Id.* at 30.

254 *Id.* at 68.

255 Joseph R. Jenkins & Amy Heinen, *Students' Preferences for Service Delivery: Pull-Out, In-Class, or Integrated Models*, 55 *EXCEPTIONAL CHILD* 516, 520 (1989). For further discussion, see Colker, *supra* note 29, at 833–34.

the resources available to children identified as disabled.²⁵⁶ They argue that one of these important services is "resource rooms," which they describe in glowing terms and contrast with self-contained special education classrooms which they describe as dead ends.²⁵⁷ The special education classrooms are supposedly "dead ends" because they are self-contained disability classrooms whereas the resource rooms are for part-time use.²⁵⁸ But they are both "separate" educational programs devised entirely for children with disabilities. One complication in understanding Kelman and Lester's argument is that they seem to conflate supplementary in-class services with resource rooms.²⁵⁹ They talk about children who are "seen" by resource specialists as if that is the same as children who are "seen" in resource rooms themselves.²⁶⁰ Yet, children can be seen by resource specialists in the regular classroom in a fully integrated setting; whereas, resource rooms are typically only for children with disabilities and therefore look a lot like the self-contained special education classrooms which they criticize.

Certainly, the special education classrooms which are populated predominantly by poor African-American boys are likely to be inferior educational alternatives. But Kelman and Lester also report that one upper-class New York school district experimented with creating resource room services for any student who wanted to use them.²⁶¹ They had to abandon this experiment because of excess demands on expensive resource room services.²⁶² The resource rooms then returned to disability-only environments but they were apparently highly desirable environments.²⁶³ If resource rooms—a separate type of educational environment—can be considered so desirable, one must wonder if special education classrooms could also become so desirable.²⁶⁴

256 KELMAN & LESTER, *supra* note 245, at 75, 92.

257 *Id.* at 75.

258 *Id.*

259 *See id.* at 76.

260 *Id.* at 77.

261 *Id.* at 86.

262 *Id.*

263 *Id.*

264 For example, when my son was in preschool, he attended a special education classroom called the "Teddy Bear" room. Each day, a few children from regular classrooms spent about an hour in his class to act as typically developing role models. Children in the regular classrooms were not forced to attend; they were allowed to volunteer. Nearly all the children in the regular classrooms did volunteer because they enjoyed attending the special education classroom. No one called the special education classroom a classroom for children with disabilities. It was simply the

Kelman and Lester's description of the resources made available to upper-class students with learning disabilities shows how separate can be superior rather than unequal.²⁶⁵ Like gifted pull-out services, which are often popular despite the "separate" educational element, special education resource rooms can be popular despite the "separate" educational element.

Unfortunately, many "dead-end" self-contained special education classrooms still do exist that are populated primarily by African-American male students. The federal government should collect data on the educational progress of African-American students within special education settings. Self-contained special education classrooms should not be the new ghetto and disability resource rooms should not be the new Taj Mahal. Instead, all children with disabilities should have a claim to an appropriate configuration of resources. The emphasis on the degree of integration, however, may deter a focus on quality of services. Self-contained special education classrooms may be dead ends, but that may be due to the limited educational resources devoted to those classrooms rather than due to their segregated nature.

Daniel Losen and Kevin Welner connect race with the quality of services provided to children with disabilities. They note that "white students are overrepresented among students with disabilities seeking accommodations for the SAT, whereas minority students with disabilities are grossly underrepresented among this same group."²⁶⁶ They argue that these statistics reflect the "racially differential use of special

"Teddy Bear" room. In fact, my son did not learn until he was nine that he had ever attended a classroom for children with disabilities. Older children may be more aware of such distinctions, but Kelman and Lester seem to assume an inherent stigmatization and inferiority that need not exist.

265 Their work also reflects the challenges of applying an anti-subordination model to the education context. Their work is premised on an anti-subordination model because they are trying to demonstrate how one group of children with disabilities—middle or upper class children with learning disabilities—are treated more favorably than another group of children with disabilities—poor or minority children with mental retardation. See KELMAN & LESTER, *supra* note 245, at 68. They even go so far as to question whether the first category is even a subordinated group because they question the disability label for these children and suggest that their parents have co-opted the disability label as a way to make a claim for additional resources for their already-privileged children. *Id.* I would agree with them that we should not use an anti-subordination perspective to benefit those who are, at most, mildly disabled at the expense of those who are both more disabled and face subordination through race and class. But I do not accept their premise that the learning disabled category is a "soft" and less stigmatizing category than the mental retardation category. I suggest that they have confounded race and disability to make those arguments.

266 Losen & Welner, *supra* note 87, at 419.

education: the use by schools to isolate difficult minority children versus the use by white parents to gain additional resources and advantages for their children.”²⁶⁷ Race and class, rather than the disability label, may be producing differential outcomes. Federal law should be seeking to ensure that all children with disabilities have the opportunity to seek the appropriate configuration of resources, irrespective of their race or class.²⁶⁸

The overall problem in this area is that integration rather than quality of education is considered the measure of success. Researchers need to develop reliable measures of progress for children with disabilities so that we can have an accurate indication of whether various special education classrooms or institutions are achieving appropriate progress for children with disabilities.²⁶⁹

2. Private Schools for Children with Disabilities

Most of the discussion of the invidious nature of disability-only educational institutions has focused on public disability-only schools when parents have wanted their children not to attend those schools.²⁷⁰ From those cases, it has been easy to conclude that sepa-

²⁶⁷ *Id.*

²⁶⁸ This problem is, of course, compounded by general inequities in our society in educational opportunities on the basis of race or class. The disability label, however, should not be used to further widen those inequities. It is hard to imagine that we can equalize the resources available to children with disabilities so long as widespread educational inequities exist for children in our society on the basis of race and class.

²⁶⁹ One of the best studies of special education results that I found was conducted by Beth Harry and Janette Klingner. They were able to document the overrepresentation of minority children in special education while also noting that some children achieved positive results in special education environments. Rather than globally dismiss or accept special education, they tried to note what factors made special education successful for poor minority children. See BETH HARRY & JANETTE KLINGNER, *WHY ARE SO MANY MINORITY STUDENTS IN SPECIAL EDUCATION?* 159–72 (2006).

²⁷⁰ One general problem in discussing this area of the law is that the stories are told from the perspective of the parents and the school districts. In the K–12 context, the IDEA grants the cause of action to the parents, not the child. And, of course, parents are socialized by society to have particular views about disability. Therefore, it is naïve to assume that parents are always making arguments in the best interest of their child with a disability. Even if children had a greater voice in the litigation in this area, we would have to question whether they are in a good position to assess what configuration of educational resources is most appropriate for them. This Article cannot begin to resolve such problems of what we might call “false consciousness” or “false standpoint.” Such problems exist in all areas of the law in which we purport to grant choices to individuals. Nonetheless, it is compounded in the disability area where we expect others to make judgments on behalf of individuals with disabilities as to their needs, desires, and capabilities.

rate is unequal. But there is another line of cases which suggests a different result—cases involving parents who want the state to reimburse them for the cost of sending their children to private disability-only schools when the public schools were not able to provide them with an adequate education for their children. The poor quality of the public school offerings has forced these parents to pursue other options. Interestingly, the private schools they explore tend to be disability-only. As with the evidence from the learning disability field, these cases suggest that separate need not necessarily carry the invidious segregation stigma. If school districts are incapable of developing high quality disability-only institutions, then possibly the case law should be more flexible in having the state pay for children to attend private disability-only institutions. Although the tuition for these schools may seem high, the tuition may still be less than what it would cost the public school district to create such an institution within its own school district.

One of the major cases concerning parents seeking to have their children attend private schools culminated in a 1985 Supreme Court decision in *School Committee of Burlington v. Department of Education*.²⁷¹ The case is known for setting the standards with respect to reimbursement if a parent rejects the school district's proposed individualized education plan (IEP) and sends a child to a private school. Most of the case law on this case involves procedural issues about reimbursement, but hidden in the case is an example of a parent preferring a private disability-only school over the more integrated option put forward by the school district.

John Doe's father began this litigation when he objected to the school district's proposed placement for his son who was entering fourth grade.²⁷² The town proposed that John Doe attend Pine Glen School, a public school that provided both regular and special education.²⁷³ Mr. Doe preferred the Carroll School, a disability-only private school for children with learning disabilities.²⁷⁴ Although the case

271 471 U.S. 359 (1985).

272 *Town of Burlington v. Dep't of Educ.*, 655 F.2d 428, 429 (1st Cir. 1981), *aff'd sub nom. Sch. Comm. of Burlington*, 471 U.S. 359. Although the son is called "John Doe" in the early litigation, he appears to proceed under his own name in later litigation. *See Sch. Comm. of Burlington*, 471 U.S. at 361 (referring to the child as Michael Panico and the father as Robert Panico).

273 *Town of Burlington*, 655 F.2d at 429.

274 *Id.*; see The Carroll School, http://www2.retrieve.com/carrollschool/upload/scs_images/the_carroll_school_home.html (follow "About Us" hyperlink) (last visited Mar. 26, 2007) ("Carroll is a thriving community where children come together in an environment that values their differences and remediates their learning difficulties.").

involved extensive litigation, the reported decisions do not provide many facts about Doe's situation. One appellate decision reports that the Carroll School cost a total of \$6466 a year, of which the state would reimburse to a maximum of \$2795.²⁷⁵

The *Burlington* case reflects how a school system may not have sufficient disability-only programming for a particular child, necessitating a private placement. The child, whom the Supreme Court calls "Michael Panico," began to experience difficulties in the public school in first grade.²⁷⁶ In third grade, the public school developed an IEP that included some individual tutoring, plus individual and group counseling.²⁷⁷ When those services did not help Michael, the school district proposed placing Michael in a highly structured class of six children with special academic and social needs at another public school.²⁷⁸ Michael's father objected to this placement, believing Michael needed to be educated at Carroll School, a state-approved private school for children with learning disabilities.²⁷⁹ It appears that part of the dispute with the school district involved whether Michael's problems were primarily social or neurological.²⁸⁰ In the school district's proposed placement, Michael's "reading skills would have been lower than those of five of the six students and he would have been one of the older students in the class."²⁸¹ The class also exceeded the maximum thirty-six months chronological age span in the classroom considered appropriate for Michael, and had a shorter school day than the Carroll School.²⁸²

In Michael's case, the school district had available a disability-only program for children with social and emotional difficulties but did not have available a disability-only program for children with learning disabilities. Both the school district and Michael's parents agreed that Michael should not be educated in the regular classroom, even with assistance, but needed some kind of special education. At the time of the dispute, the Carroll School placement would apparently cost

275 *Town of Burlington*, 655 F.2d at 432 n.7. According to the school's website, tuition in 2006–2007 was \$32,200 for the winter program. See The Carroll School, *supra* note 274 (follow "About Us" hyperlink; then follow "Most frequently asked questions about the Carroll School" hyperlink).

276 *Sch. Comm. of Burlington*, 471 U.S. at 361.

277 *Id.*

278 *Id.* at 362.

279 *Id.*

280 *See id.*

281 *Town of Burlington v. Dep't of Educ.*, 736 F.2d 773, 789 (1st Cir. 1984), *aff'd sub nom. Sch. Comm. of Burlington*, 471 U.S. 359.

282 *Id.* at 789–90.

\$6486 and the school district was only willing to reimburse \$2795.²⁸³ From an efficiency perspective, it made sense for the school district to reimburse the private school for Michael's education rather than try to replicate their school in the public setting. The case also revealed how it was important for disability-only options to be available because a regular classroom, with assistance, had not benefited Michael.

A similar fact pattern existed for the other leading Supreme Court case on parental reimbursement for private schooling.²⁸⁴ Shannon Carter was classified as learning disabled in ninth grade.²⁸⁵ The school district proposed keeping Shannon in regular classes except for three periods of individualized instruction per week.²⁸⁶ Her parents wanted to place her at Trident Academy, a private school specializing in educating children with disabilities.²⁸⁷ Shannon made significant progress at Trident; her reading comprehension rose three grade levels in her three years at the school.²⁸⁸

Shannon's case, like Michael's case, appears to involve a school system with inadequate disability-only alternatives. The school system proposed a program placing Shannon in a regular classroom for three periods per week of individualized instruction.²⁸⁹ The stated goals for her progress constituted approximately four months of progress on a yearly basis.²⁹⁰ The school district had originally proposed placing Shannon in a resource room, but the parents objected because the other students in that room had very different types of disabilities.²⁹¹ When the parents insisted on specialized assistance by a learning disability expert, the school responded with its three periods per week proposal.²⁹² By contrast, when Shannon attended a private school for children with learning disabilities, she was able to make more than three years' progress in reading comprehension in three years.²⁹³

The school district and Shannon's parents initially agreed that Shannon needed disability-only services to make adequate progress, but the school district did not have a disability-only program for chil-

283 *Town of Burlington v. Dep't of Educ.*, 655 F.2d 428, 432 n.7 (1st Cir. 1981), *aff'd sub nom. Sch. Comm. of Burlington*, 471 U.S. 359.

284 *See Florence County Sch. Dist. Four v. Carter*, 510 U.S. 7, 10-11 (1993).

285 *Id.* at 10.

286 *Id.*

287 *Id.*

288 *Id.* at 11.

289 *Carter v. Florence County Sch. Dist. Four*, 950 F.2d 156, 159 (4th Cir. 1991), *aff'd*, 510 U.S. 7.

290 *Id.*

291 *Id.* at 158-59.

292 *Id.* at 159.

293 *Id.*

dren with learning disabilities. By attending a private disability-only school, Shannon was able to have her educational needs met without the school district investing in a new institutional arrangement.

Most of the attention under the IDEA has been on the issue of whether children are being educated in the most integrated setting possible. For many children, the best educational outcomes may occur in those settings. But for children like Michael and Shannon, the empirical literature suggests that disability-only settings targeted to the different learning style of children with learning disabilities are more likely to be effective.²⁹⁴ Under the existing case law, parents have an exceedingly high burden of proof to have the school district pay for their children to attend such institutions.

A private school placement can occur under two scenarios under the IDEA. First, the school district and parent can voluntarily agree that a private school is the appropriate placement for a child.²⁹⁵ In that case, the statute provides that such schooling shall occur at "no cost" to the parents.²⁹⁶ Second, the parents can unilaterally choose to place their child in a private school and seek reimbursement for that education from the school district. The parent is only entitled to reimbursement "if the court or hearing officer finds that the agency had not made a free appropriate public education available to the child in a timely manner prior to that enrollment."²⁹⁷ Shannon's and Michael's cases proceeded under that legal standard. Their parents were able to obtain reimbursement because the programs suggested by the school district were found not to constitute an "appropriate" education. Both children had made little progress in their existing public school program, the proposed program by the school district was unlikely to change those results, and the private school programs worked well for them.

The standards for an "appropriate" education, however, are very low. The Supreme Court in *Board of Education v. Rowley*²⁹⁸ made it clear that maximizing each child's potential "was further than Congress intended to go."²⁹⁹ Adequate yearly progress is sufficient under this standard, rather than evidence that the child with a disability has

294 See Colker, *supra* note 29, at 825-35 (surveying empirical research).

295 See 20 U.S.C. § 1412(a)(10)(B)(i) (Supp. IV 2004).

296 *Id.*

297 *Id.* § 1412(a)(10)(C)(ii).

298 458 U.S. 176 (1982).

299 *Id.* at 199.

attained progress fully "commensurate with the opportunity provided to nonhandicapped children."³⁰⁰

One can understand that courts are reluctant to impose the cost of private education on public school systems. Hence, parents have a high burden of proof to attain reimbursement when they unilaterally choose a private school option for their children.

The issue of cost, however, is a complicated one. In the *Burlington* case, the private school was not much more expensive than what the school district was ordinarily prepared to pay for special education schooling. Further, no one even considered in either case what it would cost for the school district to create a comparable educational opportunity for these children. If these children needed an effective disability-only educational setting to make adequate academic progress, it would have been very expensive for the school district to create a publicly funded program for the small number of children likely to need such a program. It made more sense financially for the school district to pay the cost of educating one child at a private facility that already existed. In the private facility, the school district is spreading out the fixed overhead costs with parents or other school districts.

Another background assumption that may be operating in these cases is that children should be in an integrated public school setting rather than a private disability-only setting. If the private school were the only way for these children to attain an integrated setting, the case law might not be so stringent. But courts seem skeptical of the value of these private schools because they are only for children with disabilities. The courts are proceeding from an integration bias.

Yet, the evidence in these cases indicates that the parents are very desirous of having their children educated in these private schools. Despite the high burden of proof for reimbursement, parents are willing to advance the costs of attending these schools in the hope that they will be reimbursed later. The parents have abandoned the integration presumption at a high personal and financial cost.

It is hard to see what structural policies are furthered by the rigid integration perspective that courts bring to the discussion of schools reimbursing children for attendance at private disability-only schools. If the private school reimbursement were substantially more expensive than public school alternatives, one might see a structural argument that school districts should not divert money to these private

300 *Id.* at 200. The Supreme Court in *Rowley* rejected this more rigorous standard, which had been applied by the lower court. Compare *Rowley v. Bd. of Educ.*, 483 F. Supp. 528, 534 (S.D.N.Y. 1980) with *Rowley*, 458 U.S. at 192.

schools rather than spend this money on the education of other children with disabilities. But marginal cost issues are not even a part of the discussion in these cases. The private school option may not have been more expensive than providing appropriate support in an integrated public school classroom.

The private school option furthers the principle of anti-subordination by giving courts the option of finding a segregated placement for some disabled children while not forcing the state to finance its own disability-only institution. In the health care context, we saw courts express concern about public institutions being insufficiently populated to be cost effective. A private sector option can make it possible for some students to receive segregated services without the state bearing the cost of building and maintaining a disability-only institution. Hence, private segregated options for some children can help serve the availability of public integrated options for others.

A common criticism of segregation is that segregation is often equated with stigma. But these cases reveal how segregation need not be more stigmatizing than integration. In the *Burlington* case, for example, the parents seemed to be concerned that Michael would be stigmatized by being placed in a classroom with younger children who had disabilities very different from Michael's. They thought he would benefit from being in a classroom with children of the same age and similar disability. Possibly, the fact that the private school was at a different location also provided Michael with more privacy as he sought to improve his academic skills. Stigma is a vague concept, but private segregated options may help reduce stigma in some cases. Private school, in general, seems to be a valued alternative in our society. By allowing more children with disabilities to take advantage of private schooling, we may alleviate rather than increase stigma.

The private school option is not a panacea. Many children live in areas where no private school alternatives exist. Also, few parents can afford to pursue private education unilaterally in the hope that they may be reimbursed later by the school district. If the standards for private education were relaxed, however, then more parents could secure private schooling as part of the initial IEP rather than have to seek reimbursement for tuition dollars later. The current system only allows parents with the most financial resources to risk having to pay for the entire schooling themselves while they await the results of litigation. From an equality and diversity perspective, the stringent standards make little sense. They provide a range of options to middle-class parents but make it hard for poorer parents to secure nonstigmatizing and effective options for their children. If progress were measured by educational gain rather than integration, courts might be

more willing to require school districts to offer private segregated options to poor and minority children with disabilities.

3. Deaf Culture Educational Movement

Separate organizing by individuals with disabilities played a crucial role in the development of modern strategies for the delivery of services to individuals with disabilities. An important point in the development of the disability-based civil rights movement was the empowerment of individuals with disabilities to advocate on their own behalf and, in some cases, to resist a complete integrationist perspective.

Individuals with hearing impairments have been in the forefront of this movement through the "Deaf Culture" movement.³⁰¹ They resisted the movement to push them toward lip reading rather than sign language. They also insisted on the creation and maintenance of institutions like Gallaudet University that only educated individuals with hearing impairments. They also resisted the cochlear implant movement, arguing that deafness did not necessarily have to be "cured."³⁰²

The Deaf Culture movement had a profound impact on the development of policy under the ADA. Deaf culture advocates successfully argued to Congress that they should not be required to seek to alleviate their deafness while also receiving special services to alleviate the effects of their deafness.³⁰³ Bonnie Tucker argues that the "yearly cost of educating one child in a residential school for the deaf is \$35,780 and educating one child in a self-contained class for the deaf is \$9689, compared to only \$3383 to educate the same child in a

301 See, e.g., CLAIRE RAMSEY, *DEAF CHILDREN IN PUBLIC SCHOOLS* 3–5 (1997); Harlan Lane & Michael Grodin, *Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability, and the Best Interests of the Child*, 7 KENNEDY INST. ETHICS J. 231, 233–35 (1997); Harlan Lane, *Ethnicity, Ethics, and the Deaf-World*, 10 J. DEAF STUD. & DEAF EDUC. 291, 291–95 (2005); Claire Ramsey, *Ethics and Culture in the Deaf Community Response to Cochlear Implants*, 21 SEMINARS IN HEARING 75, 75–76 (2000) [hereinafter Ramsey, *Ethics*]; Claire Ramsey & Carol Padden, *Natives and Newcomers: Gaining Access to Literacy in a Classroom for Deaf Children*, 29 ANTHROPOLOGY & EDUC. Q. 5, 6–7 (1998); Claire Ramsey, *What Does Culture Have To Do with the Education of Students Who Are Deaf or Hard of Hearing?*, in LITERACY AND DEAF PEOPLE 47, 52–55 (Brenda Jo Brueggemann ed., 2004) [hereinafter Ramsey, *Culture*]; Robert Spartow, *Defending Deaf Culture: The Case of Cochlear Implants*, 13 J. POL. PHIL. 135, 139–43 (2005).

302 See Lane & Grodin, *supra* note 301, at 244–46.

303 Bonnie Poitras Tucker, *The ADA and Deaf Culture: Contrasting Precepts, Conflicting Results*, 549 ANNALS AM. ACAD. POL. & SOC. SCI. 24, 33 (1997).

regular classroom.”³⁰⁴ In 1995, Congress allocated nearly \$24.8 million for various schools for the deaf in the District of Columbia.³⁰⁵ Based on these and other cost estimates, Tucker argues that deaf people, who choose to remain deaf despite available cures, should not be eligible for state financial assistance to accommodate their deafness.³⁰⁶ Tucker argues: “Deaf people cannot have it both ways. Deaf people cannot claim to be disabled for purposes of demanding accommodations under laws such as the ADA, yet claim that deafness is not a disability and thus efforts to cure deafness should cease. The two precepts are not reconcilable.”³⁰⁷

Tucker’s argument is a strong integrationist perspective—society should not be expected to subsidize segregating practices by individuals with disabilities. Her primary argument is financial and shows how financial concerns, rather than egalitarian concerns, can cause integrationist arguments. She acknowledges that “[f]rom a purely altruistic perspective, it might be ideal if Deaf culturists could choose to be deaf and at the same time require society to pay the costs of that choice.”³⁰⁸ Economic realism, however, causes her to conclude that Deaf Culturists must balance their individual needs with societal concerns about expense.

Members of the Deaf Culture community disagree sharply with Tucker because they place a high value on the acquisition of American Sign Language (ASL) as the primary mode of communication for deaf children.³⁰⁹ Segregated schools and classrooms are not an end in themselves. They are a mechanism for deaf children to learn ASL. They dispute the evidence that cochlear implants are successful for young children and argue that ASL is the best option for these children.³¹⁰

Many deaf children, however, face a very difficult situation. They are born to hearing parents who do not speak ASL. During the critical young years when most children learn language, they may be exposed to no natural language—they cannot hear their parents, yet

304 *Id.* (citing Jean L. Johnson et al., *Implementing a Statewide System of Services for Infants and Toddlers with Hearing Disabilities*, 14 SEMINARS IN HEARING 117 (1993)).

305 *Id.* at 33–34.

306 *Id.* at 35.

307 *Id.* at 36.

308 *Id.*

309 *See, e.g.,* Ramsey, *Culture*, *supra* note 301, at 56.

310 “Rather than improving the child’s linguistic situation, implant surgery may prolong the period of time that the deaf child, who is already atypical from a developmental linguistic point of view, lives without access to a language.” Ramsey, *Ethics*, *supra* note 301, at 78; *see* Lane, *supra* note 301, at 295–302; Sparrow, *supra* note 301, at 140–52.

they are also not exposed to ASL at home. They may need an intensive segregated deaf environment in order to develop appropriate language skills.³¹¹ Even assuming that Tucker's statistics are accurate about the cost of educating them in a deaf-only environment, that environment may present them with the only realistic option of developing sufficient linguistic skills to be productive members of society. Tucker offers statistics about short-term costs, overlooking the evidence about comparative long-term results.³¹²

No easy resolution exists in the dispute between Tucker and the Deaf Culture community. Deaf Culture activists argue that Tucker's position is disrespectful of their basic right of self-determination.³¹³ They argue that we would never ask an African-American to undergo surgery to make his life "easier" by becoming white or ask a woman to undergo surgery to make her life "easier" by becoming a man.³¹⁴ Analogizing to arguments by black social workers that black children should preferentially be raised in black households, they argue that deaf children should be educated in households that value Deaf Culture.³¹⁵

Unfortunately, Deaf Culturists have no answer to Tucker's economic arguments. If children who are born deaf could begin to hear by taking one inexpensive pill that caused no negative side effects, would they still insist that society should subsidize the cost of deafness? Could an argument for taking such a pill be made in a way that is respectful of Deaf Culture? From an anti-subordination perspective, the important question would be whether the argument for taking the pill was premised in a degrading view about disability. At present, that possibility is only theoretical. Deaf Culture advocates argue that society has exaggerated the benefits of cochlear implants out of disrespect for the Deaf Culture movement.³¹⁶ An anti-subordination perspective would counsel us to be aware of such potential exaggerations given the anti-disability history of our society.³¹⁷

311 See Ramsey & Padden, *supra* note 301, at 11–13.

312 "The long-term outcomes of implants are not well-understood. Documentation of the primary hoped-for benefit to prelingually deaf children—acquisition of spoken language—is difficult to find in published research." Ramsey, *Ethics*, *supra* note 301, at 85.

313 Tucker herself is deaf but does not subscribe to the tenets of the Deaf Culture movement. See Tucker, *supra* note 303, at 34–36.

314 See Neil Levy, *Reconsidering Cochlear Implants: The Lessons of Martha's Vineyard*, 16 *BIOETHICS* 134, 137–41 (2002).

315 Lane & Grodin, *supra* note 301, at 232–35.

316 See, e.g., Ramsey, *Ethics*, *supra* note 301, at 84.

317 We also should be mindful that individuals within the Deaf Culture movement have also been socialized by society. That socialization could be causing them to exag-

Claire Ramsey offers a respectful framework to consider difficult issues like cochlear implants and ASL instruction for deaf children. She says:

Those of us who work to educate deaf children see them as whole human beings. From this point of view, speech ability and amplified ability to perceive sound are not our dominant goals for deaf children. We know that rich linguistic and intellectual lives do not depend on detection of sound. Like the deaf community, many teachers question the linguistic, social, mental health, and psychological consequences of implants in prelingually deaf children. It is essential that we devote thoughtful, rigorous reflection to the risks and benefits of cochlear implants for prelingually deaf children and that, at the same time, we give respectful attention to the ethical concerns of the deaf community and those who study the linguistic and social implications of early childhood deafness because they are concerned about the quality of a deaf child's entire lifespan.³¹⁸

Ramsey seeks to develop policy that will consider the long-term impact on the child while also valuing the social network in which the child might live. Her approach leaves open the possibility that cochlear implants might be considered the best option for some children, with education in the mainstream classroom, while also respecting the option of a focus on ASL in an intensive deaf-only classroom. That range of possibilities is evident from an anti-subordination perspective that does not presuppose the benefits of integration.

B. Institutionalization Lessons

Attempts to close state institutions entirely may offer insight into how states can go too far in the deinstitutionalization movement. New Hampshire is well known for being the first state to provide services for individuals with developmental disabilities without any use of institutional care.³¹⁹ It went from having 1200 individuals in residential institutions in 1970 to zero individuals in such programs by 1991.³²⁰ The legal action that helped spur this development did not, in fact, insist upon the closure of all state disability-only institutions. The goal was to have fewer than 400 individuals in such institutions, a number

gerate the benefits of their own position. Nonetheless, on balance, I think that problem is unlikely because the dominant social position supports integration rather than segregation.

318 Ramsey, *Ethics*, *supra* note 301, at 85.

319 See Donald Shumway, *Closing Laconia*, in *DEINSTITUTIONALIZATION AND COMMUNITY LIVING* 19, 19 (Jim Mansell & Kent Ericsson eds., 1996).

320 *Id.* at 19-20.

that was thought to be appropriate.³²¹ But when only thirty individuals remained at the only state facility, “the high overhead for the single facility dictated that it ultimately be closed”³²² even though the family members of those individuals had previously objected to community alternatives for those people. No new admissions were made to the state facility in its last five years of existence.³²³ The state reported “very high satisfaction levels” by the families and individuals affected by deinstitutionalization, including the thirty “hold out” families.³²⁴

No critical inquiry is suggested as to whether this complete deinstitutionalization has been a problem for some individuals.³²⁵ The author of the New Hampshire study reports that one ongoing challenge is to “[f]ight hard to keep people from having to return, once placed.”³²⁶ Because the only residential setting has been closed, one must ask—where would they return if community placement fails?

Most of the 1200 New Hampshire citizens who left institutional care probably fared much better in the community settings that became available to them. The increased infusion of funds into programs for these individuals virtually guaranteed some improvement. But this reallocation of funds may be problematic for those who are unlikely to benefit from community settings. Rather than coercing individuals to remain in disability-only institutions so that they have sufficient population to survive, we may be coercing individuals to enter community-based settings so that we can close disability-only institutions. Coercion in either direction is inappropriate.

One deinstitutionalization complication is that the population that was released from state institutions after living there for a long period is not the same as the population that has never lived in an institutional setting. Richard Lamb notes that “[p]ersons who have been hospitalized for long periods have been institutionalized to passivity.”³²⁷ When they are placed in community settings they “tend to stay where they are placed and to accept treatment.”³²⁸ But what he calls the “new generation of severely mentally ill persons” does not

321 *Id.* at 21.

322 *Id.* at 22.

323 *Id.*

324 *Id.* at 25.

325 Similarly, another author describes the New Hampshire experience as nearly perfect. See JULIE ANN RACINO, POLICY, PROGRAM EVALUATION, AND RESEARCH IN DISABILITY 53–71 (1999).

326 Shumway, *supra* note 319, at 27–28.

327 Lamb, *supra* note 148, at 4.

328 *Id.*

have this culture of passivity and finds it difficult to fare well in community settings.³²⁹ Lamb does not argue for returning the mentally ill to “the back wards of state hospitals,” but he does argue that we need to be realistic in some cases and promote a “restricted lifestyle” for some people who are severely mentally ill that will help them enjoy the liberty of staying in the community.³³⁰ He also supports the relaxation of involuntary commitment laws so that states can order outpatient civil commitment rather than commitment to a state mental hospital.³³¹ Finally, he supports the appointment of a conservator for individuals who cannot care for themselves without supervision. The conservator “has the authority to place the conservatee in any setting . . . and to require that he or she participate in psychiatric treatment and take medications in order to remedy or prevent the recurrence of severe disability.”³³² Lamb’s suggestions are inconsistent with a full deinstitutionalization approach but may offer more realistic and effective support for individuals with severe disabilities.

Some states have followed Lamb’s suggestions, whereas others continue to have a very narrow standard for mandatory treatment. The District of Columbia, for example, only permits mandatory treatment when a person is a danger to self or others.³³³ By contrast, Minnesota has developed a sophisticated set of statutes which distinguishes between mandatory inpatient and outpatient treatment and tries to provide both assistance and due process safeguards. In order to receive mandatory *inpatient* treatment, an individual must demonstrate a clear danger to others or the likelihood of physical harm to self or others as demonstrated by:

1. failure to obtain necessary food, clothing, shelter, or medical care as a result of impairment, or
2. inability to obtain necessary food, clothing, shelter or medical care and likely to suffer substantial harm, significant psychiatric deterioration or debilitation, or serious illness, or
3. a recent attempt or threat to harm self or others, or

329 *Id.* at 4–5.

330 *Id.* at 7.

331 *Id.* at 9.

332 *Id.*

333 D.C. CODE ANN. § 21-545(b) (LexisNexis Supp. 2005); *see also* MD. CODE ANN., HEALTH-GEN. § 10-632(e)(2) (LexisNexis 2005); MASS. GEN. LAWS ch. 123, §§ 1, 8 (2004); NEV. REV. STAT. § 433A.310(1) (2005); N.J. STAT. ANN. 30:4-27:10 (West 1997); R.I. GEN. LAWS § 40.1-5-8(j), 40.1-5-2(7)(i) (2006); TENN. CODE ANN. § 33-6-501 (2001) (narrow standards for mandatory treatment). For an excellent overview of state laws, *see* TREATMENT ADVOCACY CTR., STATE STANDARDS FOR ASSISTED TREATMENT (2004), <http://www.psychlaws.org/legalresources/statestandardschart.pdf>.

4. a recent volitional conduct involving significant damage to property.³³⁴

In addition, an individual can obtain mandatory *outpatient* treatment if one of those four factors is present and there is evidence that:

1. manifestations interfere with ability to care for self and, when competent, the individual would choose substantially similar treatment, or
2. the individual has at least two court-ordered hospitalizations in past three years, exhibits symptoms or behaviors that are substantially similar to those precipitating one or more of those hospitalizations, and the individual is reasonably expected to deteriorate to inpatient standard unless treated.³³⁵

These factors are premised on an anti-subordination rather than integrationist perspective because they measure equality on the basis of the quality of an individual's life rather than on integration. These standards may not be perfect and the disability rights community may disagree on their exact formulation. But they place the focus in the right place—trying to provide a sufficient safety net so that individuals with disabilities can live in dignity, whether the setting is community or institution.

C. Voting Alternatives

Individuals with cognitive and emotional impairments and individuals with physical impairments face explicit and subtle barriers to voting. The legal approach has been to remove those barriers so that individuals with disabilities can vote alongside others in public polling places. The legal approach has been governed by the integrationist premise that everyone should vote at a public polling place as a basic act of citizenship.

But what if we abandoned the integration premise and, instead, asked how we could best achieve independent and private voting for individuals with disabilities? Under an anti-subordination approach, we might think about how to bring the polling place to the person rather than how to get the person to the polling place.

The example of individuals who live in nursing homes reflects this problem. Federal voting law has focused on making it possible for individuals with physical or visual impairments to vote in public pol-

³³⁴ MINN. STAT. § 253B.09(1) (2006).

³³⁵ *Id.* § 253 B.02(13)(a), (17), 253 B.065(5)(b). Some other states have similar standards. See, e.g., MONT. CODE ANN. §§ 53-21-126(1), 53-21-127(7) (2005); OR. REV. STAT. § 426.005(1)(d) (2005).

ling places. Success is measured by how many polling places have become accessible and whether technology permits blind voters to vote privately and independently. Meanwhile, voting participation rates by individuals with disabilities have barely changed.³³⁶

One problem is the assumption that integrated public voting is the best solution to the problem of the disenfranchisement of individuals with disabilities. Individuals typically live in nursing homes because they do not have the physical strength or ability to live independently. Many people who live in nursing homes find basic daily activities to be exhausting because they suffer from conditions which involve chronic pain. Accessible voting equipment may make it *possible* for them to vote at a public polling place. Nonetheless, the effort of public voting may also exhaust them so that they have to choose, for example, between voting and a visit with a relative the next day.³³⁷ If we bring voting technology to the nursing home rather than expect the residents of the nursing home to travel to the polling place, we might see a significant increase in voting participation rates by some individuals with disabilities.³³⁸ Their bus ride from the nursing home can also no longer be the basis for identifying them as disabled and excluded from voting.

Not all individuals with disabilities, of course, live in nursing homes. Nonetheless, problems with “getting to polling places” was one of the most common problems cited by individuals with disabilities who have not voted in recent elections.³³⁹ We could explore ways for individuals with disabilities to vote in the privacy of their homes on Election Day through telephone or electronic voting so that they would not have to “get” to the polling place. The disability rights community has appropriately criticized attempts to make individuals

336 Unfortunately, little data exist on disability turnout over time. The available data suggest that turnout rates among individuals with disabilities are fourteen to twenty-one percent below that of the nondisabled population and that recent changes in federal law have not changed those numbers. See Lisa Schur et al., *Enabling Democracy: Disability and Voter Turnout*, 55 POL. RES. Q. 167, 171 (2002).

337 I thank my colleague, Deborah Merritt, for helping me see this point.

338 Further, we might also improve the integrity of their vote. Encouraging the use of absentee balloting may facilitate others to vote on behalf of individuals with disabilities. If voting became possible at the nursing home itself, through private and confidential voting equipment, more individuals with disabilities may be able to cast the ballot of their choice. For discussion of the problems associated with absentee voting for individuals with disabilities, see Karlawish et al., *supra* note 244, at 1347–48.

339 Researchers have found that “getting to polling place” is one of the most common accessibility problems noted by individuals with disabilities who did not vote in recent elections. See Schur et al., *supra* note 336, at 177 (finding 8.8% of the individuals with disabilities in their sample reporting this problem).

with disabilities vote by absentee ballot in advance of elections. Absentee balloting requires additional proactive steps by voters, and forces them to make up their minds before the last crucial days of the election campaign. Some states, however, have devised telephone and computer methods of voting on Election Day that are no more cumbersome than traveling to public polling places. For individuals who suffer from various physical impairments, those methods of voting may even be more convenient than public voting at polling places.

CONCLUSION

We should not assume that the most integrated environment is always the preferable policy in the disability context. Before moving from a segregated to integrated method of delivery of programs or services, we should ask whether there is evidence to support the integrated method over the segregated method.

An example of how such cautiousness might be helpful involves the Special Olympics movement. This program was created in 1962 to provide athletic opportunities for individuals with developmental disabilities.³⁴⁰ It is a classic “segregated” model for delivery of services because the participants compete on teams with others who are also developmentally disabled.³⁴¹ In 2000, a broad survey was completed to attain feedback on the success of the program.³⁴² Participants, their families, and coaches reported high levels of satisfaction with the program.³⁴³ Meanwhile, the Special Olympics had also created a “Unified Sports” program under which disabled and nondisabled individuals could compete together as “partners” in athletic events in furtherance of the “full inclusion” ideal. Disabled participants were supposed to be given a choice of participating in the traditional or integrated program. A 2001 report of that integrated program found that participants were generally very happy with it but that some participants complained that nondisabled partners dominated the activities, and that individuals with disabilities were not given the choice whether to participate in the unified, rather than traditional, Special Olympics programming.³⁴⁴

340 See GARY N. SIPERSTEIN ET AL., A COMPREHENSIVE NATIONAL STUDY OF SPECIAL OLYMPICS PROGRAMS IN THE UNITED STATES 2 (2006), available at http://www.specialolympics.ca/SOC/ref_r_1.pdf.

341 *Id.* at 8–9.

342 *Id.* at 2.

343 *Id.* at 9–14.

344 CTR. FOR SOC. DEV. & EDUC., UNIV. OF MASS. & DEP’T OF SPECIAL EDUC., UNIV. OF UTAH, NATIONAL EVALUATION OF THE SPECIAL OLYMPICS UNIFIED SPORTS PROGRAM 19, 20, 22 (2001), available at <http://www.specialolympics.org> (follow “Initiatives”

These two programs create a choice for the Special Olympics movement. Should it put more emphasis on the Unified Sports program approach so that individuals with disabilities are likely to compete alongside individuals without disabilities? Or should the Unified Sports program approach simply be one choice among many for individuals with disabilities? An anti-subordination approach suggests that the unified approach is not inherently superior but is merely one possible approach among many and should have to be justified in its own right to receive support.³⁴⁵ It is consistent with the anti-subordination model that the Unified Sports program, along with the traditional program, is being rigorously examined. So long as the reports of both programs demonstrate positive results, neither should be abandoned for the sake of an integration (or segregation) principle.

One special challenge in the disability area that is reflected by the Special Olympics/Unified Sports controversy is the use of the “disability” category. Under the traditional model, only individuals who meet certain criteria involving developmental disability may participate.³⁴⁶ In our highly competitive society, in which great emphasis is placed on sports at an early age, the restrictive definition of disability leaves many children who may be mildly disabled, or merely uncoordinated, with few, if any, athletic opportunities because they do not qualify for the Special Olympics. This same problem exists elsewhere in society as only individuals with disabilities are legally entitled to seek accommodations under the ADA. Individuals with physical or mental impairments that do not rise to the legal level of “disability” cannot take advantage of that statutory obligation.³⁴⁷

hyperlink; then follow “Research” hyperlink; then follow “Impact of Special Olympics Programming” hyperlink; then follow “National Evaluation of the Special Olympics Unified Sports Program” hyperlink; then follow “Adobe PDF” hyperlink) (finding 53% of coaches and 43% of family members reporting problems with partner dominance; 29% of families indicating that they did not have a choice regarding unified versus traditional participation in the Special Olympics).

³⁴⁵ For a social construction perspective on this issue, see Mary Ann Devine, *Inclusive Leisure Services and Research: A Consideration of the Use of Social Construction Theory*, 24 J. LEISURABILITY 1, 3, 5 (1997), available at <http://www.lin.ca/resource/lin/html/Vol24/v24n2a2.htm> (suggesting that the Special Olympics may impede inclusion in leisure services for people with mild developmental disabilities).

³⁴⁶ See SPECIAL OLYMPICS OFFICIAL GENERAL RULES § 6.01(d) (2004), available at <http://www.specialolympics.org> (follow “About Us” hyperlink; then follow “Special Olympics General Rules” hyperlink; then follow “General Rules (Adobe PDF document, 724K)” hyperlink) (defining the term “mental retardation”).

³⁴⁷ See 42 U.S.C. § 12102(2) (2000) (defining the term “disability” as it is used throughout the ADA).

The issue of whether policy makers should use a restrictive definition of disability is beyond the scope of this Article. But the restrictive definition puts pressure on the integration/segregation issue. It raises the broader question of what we mean by "integration." Currently, the Special Olympics model, for example, is segregated on the basis of whether an individual is developmentally disabled. The Unified Sports model, by contrast, is integrated with the participants either qualifying as "developmentally disabled" or as "nondisabled partners." But what if the "nondisabled partners" were themselves individuals with physical or mental impairments that did not meet the restrictive definition of "disability" used in the Unified Sports model? Then, the Unified Sports model could become a mechanism for individuals with developmental disabilities along with individuals who have trouble participating in traditional sports programs to gain athletic opportunities. Would that model be considered an "integrated" model or a "segregated" model? That model—whether we call it integrated or segregated—might be the most beneficial because it could meet the needs of individuals with developmental disabilities as well as the needs of individuals who have few athletic opportunities in our competitive society. It also might lessen the problem of "nondisabled partner domination" if the partner is not a typically athletic individual. The integration/segregation dichotomy may cause us not to consider that intermediate option.

The Special Olympics/Unified Sports program is not the only place where a more flexible understanding of the term "integration" might achieve positive benefits. In the educational context, for example, we might seek to integrate individuals who qualify as "disabled" with other individuals who would benefit from more attention and smaller class size but who do not meet the restrictive definition of "disabled." Psychologists, for example, use the term "autism spectrum disorder" to describe individuals who have autism-related impairments.³⁴⁸ They recognize that autism exists along a spectrum, yet our legal definitions insist on individuals either having "autism" or otherwise being "nondisabled." An anti-subordination model could suggest that we might modify a traditional special education classroom for individuals who meet the legal definition of "autism" by making the classroom available to other students who have sensory/social impairments along the autism spectrum but who do not meet the legal definition of "disability." Some might call this approach segregation; others might call it integration. From an anti-subordination

³⁴⁸ See Abigail Sullivan Moore, *Students on the Spectrum*, N.Y. TIMES, Nov. 4, 2006, at 28.

perspective, however, we would simply ask whether it meets the needs of as many students as possible. Is it effective?³⁴⁹

One problem with the anti-subordination approach, one might argue, is that it does not give sufficient attention to the benefits of integration to the nondisabled community. Some might argue that children without disabilities benefit from being exposed to children with disabilities from a young age. The proliferation of special education classrooms in which they do not have contact with such children unless they share a similar impairment might result in more stereotypes (from lack of exposure) of individuals with disabilities. This factor, however, can be part of the anti-subordination model, but it would have to be reframed. The issue would not be whether the nondisabled community benefits from early exposure to individuals with disabilities. The issue would be whether individuals with disabilities benefit from the nondisabled community having early exposure to individuals with disabilities. From an anti-subordination perspective, the issue is not the benefits to the nondisabled community; instead, the issue is the benefit to the historically subordinated group—individuals with disabilities.

Nonetheless, we should not forget that segregation can be problematic. Parents are continuing to bring cases on behalf of their children complaining about the low quality of disability-only education that school districts are seeking to impose on their children. Guardians are continuing to represent individuals with disabilities to oppose their placement in segregated and inhumane disability-only institutions. And people with disabilities continue to object that they are disenfranchised due to the inaccessibility of polling places. Invidious segregating practices continue today. And integration is often the correct response to these practices.

The field of disability studies needs a theory of equality that goes beyond the mantra "separate is inherently unequal." This theory needs to take into account that some guardians are frustrated at the lack of disability-only institutions available to some people with profound disabilities who cannot safely live in the community. It needs to consider that some parents desire their children to have a disability label to secure a space in private disability-only institutions. It needs to respect the request for disability-only educational settings for children with hearing impairments so that they can get a strong foundation in American Sign Language. Finally, it needs to adjust to

³⁴⁹ Some researchers argue that the empirical evidence does not support an integration presumption for children with autism. See, e.g., Bernard Rimland, *Inclusive Education: Right for Some*, 7 *AUTISM RES. REV. INT'L* 3 (1993).

the possibility that public voting will be considered inconvenient and antiquated as voting in the privacy of one's home becomes more feasible.

The mantra "separate is inherently unequal" needs to be replaced with the slogan "invidious segregation is inherently unequal." Unfortunately, this is not a catchy slogan that can spur another *Brown v. Board of Education*. Catchy slogans may facilitate fundraising and even achieve some needed structural reforms. But they may also miscalibrate the balance between equality and justice. The challenge for the disability rights movement is to construct a theory of equality that can safeguard against invidious segregation while promoting new practices that can protect those who need or desire separate disability-only programming or institutions. Rather than celebrate the closing of the last disability-only institution in a state, we should ask what is happening to those in the disability community who need or want such institutions. The measure of equality should be anti-subordination rather than integration for individuals with disabilities.

APP E

CARE FOR THE MENTALLY ILL: WASHINGTON'S CONSTITUTIONAL OBLIGATION

By Hugh Spitzer

State constitutions are distinctly different, in form and substance, from the United States Constitution. Washington's 1889 Constitution was much broader than the national document. And, as in many states, it included positive social service obligations entirely unknown to the federal constitution.

The 1787 federal constitution established a national government with limited powers focused on the areas of defense, international relations, communications and commerce. The Bill of Rights was a list of restraints on the national government, but provided no affirmative rights to receive anything. Although the federal government's activities have steadily grown, nothing in the U.S. Constitution requires Congress to assist specific groups.

State constitutions are quite different. To the surprise of most people, states inherently have more powers than the federal government, which is limited to those activities expressly or impliedly granted by the U.S. Constitution. A state can do anything except that which is expressly prohibited to it by the national constitution or by its own constitution. Consequently, state constitutions tend to have stronger declarations of rights and stronger controls on the legislature and executive.

Like many state constitution's, Washington's also includes positive rights and obligations. Article 9 provides that it is the "paramount duty of the state to make ample provisions for the education of all children." Article 2, Section 35, requires the legislature to pass laws to protect workers in hazardous workplaces, and Article 10, Section 3 requires a home for disable veterans.

One of the most important constitutional directives to the legislature is in Article 13, Section 1, which requires:

"[Institutions] for the benefit of youth who are blind or deaf or otherwise disabled; for persons who are mentally ill or developmentally disabled...shall be fostered and supported by the state, subject to such regulations as may be provided by law...."

The 1889 version spoke in terms of required institutions for "the insane or idiotic", and the language was modernized in 1988 with the active help of Secretary of State Ralph Munro, among others. But the basic idea is the same: The state government has an obligation to provide adequate care for those who are mentally ill or developmentally disabled.

Horace Mann and the Institutions Movement

The origin of this state constitutional language goes back to the 1830's, when Horace Mann, a Massachusetts lawyer-legislator, sparked consecutive struggles for state mental asylums, for modern "reformatories" and for free public schools. The underlying idea was that the community, through state government, could improve society by fostering institutions for those in need. Starting in New England, laws and constitutional language mandating adequate institutions and schools spread across the country. By 1860, 28 of 33 states had built public institutions for the insane. Institutions in Washington State

Dan Okada, a student of mine at the U.W. Law School, recently completed a thoughtful study of Washington State's constitutional obligation to provide institutions for the mentally ill. He notes that the Territorial Legislature in 1862 contracted with the Sisters of Charity (now the Sisters of Providence) for the care of mentally disabled persons, but the arrangement fell apart over financial disputes. Care continued, to be spotty, but the contract system was not abolished until 1875 due to lobbying by physicians and advocates associated with mental health crusader Dorothea Dix. Land for a mental hospital at Steilacoom had been purchased in 1871, but a permanent hospital was not erected until 1886-87.

Thus there was an established history of state care for the mentally disabled by the time the 1889 state constitutional convention inserted an affirmative requirement for their care. The number of institutions grew until the 1970's, when another "reform" movement placed many mentally disabled people back in the community

at large. For a 1973 law school class: legislation, I tracked the bill that m involuntary commitment of the mentally immensely more difficult. I remem representatives of state government insisting: people who previously had been sent to me: hospitals would receive improved care community-based institutions.

The Constitution's Mandate Today

Although many of those local facilities ha been built, some have asserted that the state not met its obligation to adequately care for mentally ill and disabled. In his paper, N Okada argues: (1) the state constitutio: mandate of that care has its origin in the sa historical movement that brought us free pu: schools; (2) the Washington Supreme Court 1978 held that the state constitution requirement of ample support meant that : legislature must increase state funding for : common schools; (3) although the "foster a support" language of the mental disability ca provision is not as strong as the "ample suppo language for education, the two are simi enough that someone might launch an effecti legal challenge to force an increase in fundi for community-based facilities for the menta ill and disabled.

Dan Okada's paper gives us something think about, and it also illustrates the spec nature of state constitutions and their role the development of adequate institutions for c statewide communities.

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AN ANALYSIS OF ARTICLE XIII OF THE WASHINGTON STATE
CONSTITUTION: WHAT DUTIES DOES THE ARTICLE IMPOSE ON
WASHINGTON TO CARE FOR ITS MENTALLY ILL?

By: Dan Okada

"It has been wisely said that nations are seldom impoverished by their charities. The provisions, made by a nation, or community, for the care of those whom misfortune has rendered incapable of taking care of themselves, and who make no substantial return for the benefits conferred upon them, may be considered an index to their degree of civilization. A heavy tax is levied yearly upon the industry of the people of the territory, for the support of our insane, and be it to their honor said, it is paid out undgrudgingly, because their hearts go out in sympathy toward these poor unfortunates."

*From the introduction of A Supplement to the Late
Asylum Controversy by the Medical Society of
Washington Territory.*

Many changes in the field of psychiatry have taken place since Washington adopted its constitution in 1889. In the middle to late 1800's the prevailing view among psychiatrists was that institutionalization was the most effective treatment for the mentally ill. Article XIII was adopted in the midst of this movement.

As trends in the treatment of the mentally ill have shifted the focus from the use of institutions to community based care, Article XIII's language has retained the focus on the use of institutions. However, in examining the history, language and framer's intent of Article XIII, the scope of Article XIII may go beyond the buildings of the institutions. What is significant is the emphasis on caring for the mentally disabled that Article XIII imposes on the state. This duty on the state to care for its mentally ill has many practical effects today relating especially to issues of access to treatment.

I. ORIGINS OF CARE FOR THE MENTALLY ILL

A. The rise and fall of the mental institution in the United States

In the mid 1800's the use of asylums to care for the mentally ill became predominant throughout most of the United States.¹ It was generally believed by most physicians of the period that insanity was a curable ailment and that asylums were the most effective form of treatment.² Claims of almost 90% effectiveness of treatment were not uncommon, and crusaders for the use of asylums used these exaggerated claims to generate public support for erecting more institutions.³ By 1860, twenty-eight of the thirty-three states had built public institutions for the insane.⁴

This movement toward state-sponsored asylums represented a remarkable leap forward for the care of the mentally ill. Prior to this time, they were treated with little compassion, and often with cruelty.⁵ The rise in the belief in institutions, as a cure for mental illness, that developed in the mid-nineteenth century changed this situation.⁶ Old notions that "once insane, always insane" were replaced by the new dogma that insanity is the

¹ See David J. Rothman, *The Discovery of the Asylum: Social Disorder in the New Republic* 130 (1990).

² *Id.* at 131.

³ *Id.* at 132.

⁴ *Id.* at 130.

⁵ See Albert Deutsch, *The Mentally Ill in America: A History of Their Care and Treatment From Colonial Times* 495 (1937) (Describing the history of care for the mentally ill in the United States. Early in America's history, the mentally ill were believed to be possessed and elaborate rites were performed to drive the spirits out. Blood letting was another common treatment technique designed to cool fevered brains. The first public institutions provided for the mentally ill were prisons or almshouses where conditions were often harsh and even brutal. The mentally ill were often auctioned off as labor like common chattel.)

⁶ *Id.* at 133.

most curable of all diseases.⁷ The first concrete manifestation of this movement was the opening of the State Lunatic Hospital at Worcester, in Massachusetts.⁸ The development of the hospital resulting from a stirring plea by progressive reformer Horace Mann to the Massachusetts legislature that "the insane are the wards of the state."⁹

Even more prominent than Horace Mann as a reformer and crusader for mental institutions was Dorothea Dix. Credited with being directly responsible for the founding or enlarging of thirty-two mental hospitals in the United States and abroad, Ms. Dix was a tireless proponent of state mental institutions.¹⁰ Taking a view that society causes mental illness and therefore society should take responsibility for its treatment, Ms. Dix addressed state legislatures, demanding: "Should not society, then, make the compensation which alone can be made for these disastrous fruits of its social organization."¹¹ Her formula for getting states to act and build institutions was simple and repeated everywhere she traveled.¹² First she would assert the curability of insanity, link the cure to the proper institutional care, and finally quote prevailing medical opinion on the rates of recovery.¹³ Her record of success with this formula speaks for itself.

This golden age of faith in the treatment powers of mental institutions was not long lasting, and by the latter part of the 1800's most of the optimism

⁷ Id.

⁸ Id. at 137.

⁹ Id.

¹⁰ Id. at 184.

¹¹ Rothman, *supra* note 1, at 128-129.

¹² Id. at 132.

associated with mental institutions was lost.¹⁴ The claims of ninety percent success rates for the cure of the mentally ill were found to have been grossly over-inflated.¹⁵ Also, the number of mentally ill needing treatment continued to vastly overwhelm the capacity of state mental institutions.¹⁶ The result was a system of state mental institutions that no longer held the promise of cure for the mentally ill, but instead, confinement.

B. The History of Mental Institutions in Washington State

The development of mental health institutions in Washington corresponded with rise of asylums experienced throughout the United States. From its early territorial days, Washington had to contend with the problem of mentally ill people. The Territorial Legislature responded in 1860 with the passage of a law "Relating to Idiots and Insane Persons."¹⁷ This Act delegated to the counties the duty to care for mentally ill people.¹⁸ Problems arose when the cost for such care became a burden upon counties. For example, in 1854, the first case of a mentally ill person was recorded in Seattle. A sailor, Edward Moore, was found partially frozen, disoriented and wandering on the beach outside of town.¹⁹ The people of King County, numbering around 170, attempted to care for the sailor. The cost of the care amounted to \$1659 which

¹³ Id.

¹⁴ Id. at 265.

¹⁵ See Deutsch, *supra* note 5, at 155-156. (In records from asylums at the time, forty people were reported to have been cured 484 times, averaging twelve recoveries each.)

¹⁶ See Id. at 232. (Table showing the estimated number of insane in the United States was greater the number of insane in hospitals and asylums.)

¹⁷ See Territory of Washington, *Laws of Washington Territory 1857-1860*. 230-234 (1860).

¹⁸ Id. (Relatives were to have primary responsibility for support. However, when relatives lacked sufficient funds, the county treasury was to make up for any shortfalls.)

¹⁹ William H. Cochran, *Washington's State Institutions* 69 (1915).

the county asked the state to reimburse.²⁰ Not surprisingly, the Territorial government rejected the request, as the amount requested exceeded the total government revenue for the entire year.²¹ The Territorial government did resolve to request from Congress funds to establish a marine hospital in which an asylum for the insane could be included.²²

As the territory continued to grow, the need to deal with the mentally ill became greater. The counties began to demand that the Territory begin to share the burden of providing for the mentally ill.²³ Requests to the U.S. Congress by the Territorial legislature for funds were denied, so the Territory was forced to take action on its own.²⁴

In 1862, the legislature took the first concrete steps for the Territory to care for the mentally ill. At the time, a territorial asylum was considered beyond the means of the Territorial government so a contract system of care was developed.²⁵ The first such contract was made with the Sisters of Charity (now the Sisters of Providence) for the care, safe-keeping and medical

²⁰ Russel Hollander, *The Development of Human Services in Washington 1853-1932 in A Shared Experience: A History of Washington State's Human Services from Territorial Days to the Present 2* (Sisters of Providence et al. eds. 1989).

²¹ *Id.*; see also Cochran *supra* note 19, at 70 (quoting the House of Representatives Committee on Claims report on King County's request "...your committee is under the opinion that, although, the case is one that should touch all the finer feelings of our nature, yet, upon mature consideration, it is believed to be impolitic for this legislature at this early date of our territorial existence, as well as under this present aspect of affairs, to pass a law for the relief of those interested, because it would be setting a precedent that would, if carried out, bring a heavy burden of taxation upon the people of the territory.")

²² See Territory of Washington, *Laws of Washington Territory 1855-1856* 33 (1861).

²³ See Hollander, *supra* note 20, at 2.

²⁴ *Id.* (The reason for the territorial legislature's request was that it was not Washington's fault if settlers arrived insane to the territory or became insane prior to establishing a permanent residence. Thus, the United States should bear the cost to confine such people.)

²⁵ *Id.* at 3.

treatment of the insane.²⁶ The Territory committed itself to pay for the expenses, in all cases, for those people residing in Washington who were unable to pay for their care and treatment.²⁷ This arrangement fell apart when it came time for the Territory to pay the Sisters.²⁸ The reason for this was that the Sister's bill for the care of the patients exceeded the Territory's ability to pay.²⁹ The next contract was given to businessmen to handle.

This system of contracting out for the care of the mentally ill came under increasing attack. It was thought to be open to abuse by contractors who might be more concerned with profits than the well being of the mentally ill.³⁰ This fear was borne out when representatives of Dorothea Dix inspected Washington's facility for the mentally ill and found that patients lived in unsanitary and inhumane conditions.³¹ In 1871, the territory purchased an abandoned army base, Fort Steilacoom, to be a permanent asylum for the insane, but continued with the contract system.³² It wasn't until 1875 that the contract system was abolished, after complaints of poor

²⁶ Id.

²⁷ Id. at 4.

²⁸ Id. at 3. (After the first year, the Sisters were owed \$1351.78 which greatly surpassed the balance of the territorial treasury. When the legislature finally began to make payments to the Sisters in 1864, it was made with greenbacks, a currency that was worth only half of its face value in Washington.)

²⁹ Id.

³⁰ Gov. Moore, *Message to the Legislative Assembly of Washington Territory of 1867*, reprinted in *Medical Society of Washington Territory, A Supplement to the late asylum controversy, by members of the Medical Society of Washington Territory 5 (1875)* ("I would specially call your attention to the importance of making some different provision for our insane and idiotic. The present system of providing for the care of this class of unfortunates by contract let to the lowest bidder, is wrong in principle and cruel in practice.")

³¹ See Hollander, *supra* note 20, at 3. (Such reports horrified the territorial legislature not only due to the treatment of the mentally ill, but also because such reports could discourage settlement in Washington.)

³² Id. at 6. (The site is now the current location of Western State Hospital.)

living conditions and brutality were made by physicians working at the asylum, as well as lobbying from the Medical Society of Washington.³³ It was replaced by a system putting the asylum under direct state management run under the supervision of a competent physician director who would be recommended by the governor and approved by the legislature.³⁴

In 1886-87, the institution was expanded and a more permanent hospital erected at the Fort Steilacoom site. It is significant to note that the cost of the improvements to the facility amounted to nearly two-thirds of the total territorial budget for 1885-1887.³⁵ The new hospital for the mentally ill was opened in December of 1887, two years before Washington was officially granted statehood.

In time, two other state institutions for the mentally ill were built. Northern State Hospital was built to handle the overcrowding conditions at the Fort Steilacoom facility and to provide a facility for patients who would be benefited by an outdoor environment.³⁶ In 1888, Eastern State Hospital was constructed at Medical Lake to provide a mental institution for the east side of the state.³⁷

³³ *Id.*

³⁴ *Id.*

³⁵ *Id.*

³⁶ See Cochran, *supra* note 19, at 12.

³⁷ *Id.* at 45.

II. WASHINGTON CONSTITUTION - ARTICLE XIII

A. Background

The Enabling Act for the Washington Constitution contains no requirement for the state to provide institutions for people suffering from mental illness. The only reference is contained in section 17 which grants two hundred thousand acres of land for State charitable, educational, penal, and reformatory institutions.³⁸

B. The Origins of Article XIII, Section 1: Educational, Reformatory and Penal Institutions

Article XIII, § 1 of the Washington State Constitution provides:

Educational, reformatory, and penal institutions; those for the benefit of youth who are blind or deaf or otherwise disabled; for persons who are mentally ill or developmentally disabled; and such other institutions as the public good may require, shall be fostered and supported by the state, subject to such regulations as may be provided by law....

The original language of the provision was amended in 1988. Amendment 83 modernized the original text of the Constitution by exchanging the archaic language "...blind, deaf, dumb, or otherwise defective youth; for the insane or idiotic..." with "...youth who are blind, deaf or otherwise disabled; for persons who are mentally ill or developmentally disabled...."³⁹ The vote to pass the 1988 resolution was unanimous in both the House of Representatives and the

³⁸ Enabling Act, § 17, 25 Stat. 679 (1889).

³⁹ See Office of the Secretary of State, *House Joint Resolution 4231: Proposed Constitutional Amendment*, 1988 Voter and Candidates Pamphlet 14 (Statement supporting House Joint Resolution 4231 says the reason for the change is to update language that reflected past prejudice and ignorance. The change would treat everyone with the respect they deserve and would not result in any change in policy. No one could be found to write a statement against the amendment.)

Senate. The change in language was characterized as not imposing any substantive change to Article XIII.⁴⁰

An earlier draft Constitution of 1878, referred to as the Walla Walla Constitution, contained the same language in its Article XIV.⁴¹ The only difference is that in the final 1889 version of the Constitution, the seat of government provision was separated out from the provision for institutions.

Article XIII was not controversial, and was passed by an overwhelming vote of 67 to 1 on August 8, 1889 of the Constitutional Convention.⁴² The only action taken on the Article was to reject an additional section recommended by the Committee for State Institutions and Public Buildings that provided that all future public institutions be located at the seat of government.⁴³

The wording of Article XIII came from similar language in the Ohio and Colorado Constitutions.⁴⁴ It is interesting to note that Ohio and Colorado, as well as Washington, drafted constitutions during the period when the belief of success in mental institutions was the highest in the United States. Ohio's first Constitution was written in 1802 and contained no

⁴⁰ See Journal of the Senate 1988 1140. (The point of inquiry by Senator Nelson asks the mover of the amendment, Senator Halsan, whether the amendment would increase or decrease the level of the state's responsibility in the area. Senator Halsan answered that the amendment was in keeping with the original intention of the resolution and nothing more than the updating of old language.)

⁴¹ Draft Constitution of 1872, in 10 William F. Swindler *Sources and Documents of United States Constitutions* 265 (1979).

⁴² See Beverly P. Rosenow, ed., *The Journal of the Washington State Constitutional Convention 1889, with Analytical Index by Quentin Shipley Smith* 774 (1962).

⁴³ Id. at 773.

⁴⁴ Id.

provision for the state to provide institutions for the mentally ill.⁴⁵ However, when the Ohio Constitution was rewritten in 1851, an Article was added that required the state to support and foster institutions for the insane.⁴⁶

Colorado's Constitution was written in 1876, which fits into the period of expansion of asylums in the mid-1800's, and contains a provision to provide institutions.⁴⁷

The language in Article VII § 1 of the Ohio State Constitution states that "(i)nsitutions for the benefit of the insane, blind, and deaf and dumb shall always be fostered and supported by the state; and be subject to such regulations as may be prescribed by the general assembly." Similarly, the language of Article 8 § 1 of the Colorado Constitution provides that "(e)ducational, reformatory and penal institutions, and those for the benefit of insane, blind, deaf and mute, and such other institutions as the public good may require, shall be established and supported by the state, in such manner as may be prescribed by law." The framers of the Washington State Constitution took language from both Ohio and Colorado in drafting Article XIII.⁴⁸

C. The Meaning of Article XIII

1. "Shall be Fostered and Supported by the State"

Understanding the "shall be fostered and supported by the state" language in Article XIII is important in determining the state's duty to care for

⁴⁵ See 7 Swindler, *supra* n. 41 at 547-556.

⁴⁶ Id. at 566.

⁴⁷ See 2 Swindler, *supra* n. 41 at 79.

the mentally ill. The Washington State Supreme Court addressed this issue in State v. Pierce County, 132 Wash 155, 131 Pac. 744 (1917)⁴⁹. The case was brought in response to a law passed by the legislature in 1923 requiring counties to pay the cost of non-dangerous indigent mentally ill people confined to state mental institutions.⁵⁰

The State Supreme Court held that Article XIII was not restrictive and that it was in the legislature's prerogative to limit who is admitted to state mental institutions, as well as who is to pay for the care.⁵¹ The court's rationale was that the clause following the "support and foster" language allowed the legislature to make such limitations.⁵² That language states "...subject to such regulations as may be provided by law...." The court's interpretation of this language was that such regulations could take the form of requiring the counties to pay the state for the care of its harmless insane.⁵³

To support its position, the court examined how other states had treated similar language in their constitutions. The court first looked at an Ohio court decision which stated that the constitutional provision was not self-executing and therefore the method in which insane asylums are to be

⁴⁸ See Rosenow, *supra* n. 42 at 774.

⁴⁹ See State v. Pierce County, 132 Wash. 155, 231 P. 801 (1925).

⁵⁰Id. at 156.

⁵¹ Id. at 158. ("It must be that the Constitution would allow the Legislature to determine the sort and nature of insanity of which the state should confine a patient and render him maintenance and treatment.")

⁵² Id.

⁵³ Id. ("If fostering and support by the state is subject to regulation of the Legislature, it would seem clearly to follow that that regulation may take the form it did in chapter 145 of providing that each county shall pay the expense of the care of its harmless insane.")

fostered and supported was left to the discretion of the legislature.⁵⁴ Second, the court looked at a North Dakota case dealing with a provision to fund institutions for the feeble minded.⁵⁵ Here, the court cited the North Dakota case *State ex rel McCue v. Lewis*⁵⁶ holding that the legislature has the power to have the counties pay for part or for the entire maintenance of such institutions.⁵⁷ Finally, the court looked at a Kansas case interpreting a Kansas constitutional provision similar to the Washington State provision. The Kansas court held that the legislature could compel the estates of persons committed to insane hospitals to pay for the cost of the maintenance of such persons.⁵⁸

The Washington Supreme Court revisited the issue in the 1978 case of *Duffy v. State Department of Social and Health Services*.⁵⁹ However, in reaffirming that the legislature is not required to provide all the funds to support mental health institutions, the court provided no additional reasoning and merely cited to the Pierce County case.⁶⁰

2. A New Look at Article XIII

Unless Article XIII is to be considered merely advisory language in the state constitution, it must impose some level of duty or responsibility on the

⁵⁴ Id. (The Ohio court going further to say "(i)nstitution is fostered and supported by the state, notwithstanding the requirement that those able to support and liable for the support of a patient committed there to be required to contribute to such expense, and that where such conditions do not obtain the county from which the patient is committed be required to do so.....")

⁵⁵ Id. at 159.

⁵⁶ *State ex re. McCue v. Lewis*, 18 N.D. 125, 119 N.W. 1037

⁵⁷ Id.

⁵⁸ See *Pierce County*, *supra* note 42, at 160.

⁵⁹ *Duffy v. State Department of Social and Health Services*, 90 Wn.2d. 673, 585 P.2d 470 (1978).

state. To assert that the "subject to such regulations as may be provided by law" language allows the legislature unfettered discretion in its providing for mental institutions, could render the article worthless. The legislature might, through the power to regulate who can be admitted into mental institutions, discontinue any further service and avoid any responsibility to care for the mentally ill. If the Washington Constitution's framers had intended to allow the legislature such discretion, it could have used the term "may be fostered and supported" in place of the "shall be fostered and supported" language they chose to use.

Under Article 1 § 29, provisions of the Washington State Constitution are to be considered mandatory unless by express words they are declared to be otherwise.⁶¹ In *Seattle School District v. State*,⁶² the Washington State Supreme Court, in 1978, discussed the meaning of this provision in relation to the constitution's requirements to support schools. In that case, the court found that where language in the constitution was clear, and there is no language expressly declaring otherwise, it must be assumed that the provision is mandatory.⁶³ The court went on to find the provisions of Article 9, § 1 of

⁶⁰ Id. at 677.

⁶¹ Washington Constitution Article 1 § 29.

⁶² *Seattle School District No. 1 of King County v. State*, 90 Wn.2d 476, 585 P.2d 71 (1978).

⁶³ See Id. at 85. See also n. 5 at 86. (The court saying that some interesting light is shed upon this provision from statements by Theodore Stiles, a member of the constitutional convention and one of the first justices of the state supreme court, in IV Wash.Hist. Q. 281, 286 (1913). "There have been some excellent provisions in the Constitution from which the people have had no benefit, because they depend for operation upon action by the legislature, and that body has neglected to do its duty in the premises. Considering that by section 29 of the first article every direction contained in the constitution is mandatory unless expressly declared to be otherwise, it is at least surprising that in some instances no attempt has been made whatsoever to set these provisions at their legitimate work.")

the state constitution to be mandatory and judicially enforceable upon the legislature.⁶⁴

If the provision that the state must "support and foster" institutions for the mentally ill is mandatory, the next step is in determining what those terms require. In the Seattle School District case, the court dealt with similarly ambiguous language when it was deciding what it meant when the legislature had to make "ample provision" for the education of children.⁶⁵ In that case, the state supreme court upheld the lower court's definition of the terms "ample provision." The court chose not to deal definitively with the terms, but rather to treat them as guidelines for the legislature to meet its constitutional mandate.⁶⁶

"As used in Const. Art. 9, sec. 1 the word 'ample' (amply) means liberal, unrestrained, without parsimony, full, sufficient....the word 'provision' (provide) means preparation, measures taken beforehand; for the supply of wants; measures taken for future exigency."⁶⁷

In doing so, the court accepted the broad definitions of the terms as provided by the trial court.

Applying a similar analysis, "foster" carries the meaning: "to promote the growth or development of."⁶⁸ The term "support" has two different meanings which are significant. The first meaning is "to uphold by aid,

⁶⁴ Washington Constitution Art. IX, § 1 ("It is the paramount duty of the state to make ample provision for the education for the education of all children residing within its borders....")

⁶⁵ See Seattle School District, *supra* n. 55 at 514-516.

⁶⁶ Id. at 515. ("Rather these...terms are treated as guidelines for giving the Legislature the greatest possible latitude to participate in the full implementation of the constitutional mandate.")

⁶⁷ Id. at 516.

⁶⁸ Webster's 3rd New International Dictionary (3d ed. 1981).

countenance, or adherence; actively promote the interest or cause of.”⁶⁹ On the other hand, “support” can also mean “to provide means, force or strength that is secondary; backup.”⁷⁰ Depending upon which definition of “support” is used, Article XIII can require different obligations. If the second definition is used, it would follow that the state need not be the primary provider for mental health care. Rather, it would only need to provide some sort of secondary assistance to meet its obligations. However, if the first definition is followed, “support” seems to require the state to take a more active and primary role in providing for institutions. The first definition of “support” seems more in line with the history of mental institutions in Washington State. All the early mental institutions in Washington were funded solely by the state.⁷¹ Thus, “foster and support” should be viewed in its more expansive and burdensome meaning to require the state to take primary responsibility of mental institutions.

III. CURRENT CARE IN WASHINGTON FOR THE MENTALLY ILL

A. The shift toward community care

In 1989, Washington State decentralized state control of mental health care and changed to a system of Regional Support Networks (RSN) through which counties would take charge to care for the mentally ill.⁷² Funding is

⁶⁹ Id. at .

⁷⁰ Id.

⁷¹ See Cochran, *supra* n. 19, at 75. (Giving figures showing that the state had paid the total costs of all the mentally ill people sent to Western State.)

⁷² See RCW 71.24.300 (1996).

primarily through federal Medicaid dollars that are matched by state funds.⁷³ The counties pay only a small percent of the total budget for mental health services.⁷⁴ Using federal and state funds, the counties are required to treat all Medicaid qualified applicants, and with any leftover money may treat those indigent persons who are not covered by Medicaid.⁷⁵

The counties are expected to treat the majority of mentally ill people within the county. The state permits only a small percentage of mentally ill to be transferred from each county to the state's two remaining mental institutions, Western or Eastern State.⁷⁶ Each county must determine a risk pool of people to determine how many may be committed in the next year.⁷⁷ Since the state pays all the expenses of caring for the mentally ill at the state institutions, one financial concern for the state is that counties not dump patients at the institutions. To prevent this, counties are charged \$10,000/day for everyday they have committed a person above their risk pool allotment.⁷⁸

B. Concerns with the system

The primary concerns with this system, as they relate to Article XIII, are 1) the level of care for non-Medicaid poor people in need of mental health services, 2) the limitation on the number of people that may be placed in mental institutions, and 3) the state's overall ability to care for its mentally ill.

⁷³ Interview with Jackie McClean, Assistant Manager of the King County Mental Health Division, on 5-23-97.

⁷⁴ Id. (In King County in 1997, the county contributed ~\$200,000 to a \$75 million budget.)

⁷⁵ Id. See also Medicaid Eligibility, 42 C.F.R. § 435 (1996).

⁷⁶ McClean, *supra* n. 73.

⁷⁷ Id. (In King County, the risk pool number is 273 people. As of 5-23-97, the county has 250 people getting treatment at Western State.)

1. Non-Medicaid individuals

The care counties can provide for non-Medicaid individuals is limited to the amount of funds remaining once all Medicaid patients have received treatment. As funds for mental health shrink, the non-Medicaid individuals are the first denied mental health care even if they would benefit substantially from care and treatment.⁷⁹ When mental institutions were first opened in Washington, these people would have been able to receive care in the state institutions at state expense. To deny them coverage now, just because the legislature has decided to shift mental health care from institutions to communities, seems to be, at best, an effective way for the state to reduce its financial responsibility to care for the mentally ill.

2. Limitations on the Institutional Care

Perhaps a more blatant violation of Article XIII is the state's restrictions on the number of mentally ill people that who are allowed to admitted to the state's mental institutions. There seems little constitutional basis for the state to restrict the number of people who can be admitted into the state's mental institutions. Article XIII clearly requires the state to support and foster such institutions, whether they are large "traditional" asylums or smaller community based institutions. To allow the state to severely curtail the

⁷⁸ Interview with Patty Alvord, Department of Social and Health Services Sr. Budget Program Specialist, 5-26-97.

⁷⁹See McClean, *supra* n. 66. (In King County last year, the county was able to service ~8000 non-Medicaid people who were well below the poverty level. That number will decrease next year due to lack of state and federal funds. At present, it is difficult to determine how many people are turned away from mental health care providers. King County does not keep such records, but is planning on doing so in the near future.)

number of people that could benefit from mental institutions in effect allows the state to render Article XIII altogether ineffective.

3. Overall State Care

With the decline of the use of institutions to treat the mentally ill, there is a question of whether Article XIII, as it relates to mental institutions, still acts a requirement to care for the mentally ill. In the Seattle School District funding case, the court made it clear that constitutional provisions must be adapted for modern times.⁸⁸ Therefore, while we may have the traditional concept of mental institutions as being the grand asylums of the past, it may now be necessary to create a new definition of "institutions." This new definition could incorporate the new Regional Support Networks as a system to care for the mentally ill. This would fit under the intent of the framers to provide adequate funding to care for the mentally in Washington, while providing an approach to care that is consistent with modern treatment theories.

IV. CONCLUSION

From territorial days, the people of Washington Territory and Washington State have been concerned with the treatment and care of the mentally ill within its borders. The first human services offered by the territory were for the care of the mentally ill, and that care consumed the

⁸⁸ See Seattle School District, *supra* n. 55 at 516-517. ("We must interpret the constitution in accordance with the demands of modern society or it will be in constant danger of becoming

largest proportion of the state budget. Article XIII reflected the state's commitment to care by requiring that institutions for the mentally ill be fostered and supported.

At the time the Washington State Constitution was drafted, the use of institutions to cure the mentally ill was accepted throughout the United States. Centralized institutions were considered the best and most effective way to care for and treat the mentally ill. It is no surprise, therefore, that the constitution reflected the framer's best intentions of the time to care for the mentally ill by fostering and supporting the institutions.

While the belief in and use of large institutions have diminished, the purpose of Article XIII remains. As the state shifts more of the burden of care for the mentally ill to the counties, and the counties handle that burden through the use of managed care providers, it is important to recognize the continuing obligation that Article XIII demands of the state. The fostering and supporting of mental institutions was meant to care for all the citizens of the state who were mentally ill, or at the very least, those mentally ill who lacked the funds to provide for their own care. Article XIII is still a mandatory provision of the constitution, and should be used as a safeguard to protect the care and treatment of the Washington's mentally ill population.

atrophied and, in fact, may even lose its original meaning....In short, the constitution was not intended to be a static document incapable of coping with changing times.")

APP F

Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research

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Abstract

A review of the literature on cost comparisons between community settings and institutions for persons with mental retardation and developmental disabilities was conducted. We selected literature for review that was published in peer-reviewed journals and had either been cited in the area of cost comparisons or provided a novel approach to the area. Methodological problems were identified in most studies reviewed, although recent research employing multivariate methods promises to bring clarity to this research area. Findings do not support the unqualified position that community settings are less expensive than are institutions and suggest that staffing issues play a major role in any cost differences that are identified. Implications are discussed in light of the findings.

The significant growth of community-based services has given rise to a dramatic shift in how services, especially residential services, are provided to people with mental retardation. As community-based services have expanded relative to institutions, aspects of costs, efficiency, and outcomes have grown in importance to practitioners, policy makers, and researchers (Braddock, Hemp, & Howes, 1986, 1987; Braddock, Hemp, & Fujiura, 1987; Campbell & Heal, 1995; Felce, 1994; Harrington & Swan, 1990; Mitchell, Braddock, & Hemp, 1990; Murphy & Dattel, 1976; Nerney & Conley, 1992; Rhoades & Altman, 2001; Stancliffe & Lakin, 1998). Despite the reduction in the number and size of large facilities that accompanied the increase in community-based residential services, large facilities are still with us. Tracking of facility trends shows that there are still more than 250 facilities nationwide with 16 or more beds serving nearly 48,000 individuals, 80% of whom are classified as having either severe or profound mental retardation (Prouty, Smith, & Lakin, 2001; Lakin, Prouty, Polister, & Kwak, 2001; Smith, Polister, Prouty, Bruininks, & Lakin, 2001). According to Polister, Smith, Prouty, and Lakin (2001), of the state-run facilities with 16 or more beds, 113 of them (nearly 60%) serve 150 or more individuals.

Several factors underlie the continued use of large facilities, including the institutional bias produced by the entitlements in federal Medicaid programs along with the pace of community expansion and the characteristics of the individuals themselves. For example, although community residential settings with 15 or fewer residents now number nearly 120,000 nationwide, waiting lists continue to grow and are a concern for policy makers and service providers. In studies of waiting lists, Davis, Abeson, and Lloyd (1997) and Lakin (1996) found between 52,000 and 87,000 individuals waiting for residential services, and nearly 65,000 were waiting for day programs. Overall, Davis et al. reported that 218,186 people were waiting for *any* type of services. Emerson (1999) has identified the same problem in the United Kingdom. Thus, the demand for community services for people with mental retardation and related developmental disabilities (MR/DD) has grown faster than the capacity of states to expand or create new community-based services.

The characteristics of individuals remaining in institutional facilities has also changed. Individuals still in institutions tend to be older and have more problems in daily living skills and in walking independently (Prouty et al., 2001). Although challenging behaviors are observed in both institutional

and community settings, more individuals remaining in large settings present challenging behaviors (Borthwick-Duffy, 1994; Bruininks, Olson, Larson, & Lakin, 1994). On average, about 47% of residents of large state facilities are reported to have behavior disorders, a statistic that has slowly increased since the late 1980s, from around 40%.

Although many have argued that institutions cost more than community settings (e.g., Heal, 1987), others have reported minimal cost differences (e.g., Schalock & Fredericks, 1990) or differences that favor institutions (e.g., Emerson et al., 2000). These different outcomes arise from the inherent complexities of research in this area, which is characterized by a heterogeneous population, complex funding strategies, methodological challenges, and substantial variability (cf. Butterfield, 1987).

Because a diversity of viewpoints exists, and because both settings are likely to coexist for some time, it is reasonable to review research in which investigators have examined the costs of these service models. This research area is rich in complexity and, although policy reports on costs and expenditures have appeared (e.g., Braddock, Fujiura, Hemp, Mitchell, & Bachelder, 1991; Braddock, Hemp, & Fujiura, 1987; Harrington & Swan, 1990; LeBlanc, Tonner, & Harrington, 2000), few reviewers of the cost literature have critically examined methodological elements of the available cost-comparison studies. This has added to the difficulty in drawing firm conclusions.

Although recent literature in this area has, to some extent, included evaluation of outcomes in addition to service costs, our primary focus in this article is on research in which costs were compared. This is not to denigrate the importance of outcomes; rather, our focus reflects the limitations of a single paper as well as the reality that although government officials and service elements typically desire to take quality and outcomes into account when planning programs, legislators often respond more directly to cost issues in funding decisions.

Considerations in Comparing Costs

Sources of Funds

Although services and supports for people with MR/DD are administered by states, the funds to pay for them are not limited to state funds; funds also come from local (e.g., county) and federal sources. The federal government plays a substantial role in states through the Medicaid Intermediate Care Fa-

cilities for the Mentally Retarded (ICF/MR) program and the Home and Community-Based Services (HCBS) Waiver program (Harrington & Swan, 1990; LeBlanc et al., 2000; Miller, Ramsland, & Harrington, 1999). Services for people with MR/DD in states are funded, to a large extent, through these two programs, which provide matching funds, with the proportions of federal and state contributions varying across the states (Braddock & Fujiura, 1987; Braddock & Hemp 1997; Braddock, Hemp, & Fujiura, 1987; LeBlanc et al., 2000; Lutsky, Alexih, Duffy, & Neill, 2000; Smith & Gettings, 1996). Currently, all 50 states have at least one active ICF/MR facility (Centers for Medicare & Medicaid Services, 2001), although not all ICF/MR facilities are large (i.e., institutions). Most large state-run facilities participate in the ICF/MR program, although there are large private ICFs/MR as well.

The HCBS Waiver program aids states in providing habilitative and other supports in community settings. Eiken and Burwell (2001) reported that

about three-fourths of (federal) Waiver expenditures are used to purchase long term care supports for persons with mental retardation and other developmental disabilities. In FY 2000, about \$9.3 billion of the total \$12.4 billion spent for HCBS Waiver services was targeted to persons with MR/DD.

This amount nearly equaled the \$9.9 billion spent on ICF/MR services in the same year. Since 1995, the average annual growth rate of HCBS Waiver services for people with MR/DD has been over 17%, whereas spending for the ICF/MR program has increased, on average, by less than 1%.

Cost Shifting

Results of early unpublished studies suggested that large facilities were up to 2.5 times as expensive as community facilities (e.g., Ashbaugh & Allard, 1983; Wieck & Bruininks, 1980). However, such conclusions are no longer valid because the analyses took place prior to the full operation of the HCBS Waiver program. Given the differences in the ICF/MR program and the HCBS Waiver program, there is the potential for costs to be *shifted* in complex ways. For example, whereas a placement in a large ICF/MR facility involves both state and federal funds, in varying proportions and at different levels across the states, not all community placements receive federal funds. Although some community-based placements are funded by both federal and state funds (e.g., under the HCBS Waiver), other services and supports are funded

solely by state funds, or are funded by complex combinations of personal/ private funds (including "entitlement" funds under Social Security) along with state funding.

In addition, the federal component of funding under both Medicaid programs varies from state to state, and for the HCBS Waiver, it varies based on what is contained in each state's Waiver agreement with the Centers for Medicare and Medicaid Services (CMS). Consequently, as fewer individuals are served in ICF/MR settings and more receive HCBS services, certain costs may be shifted to other Medicaid programs, or other state funds. According to Lutsky et al. (2001):

Per recipient Waiver spending fails to capture actual spending on Waiver recipients because it only accounts for a portion of their expenditures. HCBS Waiver recipients typically have some of their care, most notably acute care, home health, personal care, targeted case management, and adult day care, funded from the regular Medicaid program. (p. 8)

Cost Variation

Costs vary both *between* and *within* agencies and service systems, based on complex factors that affect them in several ways. Very similar services may vary widely in costs based on geography (e.g., urban vs. rural), unionization of staff, availability of professional staff, staff levels and ratios, ownership status (i.e., public vs. private), and other local factors in addition to characteristics of the consumers served. Such cost variation has been a consistent finding in the literature (Campbell & Heal, 1995; Mitchell, et al., 1990; Nerney & Conley, 1992).

Service costs also change over time as dynamic service systems constantly alter their complexion. For example, costs per resident in an institutional facility tend to rise when the most capable residents are removed and placed in community-based facilities. In addition, cost variation is typical both within and between service facility types. For example, in a study comparing costs in the United Kingdom, Hatton, Emerson, Robertson, Henderson, and Cooper (1995) reported average per person cost variations of as much as \$20,000 between institutional placements and specialized units *within* institutions and the same amount of variation among regular group homes. This phenomenon has also regularly appeared in the literature in America (e.g., Jones, Conroy, Feinstein, & Lemanowicz, 1984; Lakin, Polister, Prouty, & Smith, 2001; Nerney & Conley, 1992).

Staffing

Staffing levels and ratios have been identified as one of the major sources of cost differences across settings (Campbell & Heal, 1995; Felce, 1994). In addition to variability in staffing ratios across settings, there are clear-cut differences in salary and benefit levels. For example, public employees typically have richer compensation packages, and there may also be increased costs associated with the availability of professional and therapy staff. In short, staffing is not a stable variable with wide variability in compensation levels across settings and high rates of turnover (e.g., Braddock & Mitchell, 1992). Staffing levels and costs associated with staff, including recruitment and retention, vary depending on the needs and conditions, and the regulations in a particular setting (Larson, Hewitt, & Anderson, 1999). Therefore, costs associated with staff will prove to be a critical variable in all service models in the future.

Case Mix and Functioning Level

As community services expanded during the past quarter century, the average functioning level of individuals remaining in institutional facilities declined while, in general, their average age increased compared to the general population served by state agencies. These changes have taken place because fewer individuals overall were placed in institutional facilities, and special efforts were made to restrict the institutionalization of children (Lakin, Anderson, & Prouty, 1998). In addition, individuals with more skills and abilities are typically placed in community settings before individuals with more complex needs.

Thus, there are now stark differences in the populations served in community settings and those remaining in larger settings, typically public ICF/MR facilities. With respect to comparisons between these two groups, whether on costs, functional skills, quality of life issues, and so forth, population differences must be considered. In research terms, this process is known as *correcting for case mix* or *controlling for client mix* (Mitchell et al., 1990) and assures comparability based on characteristics of consumers. The importance of correcting for the severity of those served is underscored by Felce and his colleagues (Felce, Lowe, Beecham, & Hallam, 2000), who concluded that "costs of residential services in general have been found to depend on case mix, with the mediating variable being level of staff per resident" (p. 309). Taken together, the factors

of funding source, cost variation, staffing, and case mix are well-known and central to the cost-comparison literature. We now turn to a selective review of the literature showing how the research has addressed these and other issues in studies of service system costs in the MR/DD field.

Literature Selection

To show how the phenomena described above can affect conclusions about costs, we present a historical review of cost-comparison literature, highlighting studies that have gained prominence or address the issues raised herein. A comprehensive literature search was conducted using standard search strategies (Nerney, 2000) in several computerized databases (e.g., Medline, CINAHL, ClinPSYCH, PsychSCAN LD/MR) using keywords (e.g., *mental retardation*, *developmental disabilities*, *ICF/MR*, *costs*, *community*, *institution*) directly or in combinations to create Boolean searches. Two project members conducted literature searches using selection criteria requiring that identified documents (a) covered the MR/DD population; (b) included cost data or cost-related policy analysis; (c) were published or available since 1975; (d) were not case studies; and (e) were focused, at least in part, on residential services. Search results, including full identifying information, were saved electronically. Documents were then selected from these search results to form a document database. Documents that were selected were acquired, entered into the database, and stored in hard copy form. To assure that the two team members were selecting documents using the same criteria, we calculated average agreement at 88.5% on selections made from three large search result files. In addition, we regularly discussed search results and selections at project team meetings. Once acquired, the reference lists of documents were also searched for additional items not previously identified. Approximately 250 documents were identified and acquired in this way to form a working database.

Documents in this database were read and a smaller number selected for specific review if they (a) were published in peer-reviewed journals; (b) included community-institution cost comparisons; (c) were referenced in the cost-comparison literature; and/or (d) included a unique methodological element or approach, were frequently cited in the literature, or were illustrative of a specific historical point. Because of these stringent criteria, only a

small sample of the documents are specifically reviewed herein.

Research Review

Peer-reviewed articles were selected for review in this section to provide a historical glimpse of the cost-comparison literature over the past quarter century. Studies were selected that have a bearing on policy issues in the field, especially those related to cost comparisons. A summary of some of the selected studies is provided in Table 1. Because absolute levels of costs are less important here than comparative costs, no attempt has been made to adjust costs to a common fiscal basis. Therefore, caution must be exercised because the studies span a broad time period. Although comparisons *within* studies are possible, costs may not be directly comparable, on a dollar basis, *between* studies because of inflation and other factors.

Murphy and Dattel (1976)

In this early cost-benefit analysis, Murphy and Dattel reported that a community-placement program in Virginia produced an average net savings, across 52 residents, of \$20,800 per resident over 10 years (range = \$13,000 to \$29,000) or, on average, \$2,080 per person per year. They noted that most of these savings accrued to the state rather than to the federal government. Murphy and Dattel used complex data collected across system elements, and their often-cited 1976 study is not without methodological problems. One concern is that participants were not representative of the MR/DD population in two ways. First, over half of the 52 individuals studied (61.5%) did not even have mental retardation or other developmental disabilities, coming instead from a rural facility for persons with mental illness, thus also possibly underrepresenting urban and suburban settings. Second, participants were screened, and those who were not likely to succeed in community placement were excluded. Admittedly, Murphy and Dattel's main purpose was to assign costs to benefits of community placement and was not a formal cost-comparison study per se. Despite this purpose, the study is often cited in the context of cost comparisons. Further, with regard to methodology, the authors noted that "90 percent of the data on costs and benefits over the ten-year period were based on *projections*" (p. 169, emphasis added). The basis of these projections was, on average, only 8.5 months of community living. Al-

Table 1 Characteristics of Reviewed Studies

Source	Settings and subjects	Cost outcomes	Factors limiting generalization
Murphy & Datel, 1976	N = 52; MH = 62% MR/DD = 38% (moderate, severe, or profound); Ss placed from 4 institutions in VA	Average net savings of \$2,080 per year per client in community services. Subgroup showing no cost-benefit from community placement, most similar to current institutional population	Mixed, nonrandom, nonrepresentative (of MR/DD) sample. No correction for severity or case-mix Sample screened to eliminate potential community placement failures 90% of data derived from estimates (based on 8.5 months of community placement) No accounting for start-up or capital costs Different cost-aggregation methods across groups; relied on self-report cost data from community providers, including estimates, compared to accounting records for institutions
Jones et al., 1984	N = 140; 70 "movers" and 70 matched "stayers"; 85% severe or profound; drawn from Pennhurst facility in PA	Overall cost difference between community placement and public institution reported as \$6,886 per resident per year	Rater differences across groups Exclusion of three high-cost community cases
Schalock & Fredericks, 1990	Fairview facility (OR) with census of 1,084 compared to 4 group homes and an apartment program (combined capacity = 25)	Average annual per person ICF/MR costs = \$59,412 compared to \$53,635 in community settings; costs in two group homes most similar to Fairview population = \$60,615; equalizing raw costs for staff levels, community settings were more expensive	No accounting for start-up or capital costs Small n-size in community setting No control for case-mix factors (i.e., community setting individuals not fully comparable to Fairview population) Few client characteristics provided to allow case-mix correction Day program costs were only estimates from budgets Community medical costs estimated from individual appointment records/documentation rather than billing encounter data

(Table 1 continued)

Table 1 Continued

Source	Settings and subjects	Cost outcomes	Factors limiting generalization
Nerney & Conley, 1992	N = 375 living arrangements (group homes and nonfacility care) in 3 states (MI, NE, NH) compared with institutional costs	Institutional Care Rates (from records) Michigan: \$63,000 Nebraska: \$19,391 New Hampshire: \$28,411 Community Rates (corrected using 50% split on need) Michigan (non-ICF): \$47,359 Michigan (ICF): 48,487 Nebraska: \$25,778 New Hampshire: \$42,007	Data collected at facility level; incomplete correction for case-mix factors Different cost aggregation methods across settings Extreme variability in costs Education and Medicaid-reimbursed costs excluded No accounting for start-up or capital costs
Knobbe et al., 1995	N = 11; all severe/profound with challenging behaviors; placed from state facilities into homes serving 3 individuals	Overall cost savings in community of \$6,154 per person per year	No accounting for start-up and capital costs Estimates for community medical service costs appear to be underestimates
Campbell & Heal, 1995	N = 1,295 "observations" of clients living in all settings in South Dakota	Average annualized adjusted rates reported as: ICF/MR = \$55,560 ICF/15 = \$39,077 HCBS = 25,813 Community Training Services = \$21,210 Costs found to be associated with client characteristics, agency characteristics, funding source, staff: client ratio, and certain geo-demographic variables	Possible case-mix problems given loss of 29% of community sample Artificially high cost prediction may be due to use of aggregate vs. individual cost data
Stancliffe & Lakin, 1998; Stancliffe & Hayden, 1998	116 individuals moved to community settings and 71 remaining in institutions in MN	Average per person annual costs: \$115,168 in institutions; \$84,475 in community settings	Medical and case management costs excluded from analyses Covariance methods may not have fully equalized groups

(Table 1 continued)

Table 1 Continued

Source	Settings and subjects	Cost outcomes	Factors limiting generalization
Emerson et al., 2000	86 adults in village communities; 133 adults in new residential campuses; 281 adults living dispersed housing schemes (group homes and supported living)	Averaged annualized per person costs (converted from pounds sterling to 1997-1998 dollars): Residential campuses = \$74,516 Village communities = \$71,604 Dispersed housing in community = \$85,852	Possible bias in at least one measure selected as a covariate Cost aggregation methods differed across settings No accounting for start-up or capital costs Overall system of services in UK may not be directly comparable with United States Non-random sample with relatively few exemplars of each model of service

Note: Because the study by Rhoades and Altman (2001) is not strictly a comparison study and the authors use a national database, it is not included in the table. MH = mental handicap. MR/DD = mental retardation/developmental disabilities. S = subject. ICF = Intermediate Care Facility. HCBS = Home and Community Based Services.

though most subgroups showed some cost-benefit, the one group that did not show cost-benefit was the most similar to the current MR/DD institutional population.

Jones, Conroy, Feinstein, and Lemanowicz (1984)

This widely-cited cost-comparison study was conducted as part of the court-ordered Pennhurst Center (Pennsylvania) depopulation effort. In this study the authors reported an average cost difference of between \$6,500 and \$7,000 in favor of community residential facilities. Despite many citations in the literature, the study does not appear to have generated much critical scrutiny. At the time of the study, approximately 85% of the population of the institution was labeled as having either severe or profound mental retardation. Cost data were compared between a matched sample of 70 "movers" and 70 "stayers." Data on six types of service costs were collected: (a) residential, (b) day program, (c) entitlement (i.e., public assistance levels), (d) case-management costs, (e) medical costs, and (f) other costs. Because Jones et al. collected additional information on costs, their study extends an earlier matched comparison study of behavioral change (Conroy, Efthimiou, & Lemanowicz, 1982).

Despite the prominence of the Jones et al. (1984) study in the literature, there are several methodological problems that may compromise the generalization of findings. Five are cited by the authors: (a) the Pennhurst dispersal was under a court-order and was, therefore, unlikely to have a normative cost structure; (b) subjects were not randomly assigned to groups; (c) all community placements served only 3 or fewer individuals; (d) self-report data on costs from providers in community residential facilities were used; and (e) medical costs were not fully enumerated. In addition, the data-collection design allowed for different methods of data collection across groups. At Time 2 (postrelocation) in this study and its precursor (Conroy et al., 1982), data for 40 of 70 movers (57% of those who moved to community facilities) were collected by "county workers," whereas this was not the case for stayers (i.e., those who remained in the institution). Data for stayers were collected by a team of trained workers who used teams of professionals as respondents. Furthermore, those who collected the behavioral data at Time 1 were not the same as those who collected the data at Time 2 for any subjects. Thus, raters were different between Time 1

and Time 2 and, for 40 out of 70 movers, were different from those rating all of the stayers at Time 2. In addition, as the authors stated, the interrater reliability of the behavioral data-collection instrument, the Behavior Development Survey, "has been shown to be barely adequate" (Jones et al, 1984, p. 306). Similar problems in methodology appeared in the collection of cost data.

For example, the authors did not explicitly examine the extent to which the different cost-estimation methods in the community and the institution may have yielded systematic biases in the data. In the community, costs were obtained by phone contact, with some costs being based on estimates made by one administrator in a county; these estimates were then applied to all individuals in that county. In the institution, by comparison, the operating costs were derived from state billing rates and examination of financial records. These differences in cost-aggregation methods, especially the reliance on broadly applied estimates in community settings, raises the possibility of systematic error. It is noteworthy, given the problems delineated here, that the authors themselves noted difficulties in making valid cost comparisons between community settings and institutions, including the difficulty in capturing costs, the heterogeneity of settings, and the fact that costs can be shifted between the state and federal governments.

More problematic in the present context is that the authors identified "three people living in community facilities with extremely high costs (\$77,578, \$103,679, and \$104,565)" (p. 308) and excluded them, arguing that they were statistical outliers. It is not uncommon for investigators conducting fiscal analyses in human services to find that a small segment of a population accounts for a proportionally large share of costs. Extreme values such as these likely represent *real* costs, despite the fact that in a *statistical* sampling distribution they appear as outliers. Excluding such data may have seriously skewed the cost findings. A better strategy would have been to analyze the data with the so-called "outliers" left in the dataset and then reanalyze the data with the outliers removed, thus allowing comparison of the overall effect of such cases.

Schalock and Fredericks (1990)

In a study comparing the Fairview facility in Oregon with four group homes and an apartment program, Schalock and Fredericks (1990) reported

an average cost of \$59,412 in the ICF/MR institutional facility compared to an average cost of \$53,635 in community residences. They attributed the average cost difference primarily to staff salary levels and noted that if corrections were made to equalize salary levels, the institutional facility would actually have been less expensive. Certain methodological problems were noted in this comparison as well.

For example, of the 1,048 individuals in Fairview at the time of this study, most had profound disabilities and fewer than 100 (< 10%) were school age, yet all of the community settings but one provided services to children. Furthermore, two of the comparison group homes provided services to children with mild mental retardation and emotional problems or disturbances. When considering only the two group homes serving residents who were most similar to the Fairview population, the community settings are found to be more expensive than the institution (*without* correcting staff salaries). One of these group homes served individuals with severe motor and ambulation problems who were incontinent and who, with the exception of one individual, needed to be fed by a staff member. The other home served children with profound mental retardation, some ambulation problems, and challenging behaviors. The average costs in these two facilities was \$60,615, or slightly more than the Fairview average cost. These authors concluded that:

These data present some troubling facts, especially for staunch advocates of deinstitutionalization. A general conclusion can be drawn from these data that, for individuals with challenging behaviors, residential costs within the community cost approximately the same as institutional services in Oregon, *given the current salary rates of institutional and community residential staff*. When these data are extrapolated, to equalize staff salaries between the institution and the community residence, the conclusion must be drawn that large institutions are, in most instances, less expensive than community residences for these challenging populations. (p. 283, emphasis in original)

Nerney and Conley (1992)

In this large-scale analysis of costs in regions of 3 states (Michigan, Nebraska, and New Hampshire), Nerney and Conley (1992) compared institutional costs and costs in community-based settings (including ICF and non-ICF group homes in Michigan). An array of cost data were collected from community settings, including direct-care and family-care payments (costs of care givers' operations/administrative costs, transportation costs,

medical/clinical costs (other than those paid by Medicaid or other third-party payers), day program costs, and other costs. Data were not collected on educational costs or Medicaid-reimbursed health care costs. Data on institutional services in these regions were collected from overall state cost reports. The institutional data were not collected in the same way as the community cost data (i.e., state developmental disabilities offices provided the rates), a methodological problem shared by much of the research in this area.

The overall costs of services to community-based individuals in the specified regions of Michigan, Nebraska, and New Hampshire were \$38,098, \$19,391, and \$28,411, respectively, compared to state rates for institutional care, which were \$63,000, \$32,000, and \$72,000, respectively. The community rates in this study, however, include *both* facility (i.e., group home) and non-facility (i.e., apartment, family, and foster care arrangements). Taken separately, and partially corrected for case mix by examining the 50% of settings with "high need" individuals, the differences between group home rates and institutions in Michigan were reduced to \$15,641 (non-ICF) and \$14,513 (ICF); in Nebraska they were \$6,222; and in New Hampshire, \$28,993. Factoring in the Medicaid medical costs and applicable education costs would further attenuate the reported community-institution cost differences.

The interpretation of these findings remains difficult for several reasons. First, data were collected at the level of *facilities* rather than *individuals*. It is likely that there are substantial differences, in each of these 3 states, between the population that resides in their community group homes and the population residing in their institutional settings. It is unlikely that the level of need analysis (a 50% split) fully accounted for such variability (i.e., fully corrected for case-mix factors). Second, as noted, the procedures for aggregating costs differed between the community settings and the institution, and certain costs, as the authors noted, were excluded (e.g., health care costs covered by Medicaid or start-up and capital costs). Third, although the Nerney and Conley (1992) provided separate estimates, the aggregation of all community settings (i.e., facility and nonfacility community settings) de-emphasizes the cost differences *within* community settings. That is, they reported "enormous" variability both within and between states. For example, in Michigan, costs in 11 community place-

ments were under \$10,000, whereas costs in 4 others were over \$60,000.

In accounting for the differences between community and institutional placements, Nerney and Conley (1992) noted that staffing was a primary variable, given that between 50% and 75% of all of the program costs are associated with staffing. For example, they noted that a substantial portion of the differences in costs between Michigan and Nebraska could be directly attributed to a staffing ratio in Michigan that was 1.62 times higher than in Nebraska.

Knobbe, Carey, Rhodes, and Horner (1995)

Although employing a very small sample ($N = 11$), Knobbe et al. reported a more complete cost-aggregation methodology than is typical in this area. Similar to Schalock and Fredericks' (1990) work, all of the participants had either severe or profound mental retardation and exhibited challenging behaviors and/or mental health problems, thereby providing an interpretive link to current institutional populations. A strength of the Knobbe et al. study is that it is longitudinal; the authors followed the participants who moved from large centralized state facilities to community settings of three individuals each (thereby avoiding case-mix problems). These authors aggregated costs in 16 distinct categories, between 1988 and 1990, including food, medical, utilities, administrative costs, staff training, transportation, insurance, gas/vehicle maintenance, and others. Unlike Jones et al. (1984) and Nerney and Conley (1992), community costs were collected by Knobbe et al. in a way that was similar to how institutional costs were collected. They reported an average yearly cost per resident for the 11 individuals in the community during 1990 as \$111,123 compared to their last year in the institution, which cost \$117,277 (adjusted for inflation). The difference in costs across the settings was \$6,154.

With regard to cost shifting, there was a rather large discrepancy between medical costs in the two settings, with institutional medical costs being more than five times greater than costs in the community (\$10,939 vs. \$2,144, respectively). The estimate for medical costs in the community settings is low considering health care cost findings in this population. For example, interpolating an annual cost for health care services, for 1990, from available literature (e.g., Adams, Ellwood, & Pine, 1989; Kronick, 1997; Kronick, Dreyfus, Lee, & Zhou, 1996)

suggested that a reasonable annualized estimate for all health care costs (i.e., inpatient and outpatient costs) for this population would have been between \$4,000 and \$4,500, which would account for much (about 38%) of the community versus institution cost difference found in this study.

Although Knobbe et al. (1995) employed a commendable methodology for aggregating costs, we note that neither start-up costs nor capital costs were included in the cost estimates. Nevertheless, these kinds of expenditures are real costs associated with developing community settings and, arguably, should be amortized and entered into the cost-comparison research. Mitchell et al. (1990) noted this issue in their review and commented that it is possible that such costs during rapid deinstitutionalization periods actually cause costs to rise sharply and then return to lower levels. In most of the studies reviewed herein, none of the authors accounted for either community or institutional capital costs or community start-up costs nor was there any correction for costs necessary to pay for state-operated regional and community offices that would not be necessary in an institution-only system.

Campbell and Heal (1995)

Campbell and Heal (1995) employed complex statistical modeling techniques to predict costs of services attributable to facility location, size, funding source, and level of client functioning. They reviewed the literature and indicated that the results of many cost-comparison studies can be challenged because of (a) the difficulty in aggregating costs equitably across community and institutional settings and (b) the lack of comparability in the institutional and community-based groups with respect to functioning level and care needs (i.e., case mix). In their 1995 study, these authors endeavored to address these problems.

Campbell and Heal (1995) examined 1,295 observations in South Dakota of individuals of all ages in 79 *service groups*, which were combinations of different provider agencies, funding sources, and residential service types. Data were collected on average daily costs that were comprised of seven cost centers (administration, support, room and board, etc.); in addition, the analysis included the average daily reimbursement rate for these services as well as staff-to-client ratios. The statistical analysis linked these data to characteristics of service location, agency characteristics, client characteristics, and service funding class as well as to a set of other

demographic variables (e.g., city population, county unemployment rate). A substantial portion of individuals in community settings (29%) were excluded from consideration for various reasons, whereas all but 2 individuals in the two institutions represented were included.

In the analysis, mean average daily costs for the different funding classes, adjusted for community, agency, and client characteristic variables, were (annualized): \$55,560 (ICF/MR); \$39,077 (ICF/15, i.e., a 15-bed ICF/MR facility); \$25,813 (HCBS); and \$21,210 (Community Training Services). In a related analysis staff ratios were found to be significantly higher for the ICF/MR settings, which accounted, in part, for the cost differences. Still, the difference across ICF settings (i.e., ICF/MR vs. ICF/15) is striking and suggests that different factors may be included in the cost bases. In addition, certain geodemographic variables (city unemployment rate, population size), along with client functional and behavior characteristics, predicted over 73% of the variance in costs. Adding provider characteristics (e.g., facility size) and funding source (ICF/MR, ICF/15, or HCBS) increased prediction to over 90%. Thus, a great deal of the variability in costs was associated with (a) provider and client characteristics (clients with more intense needs required more expensive services), (b) funding sources, and, interestingly, (c) characteristics of the locale. This last finding echoes the large cost differences across states that was reported by Nerney and his colleagues in the 3 states they studied (Michigan, Nebraska, and New Hampshire).

Exclusive of the institutional placements, Campbell and Heal (1995) found that community services costs bore a U-shaped relation to agency size, with large and small agencies being *more* costly than intermediate-sized agencies. This study, although analytically complex, provides no direct comparisons of costs across comparable groups; rather, the authors sought to predict costs (and other variables) based on a wide assortment of data. Large-scale studies such as this one are important and complement controlled group comparison studies.

One finding of special interest in the Campbell and Heal (1995) study was the strong predictive nature of client characteristics on costs. This finding is in juxtaposition with certain earlier findings. For example, Ashbaugh and Nerney (1990) concluded that client characteristics were *not* related to expenditures. Stancliffe and Lakin (1998) reported

a similar lack of relation between expenditures and client characteristics. The finding of a relation by Campbell and Heal, however, is important, because predicting 65% of the variance in costs shows that client characteristics *do* matter in service costs.

Stancliffe and Lakin (1998) and Stancliffe and Hayden (1998)

In these two studies, both conducted at the University of Minnesota, the authors drew their participants from 190 individuals enrolled in an ongoing longitudinal study. Expenditures and outcomes for 116 individuals with severe and profound cognitive impairments following movement to community settings and 71 individuals who remained in institutional facilities were studied. Stancliffe and Hayden (1998) followed the 71 individuals who did not move to community placements. Because cost analysis is rather secondary in the Stancliffe and Hayden study, our focus here will be the study by Stancliffe and Lakin (1998) in which "movers" and "stayers" were compared.

Although Stancliffe and Lakin (1998) made comparisons based on residential costs as well as total costs (residential costs + day program costs), comparisons between community and institutional settings were only conducted on total costs due to the aggregation methodology. These comparisons were reported for both raw and adjusted data using resident:staff ratio as a covariate, based on staff members available on weekday evenings. Stancliffe and Lakin reported significant differences in both raw and adjusted average daily total expenditures between community and institutions. Costs for residents in community settings (annualized: \$84,475) were 36% less than costs for residents in institutional settings (annualized: \$115,168).

Some of the problems identified in this research area, such as case-mix issues, appear to be resolved by the use of statistical analyses using covariates. However, taken together, statistics from both of these articles (Stancliffe & Hayden, 1998; Stancliffe & Lakin, 1998) suggest that certain selection factors may still have been operating that affected the outcomes and conclusions. For example, it appears from the data that a behaviorally challenging group may have been initially overlooked for community placement, requiring the state to develop public community ICF/MR settings. In addition, Stancliffe and Hayden presented statistics on therapy use in the stayers group, suggesting that many of them had severe physical dis-

abilities. It is possible that some of these differences were not apparent in significance testing due to the reactivity of certain measures (e.g., using the ICAP Broad Independence score as a measure of adaptive behavior).

In addition, one of the variables used as a covariate, resident:staff ratio on weekday evenings, may have unduly penalized the institution relative to the community sample. Differences in staffing ratios across the day may simply be a proxy for differences in setting characteristics. For example, it is likely that the assessment of *overall* resident:staff ratios would have attenuated setting differences because in ICF/MR settings, there are many therapists available during the day that cannot be counted on weekday evenings. In an ICF/MR setting with residents who have multiple disabilities and restricted functioning, many resident training programs are likely to be active during the day, when specialized staff members are available to carry them out.

It is also the case that staffing levels in public ICF/MR settings that are slated for downsizing or closure may not be representative of typical staffing ratios. It is likely that, due to civil service rules, unionization, and so forth, that a lag exists between the reduction in census and the reduction in staff. In the studies conducted by Stancliffe and his colleagues, data were collected during a 4-year transition period as staffing levels were adjusted down in the institution and up in the community to accommodate the shift in consumers. Because staffing reduction in institutional settings almost certainly proceeds slower than staffing up in community settings, staffing ratios in these studies may be somewhat suspect and, as a covariate, are likely to have affected many of the analyses.

Finally, the exclusion of medical, case management, and capital costs no doubt affected the comparisons. We have already addressed the issue of the medical costs shifting from ICF/MR costs to other sources (e.g., private insurance, Medicaid fee-for-service). However, given the complexities of the community-based population described in these studies, it is not unreasonable to conclude that *additional* case management costs would accrue in the non-ICF/MR settings compared to the institution and community ICF/MR settings.

International Cost-Comparison Research

Although the main focus of the present review is the United States, there is a substantial body of literature from other countries that cannot be ig-

nored. This literature is, in some ways, strikingly different than the American literature. Felce (1994) reviewed the research on cost studies in the United Kingdom and explored what he characterized as a consistent finding that community services were more expensive than institutional services, in juxtaposition to the perception of many in America. For example, Emerson and his colleagues, who also studied costs in the United Kingdom, cited a previous meta-analysis that "adjusted costs . . . reported for hospitals [institutions] ranged across studies from \$799 to \$1,540 per week, whereas costs reported for group homes ranged from \$912 to \$2,750 per week" (Kavanagh & Opit, 1998, quoted in Emerson et al., 2000, p. 83, material in brackets added). Underlying the differences in cost-comparison research in the United Kingdom and America may be differences that exist in the service systems. For example, in America states share costs with the federal government in complex ways that promote cost shifting as state systems expand community systems relative to institutions. Because the costs that can be shifted under Medicaid programs differ and are not clearly understood by many, a perception may have arisen that there is no diseconomy of scale in smaller facilities. In contrast, because funding formula are less complex in the United Kingdom, it is assumed that community care will be more costly; in some ways just the opposite of the American view.

Still, Felce (1994) concluded that smaller community-based facilities offer the potential for increases in certain aspects of quality of life and that, in the long run, may be economically affordable. However, he cautioned that very small placements (i.e., smaller than 4) may not be able to maintain favorable costs structures if additional staff members are required based on increased needs of residents.

Recent work in the United Kingdom by Emerson and his colleagues (Emerson et al., 2000) found that costs associated with dispersed housing (i.e., housing that is integrated into existing communities) were 15% higher than those of residential campuses (i.e., institutions) and were 20% higher than village communities (i.e., clustered housing similar, in some ways, to regional centers and certain private facilities in America). After the authors adjusted for both adaptive behavior and challenging behavior, the annualized per person cost in 1997-1998 dollars (converted at £1 = \$1.63) for village communities was \$71,604; for residential campuses,

\$74,516; and for dispersed housing in the community, \$85,852.

In a multivariate study conducted by Felce and his colleagues in Wales (Felce et al., 2000), total accommodation costs were predicted from resident and setting characteristics, setting size, service processes, and indicators of quality. These researchers derived a two-factor regression solution predicting accommodation costs that included service model and client characteristics (Adaptive Behavior Scale [ABS] scores) that accounted for 51% of the variance in costs, adjusted $R^2 = .48$. Unlike the findings in America, costs in this model were found to be lower for institutions in comparison to community settings. Similar to some of the research conducted in the United States, client characteristics were important in predicting costs. According to Felce et al., the cost differences between service models were related to client characteristics, such that "costs tended to be higher for people with lower ABS scores within each service model... (and that) the consistent finding of UK research on deinstitutionalization is that community services are more expensive than institutional services" (p. 321).

At present, there is speculation as to what forces produce this juxtaposition of cost differences between the United Kingdom and the United States. Stancliffe, Emerson, and Lakin (2000) suggest that "one factor contributing to higher institutional costs in US studies may be that many US institutions have been downsized to the extent that relatively fixed institutional infrastructure and running costs are distributed over a small and diminishing population" (p. iii). This is precisely the interpretation offered by Braddock et al. (1991). This view is further echoed by Felce and his colleagues and has been voiced elsewhere in the literature. In addition, the work by Felce and his colleagues (2000) also assessed quality of life and noted that "This analysis provides additional evidence of a weak linear relationship between resource inputs and service quality, even after controlling for service recipient characteristics" (p. 323).

Rhoades and Altman (2001)

Using data from the 1987 National Medical Expenditure Survey (NMES), Rhoades and Altman (2001) used a different approach to studying costs in MR/DD services. In this survey, instead of taking the typical perspective of average aggregated costs from samples of individuals across settings, they de-

rived data at the *individual* level. That is, individuals were sampled, and then asked about their individual costs. Rhoades and Altman began by noting that despite the success of deinstitutionalization, problems remained, including (a) the more intense needs and, thus, associated increased costs, of those who remain in congregate care facilities and (b) the declining cost-benefit of community settings compared to institutional settings. These problems prompted the recognition that now that the field has effectively deinstitutionalized many individuals, "the remaining population, more likely to have multiple problems, is generally a population that would generate higher expenditures no matter where they are located" (p. 115).

From this perspective Rhoades and Altman (2001) conducted a multiple regression analysis that, among other things, predicted mean daily expenditures by several categories of person variables and facility characteristics. The authors extended the work done by researchers such as Campbell and Heal. Rhoades and Altman reported that:

The results of the multivariate analysis indicate, at a national level, what Campbell and Heal (1995) found in South Dakota. Facility characteristics, resident characteristics, and even community resources play a part influencing daily expenses for residents in facilities both large and small. . . . The results also show that for persons with borderline, mild, moderate, or severe levels of mental retardation, it is more expensive to provide care in larger facilities. For individuals with profound mental retardation, the size of the facility is not a factor in daily expenses once the increased expenses for the level of mental retardation are considered. (pp. 123-124)

In a way, the Rhoades and Altman study (2001) was the beginning of the shift in the literature away from controlled comparison studies. Instead of using static comparisons to determine specific costs in a policy-making context, results of this study suggest that researchers should approach the problem from the perspective of the individual and identify the most favorable placement based on the characteristics of the person and the service setting together. The authors showed, for example, that resident characteristics were, indeed, associated with costs of care regardless of the setting. Perhaps even more interesting is the interaction with level of mental retardation such that "Persons with similar levels of dependence had different daily expenses, related to their level of mental retardation and, thereby, the ability to cooperate and communicate with caregivers" (p. 126). This work is important because the results suggest questions that relate specific needs of individuals to specific re-

quired services independent of the setting. Again, in the words of Rhoades and Altman:

It is important to understand how organizational type, resident characteristics, number and types of services, and location come together to influence expenditures in order to develop the necessary resources for proposed health care delivery plans. Examining expenses from the individual rather than the organizational perspective allowed us to examine this complicated puzzle in a different way. (p. 127)

In such a context the question: "What costs more, community or institutions?" or "Which type of setting serves an individual better?" is no longer the critical question. Adopting the approach implied by Rhoades and Altman (2001), it becomes clear that costs and expenditures are related to the needs of the person, the quality of services provided, the desired outcomes, and perceived satisfaction on the part of the individual.

A Word on Outcomes

Although we are aware that the issues of quality of services and service outcomes necessarily go hand in hand with costs, the empirical association between costs and quality is less established when a broad array of research findings are examined. For example, positive outcomes reported in the literature associated with deinstitutionalization and community-based services include increased choice (Stancliffe, 2001; Stancliffe & Abery, 1997), behavioral improvement (Kim, Larson, & Lakin, 2001), improved social interaction of certain segments of the population (Anderson, Lakin, Hill, & Chen, 1992), integration in rural settings (Campbell, Fortune, & Heinlein, 1998), and inclusion in various day-to-day activities (Campo, Sharpton, Thompson, & Sexton, 1997; Emerson et al., 2000). However, such positive findings need to be considered in relation to findings of increased mortality in community settings (Strauss & Kastner, 1996; Strauss, Kastner, & Shavelle, 1998; Strauss, Shavelle, Baumeister, & Anderson, 1998; see also Taylor, 1998), problems in vocational services and employment (Stancliffe & Lakin, 1999), and problems of Individual Habilitation Plan objectives and behavioral technology (Stancliffe, Hayden, & Lakin, 1999, 2000). Recent work has also highlighted problems in access, utilization, and quality in community-based health care and personal care for people with mental retardation and developmental disabilities (Knobbe et al., 1995; Larsson & Larsson, 2001; Walsh & Kastner, 1999). Emerson and his

colleagues (2000) identified higher rates of verbal abuse and relatively greater exposure to crime among individuals who lived in dispersed community settings. Finally, Felce and Perry (1997) reported that in the community settings they studied, staff members generally lacked organized approaches and skill sets to promote development in those living in the settings in which they worked.

Although the assessment of consumer satisfaction and quality of life has been reported often in HCBS settings, in other evaluation reports, investigators (e.g., Lutsky et al., 2000) have noted a set of specific concerns around quality of care, as did LeBlanc et al. (2000). As stated by Lutzky and his colleagues, these concerns include (a) difficulty in state monitoring of noninstitutional care because of their dispersed nature, an increasing problem as more HCBS placements have been created; (b) inexperience in monitoring noninstitutional care, in some states including a lack of regulations and licensing requirements; and (c) the potential impact of low provider reimbursement rates on the quality of care. In the words of Lutsky et al. (2000): "The effectiveness of licensing and regulatory requirements at ensuring quality of care is impaired if states do not sufficiently monitor compliance. However, monitoring quality of HCBS services may present greater challenges than monitoring quality in institutional settings" (p. 28).

It may also be the case that quality of care and quality of life differ across community and institutional settings in their importance to stakeholders. For example, as institutions increasingly provide services to people with severe and profound cognitive deficits, complex needs, challenging behaviors, and diminishing skills, concerns about quality of care may outweigh those of satisfaction. In community settings, on the other hand, with a more heterogeneous and able population, it may be that quality of life, satisfaction, and interest in self-determination takes on more importance. Thus, the assessment of both quality of care and quality of life, although related and important in both settings, may need to be adjusted for characteristics of the setting in which they are assessed.

Therefore, we agree with Emerson (1999) that outcome measurement be expanded beyond assessment of personal outcome measures, such as choice and community involvement, to include a greater emphasis on health and safety. As Walsh and Kastner (1999) have pointed out, health and safety outcomes have been underrepresented in the MR/DD

literature (cf. Hughes, Hwang, Kim, Eisenman, & Killian, 1995). Outcome measurement needs to include direct indicator and benchmark assessment of outcomes based on clear standards. For example, individuals with profound disabilities and multiple disabling conditions may benefit from measures evaluating (a) access to comprehensive health care services (primary, psychiatric, and dental care as well as ancillary services, including care coordination); (b) rates and status of abuse/neglect reports and investigations (including victimization in the community); (c) mortality review; (d) access and utilization of behavioral services; and (e) similar direct measures.

Discussion

In this review of selected peer-reviewed studies, we have documented the complexity of research examining costs of community and institutional service models and show how methodological problems affect conclusions. The work reviewed here spanned a quarter-century during which time the field was in constant transition. Early studies were designed simply to show the cost-benefit of community placements (e.g., Murphy & Datel, 1976), whereas more recent work has highlighted the complex multivariate nature of the area and recognized the need to identify costs at the individual level (Rhoades & Altman, 2001). The shifting cost structures across settings during the period reviewed, and the heterogeneity of the population served, prompts the conclusion that the question "Which is less expensive, institution or community?" is the wrong one to ask. Rather, the questions that need to be asked revolve around the individual (i.e., What does this person need? Where is the best place to provide for these needs?" and "at what cost?").

The research reviewed here suggests, in several ways, that community placements are not inherently less expensive than institutions. First, there is an intrinsic lack of comparability between institutions and community settings. For example, community services include a diverse array of service types, ranging from minimal intermittent supports to residential and day program services, whereas institutions traditionally offer an established service package (e.g., ICF/MR services). Thus, only a part of the range of community services is comparable with the services received in a large ICF/MR. Researchers comparing costs need to assure that the service packages are comparable across settings, a

challenge given the inherent differences in these service systems. Second, during deinstitutionalization efforts, the ability to shift certain community costs to programs other than those administered by a particular MR/DD state agency will lead to reduced costs *within* that specific governmental division or authority. However, the overall cost to society may not be reduced. For example, medical costs within an ICF/MR are clearly part of the budget of the state MR/DD authority; however, when an individual moves to a community setting, medical expenses can often be shifted to another funding source (e.g., the component of state government that administers Medicaid health care benefits). Third, the apparent cost savings in community settings, to the extent that it is found, is often directly related to staffing costs. Results of the research reviewed herein suggest that the modest differences reported for community services are predominantly the result of lower staffing costs in privately operated community settings compared to state-operated settings. However, the lack of parity between staffing costs in institutions and community settings is not a desired efficiency. In fact, it is likely that any initial cost benefits claimed for community settings will be difficult to sustain as individuals with more complex needs are served in these settings. Further, over time, it is possible that the disparity between community and institutional cost structures for staffing will diminish as community workers and advocates strive to achieve parity in compensation with respect to state workers. Results of the present study suggest that the area of staff compensation deserves further study.

These elements of complexity in community-institution cost comparisons give rise to several recurring methodological problems. These problems include (a) the lack of comparability between groups based on biased, nonrandom, or convenience samples; (b) the lack of adequate case-mix controls; (c) differences in data-collection and cost-aggregation methods across groups; (d) the exclusion of critical categories of costs, such as medical expenses, case management, start-up, and capital costs; and (e) extreme variability in costs, cost shifting, and statistical-modeling problems.

These methodological problems limit generalization across settings. Three especially challenging methodological problems deserve special mention. First, few of the studies reviewed herein completely accounted for case-mix factors. Given the heterogeneity of the population of individuals with MR/

DD and the near impossibility for random assignment to residential settings, complex case-mix factors are always present. Longitudinal studies and multivariate studies using statistical controls (e.g., employing covariate methods) offer promise as long as care is exercised in the selection of variables. Ideally, covariates that include both cognitive and adaptive measures should be included, although this was not typical of the studies we reviewed.

Second, cost-aggregation methods varied widely over the reviewed studies. Often, the cost-aggregation method used in community settings was different than the way costs were identified in facility settings. In our review, researchers who employed more complex and complete cost-aggregation methods typically found smaller, if any, community-institution differences. In studies from the United Kingdom, which seem to be less susceptible to methodological artifacts (such as cost shifting or inability to estimate costs), researchers typically reported increased costs in community settings.

Third, elements of costs were routinely excluded in even the best studies reviewed here, sometimes because they were shifted to other funding sources and sometimes because the data were unavailable. In both cases it is not acceptable to assume that the effects of costs that are shifted or excluded are the same in the comparison groups. We have noted, for example, that many service costs are *built into* the ICF/MR model. The costs incurred for supporting community infrastructure for such costs cannot simply be excluded from the cost-comparison analyses. Related to this, an inherently difficult fiscal problem is the inclusion of start-up and capital costs incurred in community settings compared to long-term state ownership of institutional facilities. Excluding these categories of costs is not justifiable, and researchers need to identify methodologies that include these costs (e.g., Emerson et al., 2000). In conclusion, in nearly all of the studies reviewed, certain specific costs were excluded from the analyses, thus limiting the generalization of results.

From the cost studies reviewed here, it is clear that large savings are not possible within the MR/DD field. That is, the costs of residential care, regardless of setting, involve a specific amount of resources that vary, somewhat predictably, with staffing levels, client characteristics, and other variables as in the studies reviewed. These studies do not support the view that large cost savings are possible. In fact, researchers who conducted the studies re-

viewed here that employed more sophisticated and complete cost-aggregation methods tended to find the smallest differences across settings (e.g., Knobbe et al., 1995; Schallock & Fredericks, 1990).

Although this review provides a unique historical overview of research in this area, it is not without limitations. First, we restricted our selection of studies to those that were peer-reviewed and addressed the issues under consideration. We narrowed our selection to peer-reviewed studies for quality control reasons and because, for example, unpublished state-level reports might be especially susceptible to cost-shifting effects. A cursory review of many of these reports, however, suggested that their inclusion would not substantially alter our conclusions. Second, we did not directly review the outcomes literature, although, as we have noted, we believe it to be critically important in this field. Third, the scope of this work did not allow us to review cost comparisons made between different community settings, although published work is beginning to appear in this area and will prove to be more critical in the future. We believe that the methodological considerations presented herein will continue to be important as that literature grows.

In the final analysis, it appears that the costs of caring for people with MR/DD will be highly variable across settings and will vary with the characteristics of those served and the resources, especially staffing, devoted to serving them. Because this population ranges from individuals who are barely distinguishable in the general population to individuals who require high levels of sophisticated care, it is likely that a range of service models will continue to be needed. In the future, researchers who conduct studies that will best inform public policy are likely to be those employing multivariate methods to take such heterogeneity into account. As we have documented here, movement toward such research models is already underway.

Based on the analysis presented here, the choices made by governmental agencies about the relative mix of service types should include a consideration of consumer needs rather than being made solely on the basis of local service costs. It is also important to take into account the values of those who use the services.

References

- Adams, E. K., Ellwood, M. R., & Pine, P. L. (1989). Utilization and expenditures under Medicaid

- for Supplemental Security Income Disabled. *Health Care Financing Review*, 11(1), 1-24.
- Anderson, D. J., Lakin, K. C., Hill, B. K., & Chen, T. (1992). Social integration of older persons with mental retardation in residential facilities. *American Journal on Mental Retardation*, 96, 488-501.
- Ashbaugh, J., & Allard, M. A. (1983). *Comparative analysis of the costs of residential and day services within institutional and day settings*. Boston: Human Services Research Institute.
- Ashbaugh, J., & Nerney, T. (1990). Costs of providing residential and related support services to individuals with mental retardation. *Mental Retardation*, 28, 269-273.
- Borthwick-Duffy, S. (1994). Prevalence of destructive behaviors. A study of aggression, self-injury, and property destruction. In T. Thompson & D. B. Gray (Eds.), *Destructive behavior in developmental disabilities: Diagnosis and treatment* (pp. 3-23). Thousand Oaks, CA: Sage.
- Braddock, D., & Fujiura, G. (1987). State government financial effort in mental retardation. *American Journal of Mental Deficiency*, 91, 450-459.
- Braddock, D., Fujiura, G., Hemp, R., Mitchell, D., & Bachelder, L. (1991). Current and future trends in state-operated mental retardation institutions in the United States. *American Journal on Mental Retardation*, 95, 451-462.
- Braddock, D., & Hemp, R. (1997). Toward family and community mental retardation services in Massachusetts, New England, and the United States. *Mental Retardation*, 35, 241-256.
- Braddock, D., Hemp, R., & Fujiura, G. (1987). National study of public spending for mental retardation and developmental disabilities. *American Journal of Mental Deficiency*, 92, 121-133.
- Braddock, D., Hemp, R., & Howes, R. (1986). Direct costs of institutional care in the United States. *Mental Retardation*, 24, 9-17.
- Braddock, D., Hemp, R., & Howes, R. (1987). Financing community services in the United States: Results of a nationwide study. *Mental Retardation*, 25, 21-30.
- Braddock, D., & Mitchell, D. (1992). *Residential services for persons with developmental disabilities in the United States: A national study of staff compensation, turnover and related issues*. Washington, DC: American Association on Mental Retardation.
- Bruininks, R. H., Olson, K. M., Larson, S. A., & Lakin, K. C. (1994). Challenging behaviors among persons with mental retardation in residential settings. In T. Thompson & D. B. Gray (Eds.), *Destructive behavior in developmental disabilities: Diagnosis and treatment* (pp. 24-48). Thousand Oaks, CA: Sage.
- Butterfield, E. C. (1987). Why and how to study the influence of living arrangements. In S. Landesman & P. Vietze (Eds.), *Living environments and mental retardation* (pp. 43-59). Washington, DC: American Association on Mental Retardation.
- Campbell, E. M., Fortune, J., & Heinlein, K. B. (1998). The effects of funding packages on the outcomes of integration and independence of adults with developmental disabilities in two rural states. *Journal of Developmental and Physical Disabilities*, 10, 257-281.
- Campbell, E. M., & Heal, L. W. (1995). Prediction of cost, rates, and staffing by provider client characteristics. *American Journal on Mental Retardation*, 100, 17-35.
- Campo, S. F., Sharpton, W. R., Thompson, B., & Sexton, D. (1997). Correlates of the quality of life of adults with severe or profound mental retardation. *Mental Retardation*, 35, 329-337.
- Centers for Medicare & Medicaid Services (formerly HCFA). (2001). *ICF/MR program summary, October, 1996-November, 2000*. Retrieved 9/13/2001 from <http://www.hcfa.gov/medicaid/icfmr/icfnits.htm>.
- Conroy, J., Efthimiou, J., & Lemanowicz, J. (1982). A matched comparison of the developmental growth of institutionalized and deinstitutionalized mentally retarded clients. *American Journal of Mental Deficiency*, 86, 581-587.
- Davis, S., Abeson, A., & Lloyd, J. C. (1997). *A status report to the nation on people with mental retardation waiting for community services*. The Arc. Retrieved 10/28/01 from <http://thearc.org/report/Wait/Page.html>.
- Eiken, S., & Burwell, B. (2001). *Medicaid HCBS Waiver expenditures, FY 1995 through FY 2000*. HCBS website; retrieved 11/2/01 from http://www.hcbs.org/Waiver_expenditure.htm.
- Emerson, E. (1999). Residential supports for people with intellectual disabilities: Questions and challenges from the UK. *Journal of Intellectual & Developmental Disability*, 24, 309-319.
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Knapp, M., Jarbrink, K., Walsh, P. N., & Netten, A. (2000).

- Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. *American Journal on Mental Retardation*, 105, 81-102.
- Felce, D. (1994). Costs, quality and staffing in services for people with severe learning disabilities. *Journal of Mental Health*, 3, 495-507.
- Felce, D., Lowe, K., Beecham, J., & Hallam, A. (2000). Exploring the relationships between costs and quality of services for adults with severe intellectual disabilities and the most severe challenging behaviors: A multivariate regression analysis. *Journal of Intellectual & Developmental Disability*, 4, 307-326.
- Felce, D., & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, 16, 51-74.
- Harrington, C., & Swan, J. H. (1990). State Medicaid ICF-MR utilization and expenditures in the 1980-1984 period. *Mental Retardation*, 28, 15-27.
- Hatton, C., Emerson, E., Robertson, J., Henderson, D., & Cooper, J. (1995). The quality and costs of residential services for adults with multiple disabilities: A comparative evaluation. *Research in Developmental Disabilities*, 16, 439-460.
- Heal, L. W. (1987). Institutions cost more than community services. *American Journal on Mental Retardation*, 92, 136-138.
- Hughes, C., Hwang, B., Kim, J., Eisenman, L. T., & Killian, D. J. (1995). Quality of life in applied research: A review and analysis of empirical measures. *American Journal on Mental Retardation*, 99, 623-641.
- Jones, P. A., Conroy, J. W., Feinstein, C. S., & Lemanowicz, J. (1984). A matched comparison study of cost-effectiveness: Institutionalized and deinstitutionalized people. *Journal of the Association of Persons with Severe Handicaps*, 9, 304-313.
- Kastner, T. (2000). On the need for policy requiring data-sharing among researchers publishing in AAMR journals: Critique of Conroy and Adler (1998). *Mental Retardation*, 38, 519-529.
- Kavanagh, S., & Opit, L. (1998). *The cost of caring: The economics of providing for the intellectually disabled*. London: Politeia.
- Knobbe, C. A., Carey, S. P., Rhodes, L., & Horner, R. H. (1995). Benefit-cost analysis of community residential versus institutional services for adults with severe mental retardation and challenging behaviors. *American Journal on Mental Retardation*, 99, 533-541.
- Kronick, R. (1997). *Expenditure patterns of New Jersey DDD clients in 1995*. Division of Health Care Sciences, Department of Family and Preventive Medicine, University of California, San Diego.
- Kronick, R., Dreyfus, T., Lee, L., & Zhou, Z. (1996). Diagnostic risk adjustment for Medicaid: The Disability Payment System. *Health Care Financing Review*, 17(3), 7-33.
- Lakin, K. C. (1996). On the outside looking in: Attending to waiting lists in systems of services for people with developmental disabilities. *Mental Retardation*, 36, 165-167.
- Lakin, K. C., Anderson, L., & Prouty, R. (1998). Decreases continue in out-of-home residential placements of children and youth with mental retardation. *Mental Retardation*, 36, 165-167.
- Lakin, K. C., Polister, B., Prouty, R. W., & Smith, J. (2001). Utilization of and expenditures for Medicaid Institutional and Home and Community Based services. In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2000* (pp. 87-117). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Lakin, K. C., Prouty, R. W., Polister, B., & Kwak, N. (2001). Characteristics and movement of residents of large state facilities. In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2000* (pp. 33-48). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S. A., Hewitt, A., & Anderson, L. (1999). Staff recruitment challenges and interventions in agencies supporting people with developmental disabilities. *Mental Retardation*, 37, 36-46.
- Larsson, G., & Larsson, B. W. (2001). Quality of care and service as perceived by adults with developmental disabilities, their parents, and primary caregivers. *Mental Retardation*, 39, 249-258.
- LeBlanc, A. J., Tonner, M. C., & Harrington, C. (2000). Medicaid 1915 Home and Community-Based Services Waivers across the states. *Health Care Financing Review*, 2(2), 159-174.

- Lutsky, S., Alecxih, L. M. B., Duffy, J., & Neill, C. (2000). *Review of the Medicaid 1915(c) Home and Community Based Services Waiver program literature and program data*. Washington, DC: Department of Health and Human Services and The Lewin Group.
- Miller, N. A., Ramsland, S., & Harrington, C. (1999). Trends and issues in the Medicaid 1915(c) Waiver program. *Health Care Financing Review*, 20(4), 139-160.
- Mitchell, D., Braddock, D., & Hemp, R. (1990). Synthesis of research on the costs of institutional and community-based care. *Journal of Mental Health Administration*, 7, 171-183.
- Murphy, J. G., & Datel, W. E. (1976). A cost-benefit analysis of community versus institutional living. *Hospital & Community Psychiatry*, 27, 165-170.
- Nerney, D. B. (2000). *Meta-analysis, decision analysis, and cost-effectiveness analysis: Methods for quantitative synthesis in medicine* (2nd ed.). New York: Oxford University Press.
- Nerney, T., & Conley, R. W. (1992). A policy analysis of community costs for persons with severe disabilities. *Journal of Disability Policy Studies*, 3, 31-51.
- Polister, B., Smith, J., Prouty, R. W., & Lakin, K. C. (2001). Large state MR/DD residential facilities, 1960-2001, individual facility populations, per diem costs, and closures in FY 2000. In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2000* (pp. 19-31). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Prouty, R. W., Smith, G., & Lakin, K. C. (Eds.). (2001). *Residential services for persons with developmental disabilities: Status and trends through 2000*. Minneapolis: University of Minnesota, Research and Training Center on Community Integration.
- Rhoades, J. A., & Altman, B. M. (2001). Personal characteristics and contextual factors associated with residential expenditures for individuals with mental retardation. *Mental Retardation*, 39, 114-129.
- Schalock, M., & Fredericks, B. (1990). Comparative costs for institutional services and services for selected populations in the community. *Behavioral Residential Treatment*, 5, 271-286.
- Smith, J., Polister, B., Prouty, R. W., Bruininks, R. H., & Lakin, K. C. (2001). Current populations and longitudinal trends of state residential settings (1950-2000). In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2000* (pp. 3-18). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Smith, G. A., & Gettings, R. M. (1996). *The Medicaid Home and Community-Based Waiver program: Recent and emerging trends in serving people with developmental disabilities*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.
- Stancliffe, R. J. (2001). Living with support in the community: Predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 91-98.
- Stancliffe, R. J., & Abery, B. H. (1997). Longitudinal study of deinstitutionalization and the exercise of choice. *Mental Retardation*, 35, 159-169.
- Stancliffe, R. J., Emerson, E., & Lakin, K. C. (2000). Community living and people with intellectual disability: Introduction to Part I. *Journal of Intellectual & Developmental Disability*, 25(4), i-iv.
- Stancliffe, R. J., & Hayden, M. F. (1998). Longitudinal study of institutional downsizing: Effects on individuals who remain in the institution. *American Journal on Mental Retardation*, 102, 500-510.
- Stancliffe, R. J., Hayden, M. F., & Lakin, K. C. (1999). Effectiveness of challenging behavior IHP objectives in residential settings: A longitudinal study. *Mental Retardation*, 37, 482-493.
- Stancliffe, R. J., Hayden, M. F., & Lakin, K. C. (2000). Quality and content of individualized plan objectives in residential settings. *Education and Training in Mental Retardation and Developmental Disabilities*, 35, 191-207.
- Stancliffe, R. J., & Lakin, K. C. (1998). Analysis of expenditures and outcomes of residential alternatives for persons with developmental disabilities. *American Journal on Mental Retardation*, 102, 552-568.
- Stancliffe, R. J., & Lakin, K. C. (1999). A longitudinal comparison of day program services and outcomes of people who left institutions and

- those who stayed. *Journal of the Association for Persons with Severe Handicaps*, 24, 44-57.
- Strauss, D., & Kastner, T. (1996). Comparative mortality of people with mental retardation in institutions and the community. *American Journal on Mental Retardation*, 101, 26-40.
- Strauss, D., Kastner, T., & Shavelle, R. (1998). Mortality of adults with developmental disabilities living in California institutions and community care, 1985-1994. *Mental Retardation*, 98, 360-371.
- Strauss, D., Shavelle, R., Baumeister, A., & Anderson, T. W. (1998). Mortality in persons with developmental disabilities after transfer into community care. *American Journal on Mental Retardation*, 102, 569-581.
- Taylor, S. J. (Ed.). (1998). Methodological issues in mortality research: Commentaries on Strauss et al. and O'Brien and Zaharia [special section]. *Mental Retardation*, 36(5).
- Walsh, K. K., & Kastner, T. A. (1999). Quality of health care for people with developmental disabilities: The challenge of managed care. *Mental Retardation*, 37, 1-15.
- Wieck, C. A., & Bruininks, R. H. (1980). *The cost of public and community residential care for mentally retarded people in the United States*. Minneapolis: University of Minnesota, Department of Psychoeducational Studies.

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UPDATE

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Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research

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In the 2003 article noted above a review of selected literature was undertaken to determine the validity of institutional vs. community cost comparisons. A number of methodological problems were identified in the literature reviewed that compromised much of the earlier research on the topic. Additionally, a number of considerations were outlined – *source of funds, cost shifting, cost variation, staffing, and case mix* – that need to be taken into account when such comparisons are undertaken.

The question has arisen whether the conclusion of this 2003 review, that large savings are not possible within the field of developmental disabilities by shifting from institutional to community settings, remains current.

For the reasons explained below, we find that the 2003 article continues to be valid in 2009 and beyond. That is, cost savings at the macro level are relatively minor when institutional settings are closed and, if there are any at all, they are likely due to staffing costs when comparing state and private caregivers.

As such, the study will continue to be useful in policy discussions in states.

Several factors point to why the study's conclusions remain valid in 2009:

Review Article. As a *review* article, the 2003 publication does not generate new *data*; that is, it reviews previous research. Because of this, the article is more resistant to becoming outdated. Those reading the article, however, would do well to keep in mind that the studies reviewed in the article employ cost figures that existed *at the time the original research articles were published*. Therefore, while the findings and conclusions drawn in Walsh, et al. (2003) will continue to be timely, the actual cost figures may need to be adjusted to current levels.

Stability of the Components. Because the service and support landscape remains, in large

part, similar in 2009 to 2003 and before, the conclusions of Walsh, et al. are likely to hold. For the most part comparisons reviewed generally compared congregate ICF/MR settings and community-based residential settings (typically group homes) funded under the Medicaid HCBS waiver. Although many states have been moving toward personal budgets and fee-for-service models, group homes continue to be a primary community residential service setting. In this way also the conclusions of the 2003 article continue to be applicable.

Stability of the Issues. As noted, the 2003 article presented descriptions of various considerations that affect cost comparisons across states. Because the structural components of the issue have remained unchanged (e.g., institutional settings, group homes) and the funding models have remained largely intact (i.e., Medicaid ICF/MR and HCBS waivers), the various factors affecting them, for the most part, remain as presented in Walsh, et al.

That is, there remains a great deal of cost variation from institutional to community settings as described in the article; cost shifting, as described in Walsh, et al., is to some extent likely to be structurally fixed in most states owing to the nature of state governments. That is, when certain costs disappear, when individuals are transferred from ICF/MR settings, it is highly likely that these costs will reappear in other state budgets (such as Medicaid). In nearly all instances, this is almost unavoidable. In short, costs don't just disappear when individuals are moved.

Based on the forgoing, it appears that the conclusions drawn in the 2003 article continue to be valid.

KKW, January 23, 2009

APP G

Trends & Milestones

Edited by Charlie Lakin, David Braddock, and Gary Smith

Large State Residential Facilities: Status and Trends in Population Characteristics as of June 30, 2000

Jerra Smith, Bob Prouty, Barb Polister, Nohoon Kwak, and Charlie Lakin

Every 2 years, the University of Minnesota conducts a survey of large state-operated residential facilities in the United States for persons with mental retardation and related conditions with 16 or more residents. The most recent of these surveys was completed in February 2001. Statistics with an effective date of June 30, 2000, were gathered. A total of 189 large state facilities were identified and surveyed. All responded. Responses included 173 long forms (91.5%) and 16 short forms (8.5%). The long-form survey gathered detailed information on current residents and those in movement categories (admissions, discharges, deaths) and is the source of most of the statistics provided in this report.

Table 1 presents a summary of selected statistics to show national trends in the numbers and characteristics of residents in large state facilities over about 10-year periods between 1977 and 1996, and then 2-year periods between 1996 and 2000.

There have been rather dramatic changes in numbers and characteristics of large state facilities residents over the period shown. By June 2000, total large state facilities populations had decreased to about 31.3% of the total in June 1977. In June 1977, 35.8% of residents were 21 years and younger (or about 54,100 children and youth); on June 30, 2000, 4.5% of large state facility residents were 21 and younger (or about 2,100 children and youth). In June 1977, persons 40 years or older made up 23% of large state facility residents, whereas in June 2000, persons 40 years and older made up 61% of large state facility residents. Residents in large state facilities were, on average, substantially more severely impaired over the period, but in the last few years there has been a changing pattern. Resident

populations in June 2000 were quite similar in characteristics to those in June 1996 in terms of functional skills and secondary conditions, except that a higher percentage was identified as having *psychiatric conditions* (defined as requiring the attention of psychiatric personnel). Between 1996 and 2000, the percentage of large state facility residents reported to have a psychiatric condition increased from 31% to 42%.

Table 2 shows state-by-state summary statistics on selected characteristics of large state facility residents on June 30, 2000. As can be seen from the table, there were 9 states with no large state facility residents in June 2000, and 2 states with 60 or fewer (Minnesota and Oregon). It also shows many substantial differences among states in the proportion of total residents with various characteristics. For example, although institutions in 6 of the 42 states with large state facilities reported 12% or more of the large state facility residents 21 years or younger, 5 of the 42 reported that there were none. In 7 states more than 25% of large state facility residents were 55 or older, whereas 7 other states had less than 10%. Although only 20% of all large state facility residents were reported to have mild or moderate intellectual disability, more than 40% of large state facility residents had mild or intellectual disability in Idaho, Michigan, Minnesota, Missouri, New York, and South Dakota. Seven states reported that more than 75% of their residents had profound intellectual disability as compared with 10 with less than 50%. Similar differences were noted in ability to perform basic activities of daily living (ADLs) such as walking, dressing, and toileting independently.

Trends: Large state facilities

Table 1 Characteristics of Residents of Large State MR/DD Facilities From June 30, 1977, through June 30, 2000 (in %)

Characteristic	June 30 of the year				
	1977 (N = 151,112)	1987 (N = 94,695)	1996 (N = 58,320)	1998 (N = 51,485)	2000 (N = 47,329)
Age (years)					
0-21	35.8	12.7	5.0	4.8	4.5
22-39	41.3	54.1	44.6	38.1	34.4
40-62	19.2	27.3	42.7	48.9	52.7
63+	3.7	6.0	7.7	8.2	8.4
Level of mental retardation					
Mild/none	10.4	7.2	7.4	7.6	10.2
Moderate	16.4	9.8	8.9	9.5	9.8
Severe	27.6	20.0	17.8	18.3	17.7
Profound	45.6	63.0	65.9	64.6	62.3
Additional conditions					
Cerebral palsy	19.3	20.5	22.6	23.5	21.9
Behavior disorder	25.4	40.7	45.7	44.4	47.4
Psychiatric disorder	NA ^a	NA	31.0	34.3	42.0
Functional limitations					
Needs assistance or supervision walking	23.3	29.5	35.7	38.9	35.4
Cannot communicate basic desires verbally	43.5	54.8	59.4	59.6	59.4
Needs assistance or supervision in toileting	34.1	46.6	57.0	59.5	55.9
Needs assistance or supervision in eating	21.4	37.8	50.9	56.4	48.4
Needs assistance or supervision in dressing self	55.8	60.5	66.1	69.9	65.3

^aNot applicable.

Trends: Large state facilities

Table 2 Selected State Statistics on Characteristics of Residents of Large State Facilities on June 30, 2000

State	Total residents on 6/30/00	Age (years)						Percentage of residents					
		0-21		22-54		55+		Level of MR			Needs assistance/supervision		
		0-21	22-54	55+	Mild/moderate	Severe	Profound	Walking	Dressing	Toileting			
AL	633	1.8	79.3	18.9	26.4	18.2	55.3	31.6	47.8	40.8			
AK	0	NA	NA	NA	NA	NA	NA	NA	NA	NA			
AZ	166	0.0	77.8	22.2	18.5	30.9	50.6	38.9	63.6	61.1			
AR	1,228	9.8	83.5	6.7	13.6	21.0	65.4	31.0	58.8	45.2			
CA	3,850	5.8	78.9	15.3	17.7	15.0	67.3	36.7	70.4	68.5			
CO	122	5.7	82.9	11.4	26.0	4.1	69.9	64.5	71.3	71.3			
CT	988	0.2	63.2	36.6	18.3	51.4	30.3	16.0	72.2	65.1			
DE	253	2.0	73.9	24.1	9.1	17.8	73.1	51.8	67.2	60.5			
DC	0	NA ^a	NA	NA	NA	NA	NA	NA	NA	NA			
FL	1,502	2.2	78.9	18.9	27.2	12.6	60.3	17.8	56.3	24.6			
GA	1,535	6.2	76.4	17.3	11.9	17.1	71.0	49.4	79.7	63.5			
HI	0	NA	NA	NA	NA	NA	NA	NA	NA	NA			
ID	110	24.5	66.4	9.1	52.7	36.4	10.9	26.4	30.9	30.0			
IL	3,191	3.1	80.7	16.2	21.5	18.3	60.2	27.8	59.5	46.3			
IN	797	1.1	84.5	14.4	29.0	16.9	54.1	30.3	53.2	51.2			
IA	673	14.9	70.2	14.9	35.5	17.7	46.8	30.2	64.5	42.6			
KS	389	9.1	85.8	5.2	23.3	14.5	62.2	34.6	66.4	53.2			
KY	620	2.3	90.0	7.8	12.0	22.0	66.1	NA	78.7	62.4			
LA	1,743	5.1	79.3	15.6	13.8	13.0	73.3	47.7	77.3	73.0			
ME	0	NA	NA	NA	NA	NA	NA	NA	NA	NA			
MD	525	0.0	76.8	23.2	23.5	6.2	70.2	39.8	62.3	54.7			
MA	1,293	0.0	66.3	33.7	15.7	21.2	63.1	44.4	60.2	55.5			
MI	269	8.9	82.2	8.9	61.3	15.2	23.4	NA	46.8	46.8			
MN	48	21.6	73.0	5.4	89.2	8.1	2.7	0.0	0.0	0.0			
MS	1,409	13.6	72.5	13.8	23.0	15.4	61.6	37.1	61.3	50.0			
MO	1,278	5.6	82.7	11.7	42.0	22.5	35.6	32.7	50.8	39.7			
MT	130	4.6	82.3	13.1	33.9	3.9	62.3	46.9	75.4	66.2			
NE	399	3.8	76.2	20.1	17.6	8.6	73.8	44.4	67.4	58.7			

(Table 2 Continued)

Trends: Large state facilities

Table 2 Continued

State	Total residents on 6/30/00	Percentage of residents										Needs assistance/supervision					
		Age (years)			Level of MR			Level of MR				Needs assistance/supervision					
		0-21	22-54	55+	Mild/moderate	Severe	Profound	Walking	Dressing	Toileting	Walking	Dressing	Toileting				
NV	140	22.9	72.9	4.3	35.0	25.0	40.0	15.7	52.9	37.1							
NH	0	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
NJ	3,514	1.4	78.5	20.2	18.7	16.6	64.8	32.3	67.3	56.8							
NM	0	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
NY	2,411	7.8	71.2	21.1	40.7	16.8	42.5	30.7	52.6	54.5							
NC	1,936	1.4	72.9	25.7	7.2	15.9	76.9	43.0	81.6	74.0							
ND	153	8.5	77.8	13.7	35.9	10.5	53.6	49.0	62.1	62.1							
OH	1,990	0.7	72.1	27.2	20.1	21.8	58.2	26.6	61.7	45.8							
OK	339	3.0	95.3	1.8	7.1	19.2	73.8	62.8	71.4	74.5							
OR	60	0.0	70.0	30.0	6.7	5.0	88.3	15.0	55.0	53.3							
PA	1,969	0.0	72.5	27.5	12.5	17.3	70.2	46.4	70.2	63.6							
RI	0	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
SC	1,103	9.1	71.4	19.5	14.6	9.3	76.2	53.0	75.9	71.4							
SD	196	19.9	66.3	13.8	45.9	10.2	43.9	0.0	*	*							
TN	903	3.3	78.4	18.3	7.6	10.4	82.0	39.9	61.4	41.0							
TX	5,470	6.2	76.1	17.7	19.5	18.4	62.1	36.3	57.8	47.9							
UT	236	21	89.0	8.9	10.2	5.9	83.9	44.1	81.8	72.5							
VT	0	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
VA	1,653	2.5	80.4	17.1	34.2	16.9	48.9	32.4	71.1	60.6							
WA	1,128	1.4	80.3	18.3	13.6	25.9	60.6	35.0	63.8	53.9							
WV	0	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
WI	871	8.0	78.8	13.3	4.7	17.5	77.8	53.4	83.8	78.7							
WY	106	1.9	71.3	26.9	9.3	10.2	80.6	46.3	*	*							
U.S. Total	47,329	4.5	77.1	18.5	20.0	17.7	62.3	35.4	65.3	55.9							

*State has no large state-operated facility.

APP H

No Less Than a Person:
Liberalism and Disability Policy in Washington State

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Senior Thesis
Whitman College
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Introduction

Amy is eighteen years old. Just like her siblings, she goes to school 5 days a week, spends time with her family, and has clear interests and dislikes. Last summer, her parents went through the arduous process of naming themselves her guardians, retaining their power over her medical and financial decisions, and removing her right to vote. Amy has Wolf-Hirschhorn Syndrome, an extremely rare genetic condition that affects her physical health and cognitive development. Her frequent grand mal seizures have limited the growth she might have made. She cannot walk or speak, and she eats through a tube that slowly drips formula through the night into her overly small stomach. Her communication is limited, except to those who have learned her moods and dispositions, and tests show her cognitive function somewhat like that of a 10-month-old baby who has developed along average lines. Because of these conditions, she will never hold a job, live on her own, or survive without constant care.

My thesis focuses on how society determines care for people with severe mental and physical developmental impairments like my sister Amy. By “severe mental and physical developmental impairments,” I mean disabilities that greatly limit both bodily function and mental capacity and often accompany medical fragility. The designation of a developmental disability, legally and medically, means impairments that begin before age eighteen, impact an individual’s development into adulthood, and will remain for life. I chose to focus on those with both impairments because they often require the highest level of care and offer the hardest case for inclusion in liberal society.¹ Centrally, I ask if liberal theory and society can incorporate the personhood of people with severe impairments, and I examine the relationship between

¹ My thesis does not discuss physical disabilities, accommodation policies, life-skills level special education or other policies otherwise affecting those who, with accommodations, can participate in the liberal world.

liberalism and current disability policy. Traditionally, liberal theory has excluded people² like Amy as non-people because they do not fit the liberal definition of rational personhood. Unfortunately, our society, including much of the disability rights movement, still relies on this concept of personhood, leaving those with the most severe impairments in a problematic political space. In this vein, I explore the deinstitutionalization of people with disabilities by specifically examining the case of Fircrest School in Washington State between 2003-2005. In the controversy over Fircrest, we can see the conflict between liberal values and the care needs of individuals. I seek to find a new definition of personhood through which liberal society can fully value and care for people with their dependencies.

The deinstitutionalization movement, part of the broader disability rights movement, sought to move fairly capable individuals out of state-run institutions and schools and out into more integrated settings, commonly known as “community placement.” For those with relatively minor impairments, this move offered a greatly improved mode of life. However, for those with more severe disabilities, the deinstitutionalization movement meant the removal of necessary care facilities. Institutions, or Residential Habilitation Centers (RHCs) as they are now known, are often the only places that offer vital daily medical care. While individuals that are more capable value opportunity to seek jobs and participate in the community, people like Amy first need the medical care to keep them alive and healthy. The liberal values of freedom and autonomy do not serve everyone in the disabled community.

Writers in the liberal tradition emphasize rationality, autonomy, and the centrality of the individual. The tradition of social contractarianism, the ideological basis of modern liberal

² For the purposes of this paper, personhood, or personality, refers to the idea of a person in a political sense. The category of person is more inclusive than *citizen*, which confers membership in a particular political community, and less inclusive than the simply biological designation of human. A political person is an individual with recognized human rights, dignity and value (see “person, *n.*”)

societies, poses a particular problem for people with severe impairments because it rests its basic tenets, the freedom and equality of individuals, on individual rationality. John Rawls, drawing on the traditions of Immanuel Kant and John Locke, lays out his idea of social contractarianism based on rational personhood and mutual advantage. Rawls, following the liberal tradition, differentiates between a political person and a human being, and considers those without the requisite level of rationality and self-determination to be non-persons.³

Liberal theory broadly underpins our current conceptions of both a good political structure and what makes a human being a person. Personhood is important in liberal theory because the central liberal notions of rights and freedom stem from the idea that people are rational and autonomous. People have freedom and societal value because they can set and seek their own ends. Under this ideology, those with severe disabilities lack societal rights and dignity. We need a new definition of personhood to ensure protection and care for everyone. Although liberal theory emphasizes a duty to care for dependents in society, the denial of political personhood has thwarted that goal, as advocates value freedom over care.

The Disability Rights Movement (DRM) relies heavily on the rhetoric of liberalism. Advocates who fight against institutions use the language of independence and freedom to promote community living. As the DRM grew, advocates followed the pattern of other social movements and argued for the opportunity and autonomy of people with disabilities. Writers like James I. Charlton and Paul K. Longmore emphasize what people with disabilities *can* do, promoting their independence and self-determination. However, by focusing on abilities, the writers continue to value ability over disability and autonomy over dependence. When theorists rely on the liberal definition of personhood, care needs are forgotten and social norms and policies become about protecting the liberal individuality of people with severe disabilities

³ John Rawls, *Justice As Fairness*, ed. Erin Kelly (Cambridge, Mass: Harvard University Press, 2001), 24.

instead of ensuring their care. This means that individuals who cannot achieve these norms, like the severely mentally and physically impaired, are left out of the discussion, to the detriment of their health and well-being. Society cannot envisage a quality life outside of the liberal idea of personhood, so imposes liberal values onto people with severe impairments, and effectively values their independence over their health. We see these values reflected in the deinstitutionalization fight in Washington State. Advocates who sought to close Fircrest School argued for the independence and self-determination of the residents, putting care needs second to freedom and choice. With a changed concept of personhood in our society, we could value the care needs of an individual in more realistic relation to the need for autonomy.

Contemporary authors, particularly in the feminist tradition, critique liberalism and have sought to find a different conception of personhood, one that will bring the severely disabled into Rawlsian personhood and concepts of justice. The most successful authors in this attempt have been Amartya Sen, Martha Nussbaum, and Eva Kittay. In developing an alternative idea of personhood, I draw on their theories to construct an idea of personhood based on the idea that we are all *some mother's child*.

I divide this thesis into three sections. In the first, I explore personhood in the liberal writings of John Locke, Immanuel Kant, and John Rawls. I chose to focus on these writers because they have the most widely applied and critiqued articulations of liberal theory most likely to carry into social norms and practices. Second, I explore the case of Fircrest School in Washington State and the rhetoric surrounding deinstitutionalization there. The arguments employed by anti-institution advocates reveal their reliance on liberal personhood. Third, I look to contemporary scholars like Amartya Sen, Martha Nussbaum, and Eva Kittay who offer alternative conceptions of personhood.

In this thesis, I show how liberal theory of the rational and autonomous individual has shaped ideas and policies toward the severely disabled to the detriment of their care. I show this in the example of the controversy surrounding Fircrest School, that even those involved in disability advocacy remain stuck in the liberal values. Incorporating Kittay's idea of personhood as *some mother's child* and Nussbaum and Sen's capabilities approach will affirm the personhood of people like Amy, with limited rationality or self-determination, as *people* in liberal society. I believe that any project aimed at inclusion must begin first by affirming the personhood of individuals with severe mental and physical impairments. We must ensure personhood before we can work toward any real project of justice or rights; by first working toward personhood we can better understand and improve upon the position of those with severe disabilities in our society. A new idea of personhood will allow disability advocates and policy-makers to base public policies on a new set of criteria and advocates will be able to refocus their priorities toward essential health and medical care. If a valuable life is no longer judged by rationality and autonomy, our society and political system can properly include and care for people like Amy.

I: Liberalism and Non-Rational Individuals

"Autonomy is the ground of the dignity of human nature"
 – Immanuel Kant, *Metaphysics of Morals*

As Tamar Schapiro writes, dependency in liberal theory "is a predicament."⁴ Liberalism is a political school of thought that came out of the Enlightenment to argue for the essential liberty and equality of all men, and its basic ideas and theories have built the foundation of Western democracy. Liberalism began arguing against the European absolute rulers of the pre-

⁴ Tamar Schapiro, "What is a Child?" *Ethics*, 109 (July 1999), 725.

Enlightenment and purporting instead a system of freely consenting members who join together to form a society based on mutual interest. All of this rested on the rationality, natural rights and independence of individual members. Rights and freedom existed because of rationality, affirmed by an individual's ability to make his way in the world. Independence, rationality, and autonomy, therefore, form the liberal definition of personhood.

Despite the emancipatory project of liberalism, and the central role of freedom and rights, the concept of personhood excluded many members of society. Anyone deemed non-rational or dependent (usually the two went hand in hand) did not have a political stance. This included all women, children, and men who did not meet the requirements of productivity or rationality. Liberal writings meant to free some men from the bonds of absolutism. Ever since then, those excluded from the project have fought for their own emancipation and acceptance as people in liberal society.

The concept of liberal society based on individual reason appears early in the writings of John Locke. In his *Essay Concerning Human Understanding*, Locke lays out his concept of personal identity. He claims that personhood is entirely dependent on consciousness, the rational mind.⁵ Under that distinction, he differentiates between the waking and sleeping states. Since a man awake does not remember his time asleep, his sleeping self is in effect a different person. For Locke, a person "is a thinking intelligent being that has reason and reflection, and can consider itself as itself, the same thinking thing in different times and places."⁶ This requires self-awareness and memory. He is not only arguing that it is one's mind which makes him a person, but his consciousness of himself. He claims that infant Socrates is actually a *different person* than adult Socrates because adult Socrates cannot remember his infant state. While he

⁵ John Locke, "Essay Concerning Human Understanding," *Modern Philosophy*, eds. Roger Ariew and Eric Watkins, (Indianapolis: Hackett Publishing Company, Inc., 1998), 328.

⁶ *Ibid*, 322.

never explicitly states that a non-rational individual is not a person (as in, the infant Socrates is not a person), the conclusion is obvious if personhood is reliant on consciousness.

Ironically, the relatively minor requirement of self-consciousness would include most people in society, even people with mild to moderate mental disabilities. However, like most theories of personhood we will examine, those with limited consciousness or self-awareness prove to be the limit case of inclusion. This is precisely why I chose to focus on these people.

Locke's understanding of personhood and rationality come to a political sense in the *Second Treatise on Government*. In this work, Locke lays out his concept of a political society based on a social contract, a mutually advantageous pact made by all members of society. He argues that God gave the earth to the "industrious and rational" to use and organize as their free will saw fit.⁷ Here, Locke defines his subject as a productive and rational individual. This individual works to provide for himself, can consider the state of his own life, and seeks his own interests – in these ways he is rational and productive. Lock outlines the *state of nature* made up of men born free and equal men because of their rationality. However, in the *state of nature*, no laws govern conduct, so to better secure their mutual freedom and safety, they join together to form a political society under a social contract.

Locke bases his society on the cooperation of rational and productive men. This draws on his concept of personal identity as he includes in the social contract the individuals he would consider persons – men, of rational age, who are independent and productive. His dealings with children offer insight to the political position of those considered non-rational. Children are born *to* the status of men, they are born with the right to freedom and equality, but in their childhood, while they are not yet rational, they are neither free nor equal. Stemming from this, Locke also

⁷ John Locke, *Second Treatise on Government*, ed. CB Macpherson (Indianapolis: Hackett Publishing Company, Inc., 1980), 21.

considers, in his own way, the developmentally disabled. While children hold natural rights because they will eventually gain their rationality, “if, through defects that may happen out of the ordinary course of nature, any one comes not to such a degree of reason wherein he might be supposed capable of knowing the law, and so living within the rules of it, he is never capable of being a free man”.⁸ Here, Locke says that a non-rational person cannot be free because he cannot understand or follow the rules of the society built upon mutual consent. The non-rational subject is not a person because a person must be a rationally consenting and cooperating member of political society. Liberal theory fights for the emancipation of men based on their rationality. This criteria excludes severely impaired individuals; the inability to understand or consent to the social contract, along with the connection of mind and personality, forms Locke’s exclusionary personhood. Locke’s work formed a basis of political ideas for the centuries following, including those of Immanuel Kant, who lays out a morality, as well as a theory of freedom and autonomy, based on individual reason.

Like Locke, Kant lays out a concept of personhood based on rationality. In the *Grounding for the Metaphysics of Morals*, he describes an ethical and moral personhood based on one’s ability to make autonomous moral decisions. He argues that all rational beings have an individual will as determined by their practical reason. The autonomy of the will – ability to freely set ends for one’s life and pursue them – constitutes the dignity of human nature, the essence of human freedom, and the basis of political personhood.⁹ Kant’s second tenet is that each rational being is an end in themselves and, because of their essential human dignity, cannot be used as the means to another’s end. Society, therefore, is a Kingdom of Ends where each person is recognized as his own end and held to a moral standard to treat others as such. The

⁸ Ibid, 33-34.

⁹ Immanuel Kant, *Grounding for the Metaphysics of Morals*, Trans. James W. Ellington (Indianapolis: Hackett Publishing Company, Inc., 1993), 41.

ability to determine action is necessary for moral decision-making and therefore a prerequisite to enter the Kingdom of Ends¹⁰.

When faced with the problem of non-rational individuals, Kant makes a move similar to Locke. Kant differentiates between human beings and persons based on the idea that persons have rationality. Locke said that the consciousness makes the personal identity; Kant explicitly argues that only those of a rational and autonomous will be considered persons. Ethically, the autonomy of the will constitutes the essential freedom of a person, without which personhood is impossible.¹¹ In *The Metaphysics of Morals*, Kant draws a line between active and passive citizens. An active citizen would be a member of the Kingdom of Ends. A passive citizen, on the other hand, is one non-rational and dependent, who is excluded from active participate in the state. He defines a passive citizen as “anyone whose preservation in existence (his being fed and protected) depends not on his management of his own business but on arrangements made by another.”¹² This clearly includes anyone with severe developmental disabilities who will never gain a state of independence. Kant claims that these people lack a “civil personality” but still retain their basic equality as *men*.¹³ Kant draws a line between personhood and humanity important to liberal society, that although non-rational and dependent people lack political personhood, society still has a duty to them as human beings.¹⁴ Kant’s designation of active and passive citizens, political people and human beings greatly informs Rawls’ theory of liberal society.

¹⁰ Ibid, 40-41.

¹¹ Ibid, 35-36.

¹² Immanuel Kant, *The Metaphysics of Morals*, Trans. Mary Gregor, (Cambridge: Cambridge University Press, 1991), 126.

¹³ Ibid.

¹⁴ Schapiro, 721.

John Rawls' political theory follows in the tradition of Locke and Kant. In *A Theory of Justice* (continued in *Political Liberalism* and *Justice as Fairness*), Rawls lays out his plan for a Well-Ordered Society. In his theory, citizens begin at the Original Position where, under the Veil of Ignorance, they will attempt to build the Well-Ordered Society and the rules that govern it. They do not know their ultimate social or economic position, and so must build a society that is fair to all members. The societal rules that they construct will, because of the Veil of Ignorance, follow the Difference Principle, meaning that no societal change or rule will be made to advance the most well-off group without also advancing the least well-off group. The rules and institutions they create, following the Difference Principle, form the Basic Structure of the Well-Ordered Society.

In the fundamental tenets of his theory, Rawls excludes people with developmental disabilities. The central question of his work is: "what is the most acceptable political conception of justice for specifying the fair terms of cooperation between citizens regarded as free and equal and as both reasonable and rational, and (we add) as normal and fully cooperating members of society over a complete life, from one generation to the next?"¹⁵ Rawls focuses his attention only on those he considers free and equal, reasonable and rational, and normally cooperating. When Rawls refers to "free and equal" people, he is using the Kantian moral definitions, requiring a capacity for a "sense of justice" and a "conception of the good."¹⁶ These capacities mean a person has the ability to set ends for her life and pursue them, while understanding broader moral codes, just as Kant finds freedom in autonomy and self-legislation. This makes her a "self-authenticating source of valid claims."¹⁷ An autonomous will makes a person free, while her capacity to participate makes her equal. Here, a free and equal person has a sense of goals for her

¹⁵ Rawls, *Justice as Fairness*, 7-8.

¹⁶ *Ibid*, 18-19.

¹⁷ *Ibid*, 23.

life, understands them in context of broader morality and justice, and participates in society to achieve her own goals and the goals of the group. Given these definitions, it seems impossible that anyone with severe developmental disabilities would be either free or equal.

Rawls' requirements of reasonableness and rationality, as well as normal and full cooperation, stem from his basic ideas of freedom and equality. In these requirements, however, Rawls knows that he is only speaking to those within the average range of human functioning, which is why he includes the modifier "normal" to his group of "fully cooperating members". Rawls recognizes the exclusion that stems from the liberal foundation he uses.

Ultimately, Rawls solves his problem of non-rational individuals by making a distinction between a political person and the moral, biological, and psychological definitions of humanness. He defines a conception of the good and sense of justice as two moral powers that make up "moral personality."¹⁸ While accepting that individuals lacking the moral powers "either from birth or accident" do exist in society, "only scattered individuals are without this capacity" and therefore do not require serious consideration.¹⁹ In *Justice as Fairness*, Rawls draws on a history of those considered political persons, that they must be able to participate in society and cooperate in the forming and continuation of society, but that these ideas of personhood cannot be confused with our ideas of humanness.²⁰ Rawls cannot include as persons those who cannot participate in society because, drawing from the liberal roots before him, his society and his terms of a valuable life rely on individual rationality. From Kant he draws his moral and ethical theory of an autonomous will and definitions of freedom and equality. From Locke he draws his basic idea of a mutually derived and mutually advantageous social contract. As he demonstrates in *Political Liberalism*, Rawls understands that his normative conception of

¹⁸ John Rawls, *A Theory of Justice – Revised Edition*, (Cambridge, Mass: Harvard University Press, 1999), parts 3-4.

¹⁹ *Ibid*, 443.

²⁰ Rawls, *Justice as Fairness*, 24.

a person does not include all of humanity, but he chooses to put this problem aside. Here, Rawls may prove Eva Kittay correct when she writes, “the inclusion of people with mental retardation may well be liberalism’s limit case.”²¹

Although Locke, Kant, and Rawls make a distinction between humanity and personhood, their theories also both include a moral and civil duty to care for the non-rational. Locke states that those who do not gain their rationality remain under the government of their parents, who have a duty to care for them.²² Kant writes that the active citizenry may not create laws to the detriment of the natural freedom and equality that the passive citizenry holds as men.²³ In both of these theories, society has a duty to those non-citizens and non-persons because of their humanness. Rawls sets out a theory meant to provide egalitarian justice to everyone, and he stresses in *A Theory of Justice* that society must still assure basic rights and justice to people lacking the moral capacity for personhood. This is an essential component to the liberal treatment of disability. Liberalism, in general, does not deny the human rights of non-rational individuals, only their political personhood. The theories and policies outlined here assume a commitment to caring for the non-rational in society, which I admire. My project attempts to move beyond that and ensure the political personhood of people with severe impairments. As I will later show, the liberal definition of personhood has compromised the duty to care. Troubled by this exclusion, disability advocates seek to affirm the personhood of those with severe impairments by pretending that they hold the capacities (like independence and rationality) necessary for liberal personhood, rather than focusing on ensuring quality care. While I greatly appreciate the duties of justice and care in liberal society, the status as non-person perpetuates the devaluation of disabled lives. We must now find a way to include them as political persons to

²¹ Eva Kittay, “When Caring is Just and Justice is Caring,” *Public Culture*, 13.3 (2001): 559.

²² Lock, *Second Treatise*, 34.

²³ Kant, *Metaphysics*, 126.

ensure them the same level of dignity and value as normally functioning persons in order to provide quality care and true inclusion.

II: Deinstitutionalization and Fircrest School

“The principle that the disabled are as entitled as the nondisabled should not be held hostage to a notion that a disabled person must become “productive” or live “independently” if “suitably assisted,” or that it is less costly to place an individual in a community rather than an institution”
 – Eva Kittay

The predicament of the non-rational in liberal theory has led to a problematic position for those with severe impairments in liberal society today. Most liberal societies recognize the need to care for their dependent members, but often adults with severe mental disabilities remain undervalued as persons. While disability advocates argue for freedom and autonomy, these values do not serve everyone in the disabled population. The policies and ideologies that serve people with only physical disabilities fail for people with severe impairments and high medical needs. Many of these arguments focus against residential state-operated institutional hospitals and schools. This section will explore the deinstitutionalization movement, first through its roots in early disability advocacy, then focus more specifically on the controversy over Fircrest School in Washington State. By examining this case, I will uncover the liberal underpinning to much disability advocacy and policy, and trace how this theoretical framework disserves people with severe impairments.

Disability Rights and Deinstitutionalization

In the nineteenth and early twentieth centuries, the proper place for someone with any kind of disability was in an institution. Early schools formed especially for the deaf and blind, but other less prominent institutions also existed for the mentally ill and mentally delayed. While

attitudes and quality of care varied over time, by the turn of the century state-operated residential institutions were the only option for people with even mild mental or physical disabilities.

For most of the early twentieth century, the automatic “solution” for a family with a disabled child was institutionalization of the child. However, by the middle of the century, parents were beginning to question the institutionalization norm. Through the 1940’s parent organizations like United Cerebral Palsy, the New York Association for Help of Retarded Children, and the Association of Children with Retarded Mental Development began cropping up throughout the country. These organizations assisted parents in keeping their children at home by offering assistance in seeking education, health care, and employment for their children, as well as offering emotional support. In particular the Association for Retarded Citizens (ARC) began in the 1950’s with the goal to “liberate people confined in...custodial institutions.”²⁴ Themes of liberation and freedom reoccur throughout the movement. Many parents saw marked improvement in their mildly retarded children once they moved from institutions and especially once enrolled in school. In her book, *Becoming Citizens*, Susan Schwartzberg traces the history of several Seattle-area families with disabled children in the middle of the century. These parents, highly skeptical of institutional quality of care, formed the prominent Seattle-area organizations, like the Children’s Benevolent League. These groups laid the first groundwork for the national ARC.²⁵ This gives the Washington State and King County ARC branches particular prominence, and they will ultimately represent especially radical voices against institutionalization, an important factor in the fight over Fircrest.

²⁴ Doris Zames-Fleischer and Frieda Zames, *The Disability Rights Movement* (Philadelphia: Temple University Press, 2001), 9.

²⁵ The ARC of the United States, “A History of the ARC,” *About Us*. <http://www.thearc.org/NetCommunity/Page.aspx?pid=272>.

The anti-institutionalization movement later solidified as the Independent Living Movement (ILM) under the leadership of Ed Roberts. Roberts, who acquired massive physical disabilities from polio at age 4, fought for equality in education and accessibility, especially at his alma mater, and soon to be hub of the ILM, the University of California at Berkeley. Soon, he and his friends, the Rolling Quads, formed Centers for Independent Living to assist people with physical impairments to live in their own homes, as independently and productively as possible.²⁶

The ILM and various parent groups form two sides of the deinstitutionalization movement.²⁷ On one hand, we have parents who seek greater possibilities for their mildly retarded children, despite a society and health care system which tells parents that their children are hopeless. On the other, we have a group of adults, with only physical impairments, seeking greater fulfillment than institutional life can offer and demanding greater accessibility and equality. Both of these cases represent the strongest voices against institutions. Those with only physical impairments and those with mild retardation had the most to gain from leaving institutions in equality, education, employment, and general quality of life.

These cases against institutions are crucial to understanding the anti-institution movement because they represent the groups with the most to gain from non-institutional living and the liberal definition of personhood. Their central arguments elucidate the underpinning ideas of the ILM as Ed Roberts and others from the ILM rely on the rhetoric and ideology of liberalism. They, being of full mental capability and living in liberal society, value their freedom and autonomy. For someone of their capability, nursing home life would naturally feel like

²⁶ Zames-Fleischer, 43.

²⁷ For more on the history of early disability rights organizations, see Zames-Fleischer and Zames *The Disability Rights Movement* and Paul Longmore *Why I Burned My Book*, particularly ch. 5.

“incarceration.”²⁸ In his attempt to gain independence, Roberts valued his ability to make choices as the essence of his freedom. While these are central values for almost all members of our society, I seek to problematize those assumptions in the broader scope of the ILM.

My study focuses on the Residential Habilitation Centers (RHCs) and housing and care policies in Western Washington. I argue that the movement that began advocating against institutionalization has compromised the quality of care for the most fragile members of our population. By studying the recent fight over RHCs in Washington State, I argue that the ARC of Washington State has followed the larger deinstitutionalization movement and relied on the rhetoric and logic of liberalism. They have inadvertently defended the liberal definition of personhood and framed their advocacy around insisting on an individual’s independence and productivity, rather than advocating a more inclusive definition. They have taken on institutions in order to liberate disabled populations but, by relying on liberalism, have left behind our most vulnerable members of society. The liberal values that helped Ed Roberts argue for inclusion and equality have compromised the care and excluded the most disabled members of our population, the severely mentally and physically impaired.

Fircrest School, Washington State

The growing national trends against state operated institutions have spread across the United States and affected many states’ disability policies, including those in Washington. Washington has five RHCs,²⁹ but this study will focus on one, the Fircrest School in Shoreline, just north of Seattle. Most of these facilities were created in the period between 1930’s and 1950’s, during the rising popularity of custodial care. The national pressures against

²⁸ Simi Linton, *Claiming Disability*, (New York: New York University Press, 1998), 36.

²⁹ Frances Haddon Morgan Center in Bremerton, Lakeland Village in Medical Lake, Rainier School in Buckley, Yakima Valley School in Selah, and Fircrest School in Shoreline. In 1993, DSHS successfully ordered the closure of a sixth institution, the Interlake School, also in Medical Lake.

institutionalization also came to Washington State, and as soon as the early 1960's the state had established "Group Training Homes," the precursor to modern group homes.³⁰ In the 1970's the Department of Social and Health Services (DSHS) began programs to actively move people from institutions to community placements. The deinstitutionalization movement in Washington greatly reduced the number of people living in RHCs and helped build strong networks of community care. Increased regulation and awareness also improved conditions inside RHCs through increased staffing, training, and funding.

The term "community placement" usually refers to a group home, adult family home, or individual home where one or more people live and receive a variety of care services, from assistance a few hours a day, to 24-hour care. They are known as "community" placements because, operating out of small homes in residential areas, they offer an ostensibly more integrated setting than RHCs. Most importantly, community placements are best defined as *not* state-run RHCs but smaller-scale, usually private, operations that offer a more normatively acceptable living arrangement.

In 1999, the Supreme Court passed a landmark decision in *Olmstead v L.C.* The court found that, when determined appropriate by medical professionals and not opposed by the individual, the state must find community placements for individuals. Although the 1973 Rehabilitation Act and 1990 Americans with Disabilities Act had spoken broadly to issues of disability and discrimination, the *Olmstead* decision was the first piece of policy to speak directly to deinstitutionalization and create a state obligation to provide community care.³¹

Under the shadow of *Olmstead*, we find the case of Fircrest School and the Washington State 2003-2005 budget deficit. By the time the court ruled, the institutionalized population in

³⁰ The ARC of Washington State, "History," <http://www.arcwa.org/history.htm>.

³¹ Sara Rosenbaum and Joel Teitelbaum, *Olmstead at Five: Assessing the Impact*, The George Washington Medical University Medical Center, <http://www.kff.org/Medicaid/7105a.cfm>.

Washington had already dramatically decreased, from 4,145 in 1967 (at its peak) to just over 1,000.³² Facing a prospected budget deficit in 2003, in November of 2002 the legislature asked for a study looking into closing one of the state's five RHCs.³³ By January of 2003, the state legislature was seriously considering sale of one, Fircrest School in Shoreline. On February 26, Sen. Darlene Fairley, a Democrat of Lake Forest Park (a district including Shoreline and Fircrest School) introduced Senate Bill 5971 to close Fircrest, move the residents to other RHCs or community placements, and sell the highly lucrative land.³⁴ Almost immediately, parents, unions, and advocacy groups rallied against the closure. On the morning of Saturday, March 8, 250 Fircrest supporters stood in the rain and began an intense political battle over the allocation of DSHS funds, proper care for the disabled, and what it really means to live in an institution.³⁵

Although the SB 5971 failed in the Senate, the legislature included in the 2003-2005 omnibus budget bill a provision requiring DSHS to move 60 residents from Fircrest to other settings.³⁶ As DSHS tried to find residents to move, parent advocacy groups, including Friends of Fircrest, tried to find ways to preserve the RHC. On December 18, 2003, three residents filed suit through their guardians in King County Superior Court to create a permanent injunction against Fircrest's closure.³⁷ The suit sought to block many of DSHS's "unofficial" policies, including an approximately 15-year freeze on admissions and plan to close Fircrest within two

³² Sherrie Brown, *Washington Debates the Future of Residential Habilitation Centers for People with Developmental Disabilities*, (Unpublished manuscript, University of Washington, 2005), 3.

Jonathan Martin, "Judge OKs transfer of Fircrest residents," *The Seattle Times*, March 3, 2004, <http://community.seattletimes.nwsourc.com/archive/?date=20040303&slug=fircrest03m0>.

³³ Brown, 4.

³⁴ *Ibid.*, 8.

³⁵ Sarah Anne Wright, "250 rally against closure of Fircrest," *The Seattle Times*, March 9, 2004, <http://community.seattletimes.nwsourc.com/archive/?date=20030309&slug=fircrest09m>.

³⁶ Christine Clarridge, "Fircrest downsizing called 'truly cruel,'" *The Seattle Times*, February 28, 2004, <http://community.seattletimes.nwsourc.com/archive/?date=20040228&slug=fircrest28m>.

³⁷ Lisa Heyamoto, "Supporters of Fircrest sue DSHS," *The Seattle Times*, December 19, 2003, <http://community.seattletimes.nwsourc.com/archive/?date=20031219&slug=fircrest19m>.

years. Although DSHS never officially published these policies, the goals for Fircrest, and the other four RHCs were an “open secret” among disability workers and advocates.³⁸

On December 24, before the suit could be heard, DSHS issued an emergency ruling claiming that residents could not appeal transfers, effectively granting itself the power to move anyone out of Fircrest that it deemed appropriate, even contrary to family wishes or medical advice. DSHS tried to utilize this directive by moving nine residents, without guardian consent, on February 23, 2004, four days before the hearing date for the suit filed December 18. King County Superior Judge Terry Lukens stayed the transfers for a week because of the fragility of the residents and the upcoming hearing meant to decide the issue.³⁹ However, upon appeal, DSHS won the right to continue with the moves and moved four residents to Rainier School in Buckley.⁴⁰

On March 2, 2004 Judge Julie Spector, who had allowed the transfers, also dismissed the lawsuit to halt the downsizing and eventual closure of Fircrest.⁴¹ DSHS eventually succeeded in moving 57 Fircrest residents to either other institutions or community placements, at least 19 of them involuntary.⁴² At least three died following transfer,⁴³ including a woman who, after moving to an adult family home, died from untreated stomach acid burns on her abdomen from her gastrostomy tube.⁴⁴ In June of 2005 the Centers for Medicare and Medicaid Services, the federal agency who oversees DSHS actions, cited the agency in a leaked report for their handling

³⁸ Friends of Fircrest, “Fircrest School Residents Take DSHS to Court to Halt Eviction, Fircrest Closure,” Press Release, December 18, 2003, www.fircrestfriends.org/Press/pressrelease12-18-03.pdf.

³⁹ Angela Galloway, “State will close two Fircrest units,” *Seattle Post-Intelligencer*, February 7, 2004, http://seattlepi.nwsource.com/local.16150_fircrest21xx.html.

⁴⁰ Jonathan Martin, “4 to be moved involuntarily from Fircrest,” *The Seattle Times*, February 25, 2004, <http://community.seattletimes.nwsource.com/archive/?date=20040225&slug=fircrest25m0>.

⁴¹ Martin, “Judge Oks.”

⁴² Maureen O’Hagan, “State sued over Fircrest transfers,” *The Seattle Times*, April 13, 2006.

⁴³ Maureen Durkan, “Examine all the facts and keep Fircrest open,” *The Seattle Times*, July 15, 2005, <http://community.seattletimes.nwsource.com/archive/?date=20050715&slug=fircrest1>.

⁴⁴ Liz Patterson. Email to the author, February 25, 2009.

of the transfers and by February of the next year, DSHS issued a release ending all transfers for the time being.⁴⁵ Although both sides continued to contest the issue, the downsizing and possible closure of Fircrest had been settled.

The problem of choice

In the long history of Washington State RHCs, and Fircrest School itself, I have chosen to focus on the 2003-2005 debate because of the particular rhetoric that surrounded the issue. The debate over Fircrest became a much larger ideological debate about institutions themselves and the people who live in them. Over this issue, two clear sides emerged. The Association for Retarded Citizens (ARC), a national organization with both Washington State and King County branches, which ideologically and unwaveringly opposes institutions or any kind of large-scale living facility, zealously fought for Fircrest's downsize and closure. On the other side the Friends of Fircrest (FOF), a small parent and caregiver organization which believes that Fircrest offered the highest quality care available in Washington State, fought to keep Fircrest open. The rhetoric employed by both organizations, as well as DSHS and the ruling judge in the civil suit, reveals a great deal the broader political and social theory underpinning their arguments and ideas of valuable life.

Just as Ed Roberts argued for independence and autonomy, the ARC shapes its arguments around advocating for freedom and decision-making power. ARC texts particularly emphasize choice and empowerment – the virtues of autonomy necessary for liberal personhood. The ARC of King County, in its official position on Fircrest, claims, “Our constituents should be empowered to live in accessible and affordable housing similar to that of people without disabilities. Necessary individualized supports and adaptations should be of their choosing and

⁴⁵ Lewis Kamb, “Group blasts new Fircrest report,” *Seattle Post Intelligencer*, June 30, 2004, http://seattlepi.nwsourc.com/local/180139_fircrest30.html.

under their control or the control of their substitute decision-maker.”⁴⁶ The key words here, *empowerment* and *choice*, appear repeatedly throughout ARC advocacy literature. The national ARC contends that “people with disabilities must be empowered with the opportunity to control their housing by renting or buying their own homes.”⁴⁷ This claim further emphasizes individual control. When the ARC advocates for power and choice, it assume that readers will also value these ideals. If we look back to Kant, the power to make decisions was the essence of freedom and the essence of personhood.⁴⁸ His ideas have continued to shape our dominant political theory and, more importantly, our common social values and will recur repeatedly through ARC and DSHS literature.⁴⁹

The policy rhetoric of DSHS also reflects the liberal idea of personhood, again in the language of freedom and choice. In the *Residential Service Guidelines*, the Division of Developmental Disabilities (DDD) states its mission as promoting “maximum independence” as well as the preservation of “human dignity” and protection of “civil and human rights.”⁵⁰ It also, later in the report and under the heading “Power and Choice, ” expresses the ideal that DSHS and DDD residential programs should “protect and promote the dignity, privacy, legal rights, autonomy and individuality of each person who receives services” and that all people “gain autonomy, become self-governing and pursue their own interests and goals.”⁵¹ This means that DSHS recognizes the need for all people to have their own good, and to pursue it. When they express these values, DSHS and DDD reiterate the values of liberalism and the criteria for liberal

⁴⁶ The ARC of King County, “Position Statement on Fircrest School,” 2008, <http://arcofkingcounty.org/Fircrest/index.html>

⁴⁷ The ARC of the United States, “Position Statement on Housing,” *About Us*, 2008, <http://www.thearc.org/NetCommunity/Page.aspx?pid=1373&srcid=217>

⁴⁸ Kant, *Metaphysics*, 125.

⁴⁹ Carried throughout this as well is an importance of economic productivity. Although I do not have space to examine it here, the goal of economic productivity for all people also has roots in our underpinning ideologies of a valuable life.

⁵⁰ WSDSHS, “Residential Service Guidelines,” October 1998, 1.

⁵¹ *Ibid*, 4.

personhood. As Rawls puts it, a person is one “who can take part in, or play a role in, social life” and that free citizens of the Well-Ordered Society must be “self-authenticating sources of valid claims.”⁵² Here, he relies on the Kantian definitions of freedom and personhood. DSHS also relies on Kant and Rawls’ definitions, albeit unwittingly, when it outline its goals. As Schapiro writes, in Kant’s theory, “dependence is tolerable only as a nonideal condition...which, for the sake of justice itself, is to be regarded by each as the enemy of all.”⁵³ We can clearly see these values and ideals reflected in the literature of DSHS and the ARC, as they value choice above most other virtues.⁵⁴

Both the ARC and DSHS also rely on these definitions and, when faced with the challenge of institutionalized persons, make an ideological and theoretical move which seeks to change the individuals to fit the definition, rather than challenge the definition itself. The problem that plagues most of these arguments, when they advocate choice and empowerment, is that for most of the people they claim to speak for, choice is a near impossibility. According to the ARC, “Adults should control where and with whom they live” and “Individuals with disabilities should live together only when they *freely choose* to do so” (italicization mine).⁵⁵ These statements normatively assume that every individual can make a choice. By basing their fundamental ideologies on the choices of individuals, they pretend that all individuals can make important life decisions. This has two effects, it 1) continues to ignore those individuals who cannot make rational choices and 2) advocates for policies that do not serve the real care needs of many disabled people. The ARC imposes choice-making behavior onto people who, in many

⁵² Rawls, *Justice as Fairness*, 23-24.

⁵³ Schapiro, 721.

⁵⁴ DSHS literature, particularly their *Residential Service Guidelines*, also exhibits a generally normative concept of a valuable life. Along with emphasis on choice and empowerment, they also insist on activities and programs that mirror those of the rest of the community.

⁵⁵ ARCUS, “Housing.”

cases, do not have choice-making capabilities. While choice and autonomy may be important values for many people and form the backbone of much political thought, an autonomous definition of personhood necessarily disenfranchises those people who cannot make their own decisions.

The Friends of Fircrest, in opposition to the ARC and DSHS, took a different rhetorical turn in their arguments, emphasizing quality of care, rather than independence. However, they too occasionally fall into rhetoric of choice. According to their mission statement: “Friends of Fircrest is an all-volunteer, non-profit organization advocating for the rights to quality living choices for all people with developmental disabilities.”⁵⁶ In their press release on the 2003 lawsuit, they describe Fircrest as a “vital *choice* in care” (emphasis in original).⁵⁷ However, the FOF use choice language in a different manner than the ARC. In ARC statements, individuals do not have choices or freedom inside of an institution, but will gain them in a community placement. Alternatively, the FOF recognize that guardians, not the individuals in question, often exercise this choice. When FOF condemned DSHS for moving residents involuntarily, they criticized the moves without guardian or medical consent. FOF therefore avoids the imposition of choice-making behavior onto people, or an overreliance on ideals of freedom.

Disability advocates, as well as the public at large, emphasize freedom and choice because that is their only means by which to value a life. When I say that liberal theory shapes our ideas of personhood, I mean the liberal idea of individual value is often all we have. As Simi Linton points out, society and popular media love to show someone “overcoming” a disability, that they be “plucky and resolute” in order to live life like the rest of us. Similarly, the Seattle Times, in a report on Fircrest School from 1991 titled “Working their Way out – Determination,

⁵⁶ Friends of Fircrest, “About Friends of Fircrest,” 2009, <http://www.fircrestfriends.org>.

⁵⁷ Ibid, “Guardians of Fircrest Residents Forced to Move Sue DSHS for Damages Caused by Transfer Trauma,” Press Release, April 12, 2006, <http://www.fircrestfriends.org/Press/GuardiansSueDSHS12Apr06.pdf>.

Jobs Help Women Get Beyond Fircrest – And Society’s Perceptions.” Although the women in the article were barely verbal, the author states that one of them “kept a secret deep inside of her...she believed there would come a day when she’d work a regular job and form different friendships.”⁵⁸ This reflects what Linton argues, that society needs people to “overcome” their disabilities in order to find true value in life. And part of this “overcoming” is discovering a life in the community, that is, a life of freedom and choice. The National Council on Disability named their report on the Olmstead ruling “Reclaiming Institutionalized Lives”, denoting lives within institutions as inherently inferior and needing to be reclaimed. Similarly, Judge Julie Spector, in ruling to allow DSHS to move residents involuntarily argued all residents should be have the “freedom to pursue day to day activities, such as shopping, going to the movies, socializing with friends and family, marrying or owning a pet.”⁵⁹ Spector’s quote reveals both a deep ignorance of the people that she describes and, like the title of the Olmstead report, an exclusive idea of what makes life valuable.

As Margaret Lee-Thompson, King County ARC leader, argues, the “best practices for people with severe disabilities are now in small living situations in neighborhoods where people have *choices and freedom*” (emphasis mine).⁶⁰ Advocates repeatedly join choice and freedom as prerequisites of a valuable life. Lee-Thompson wrote this in January of 2004, while DSHS tried to move Fircrest residents against medical advice. In their drive for independent living for all, many disability advocates have forgotten the intense medical needs of many disabled people. Anecdotal evidence indicates that many individuals suffered or even died once moved from

⁵⁸ Ronald K Fitten, “Working Their Way Out – Determination, Jobs Help Women Get Beyond Fircrest – And Society’s Perceptions,” *The Seattle Times*, May 2, 1991, <http://community.seattletimes.nwsourc.com/archive/?date=19910502&slug=1280841>.

⁵⁹ Parsons, et. al. vs. WSDSHS, No. 03-2-12424-9 SEA. Superior Court of King County, Washington, <http://www.metrokc.gov/kcsc/rulings/parsons.htm>.

⁶⁰ Margaret-Lee Thompson and Joanne Whitehead, “Fircrest closure will give residents a chance to flourish,” *Seattle Post-Intelligencer*, January 6, 2004. http://seattlepi.nwsourc.com/opinion/155386_fircrestredux.html.

Fircrest to community settings. A woman died from untreated burns from a gastrostomy tube. One man drowned, unsupervised in the bathtub. Another man lasted only 48 hours away from Fircrest's high medical care when he drowned on his own mucus; the non-medically trained staff at his new group home did not know how to properly suction his airways.⁶¹ One wonders what "choices and freedom" matter when people cannot survive the liberation.⁶²

As Eva Kittay puts it, "the view that community placement has as its goal the independence and productivity of the disabled operates with a concept of personhood...that depends on 'rationality' and on the ability to partake in reciprocal cooperative arrangements."⁶³ Kittay echoes what I have argued above, that the virtues of community placement lie in liberal values of rationality and autonomy. Choice and freedom, as the ARC advocates in its housing policy, represent the fundamentals of liberal personhood. The language and values of anti-institution advocates reflects underlying values outlined by Locke, Kant, and Rawls – rationality and reasonableness; freedom, choice, and autonomy; and ability to understand, consent to, and participate in social cooperation. Because of the history of the DRM, many people believed that all disabled people could have these capacities, once "freed" from institutions. However, many severely impaired people cannot exercise these capabilities and do not fit in this idea of personhood or life-value. While I advocate choice and freedom for anyone who can make even the simplest choices in life, pretending that people can make choices, or pretending that people have an autonomy which they do not, greatly disserves people with severe impairments. Advocates attempt to foster these virtues in all impaired persons, particularly by advocating for "community placements." The goal of independence subverts the goal of quality care. In short,

⁶¹ Liz Patterson. Email to the author, February 25, 2009.

⁶² Chris Drinkwater, in his article "Supported Living and the Production of Individuals" refutes the claim that community placement offers more freedom, claiming that as a more normative environment, community placements in fact enforce a more strict code of conduct on residents.

⁶³ Kittay, *Caring*, 569.

by maintaining a liberal conception of personhood, anti-institutional policies have physically harmed many people with severe impairments, some to the point of death.

In the end, everyone who advocates for people with disabilities wants the highest care possible. However, many have lost sight of that goal in the face of the broad social need to normalize disability. Liberal definitions of personhood necessarily exclude those with severe disabilities, and when disability advocates continue to rely on them, they will not advocate for truly inclusive policies. To combat this, we need to find a different definition of personhood on which to rely. With a personhood that accepts dependency, and emphasizes other human goods, we can base policy not on the false value of autonomy, but on quality of care and quality of life.

III: Alternative Personhoods

“If personhood is limited to those who possess certain intellectual capabilities and to those who are productive, then my daughter would not be a person. But my daughter is a person. She is, after all, my daughter. How can she be anything but a person?” – Eva Kittay

As demonstrated above, the liberal tradition excludes people with profound mental impairments by considering them non-persons. When disability advocates continue to rely on the logic and rhetoric of liberalism, they perpetuate this problem. Often, advocates argue for people with disabilities by invoking liberal values like independence and productivity. As we saw in the case of Fircrest School, the imposition of liberal values onto the residents there negatively impacted their care. To solve this problem, I propose a new definition of personhood to create a new idea of a valuable life.

Many authors, particularly Eva Kittay and Martha Nussbaum, have criticized the liberal treatment of dependency issues, including the dependency brought by profound mental disability. I will examine these texts here and use them, with the capabilities approach originally

introduced by Amartya Sen, to propose a new definition of personhood. With personhood and life value newly defined, disability advocates and policy makers can rely on this new theory to base ideas and policies, and therefore improve real quality of care and quality of life, rather than continue in the same misguided perceptions.

In Sen's original conception of the capabilities approach, as proposed in his article *Justice: Means versus Freedom*, he sought to correct what he saw as a flaw in Rawls' theory of justice. He argued that the list of primary goods does not adequately ensure the material equality of individuals because Rawls ignored the individual's capacity to turn these primary goods into actual functionings. He calls primary goods the "means to freedom" as compared with "actual freedoms" that people enjoy in life (emphasis in original).⁶⁴ An individual can have the means to freedom without actually experiencing that freedom because of structural constraints. In his example, an individual who uses a wheelchair may possess all of the Rawlsian primary goods (basic liberties, income, wealth, etc) but may not have the capability to exercise these goods because of societal restraints – e.g., the individual's ability to move about will be restricted by city sidewalks without curb cuts. Because of issues such as these, Sen seeks to create, instead of primary goods, a list of capabilities central to human life that a Well-Ordered Society must protect and promote. The most important point here is that Sen emphasizes the variability of the capabilities list. He concludes, "we *are* diverse, but we are diverse in *different* ways (emphasis in original)."⁶⁵ Each person has different needs and different inherent abilities to convert goods into freedoms, so Sen allows his capabilities list to be personally variable.

Martha Nussbaum holds a similar critique of Rawls, although she focuses more specifically on the problem of contractarian mutual advantage for the severely impaired.

⁶⁴ Amartya Sen, "Justice: Means versus Freedom," *Philosophy and Public Affairs*, 19.2 (1990): 112.

⁶⁵ *Ibid*, 120.

Specifically, she argues that the Kantian concept of rational personhood shapes Rawls' ideas and that Rawls follows Kant in excluding the non-rational as non-persons. To solve this problem in Rawls' theory, Nussbaum proposes a schema of personhood based on the capabilities approach. Nussbaum's articulation of the capabilities approach includes a list of "centrally human capabilities" that constitute a life "worthy of human dignity."⁶⁶ In *Frontiers of Justice*, Nussbaum lays out her list of *Central Human Capabilities*.⁶⁷ These are: 1) Life, 2) Bodily Health, 3) Bodily Integrity, 4) Senses, Imagination, and Thought, 5) Emotions, 6) Practical Reason, 7) Affiliation, 8) Other Species, 9) Play, and 10) Political and Material Control over One's Environment. Nussbaum does two things with this list. First, she argues that the list provides a new definition of personhood, alternative to the rational personhood carried from Kant through Rawls that has so detrimentally excluded individuals with profound impairments. The capabilities approach measures personhood by an individual's capacity to exercise all capabilities on the list. Second, she outlines it as a list of social minimums that modern governments should ensure. The list functions as "the philosophical underpinning for an account of core human entitlements that should be respected and implemented by the governments of all nations, [and] as a bare minimum of what respect for human dignity requires."⁶⁸ Nussbaum defines personhood by the accomplishment of all capabilities on the list. Upon examination, however, this idea will prove problematic.

Nussbaum illustrates her argument with examples of three people who would be excluded from Rawls' definition of rational political personhood: Sessa Kittay, daughter of Eva Kittay, requires 24-hour care for her congenital cerebral palsy, suffers frequent seizures, and cannot walk, talk, or read; Nussbaum's nephew, Arthur, has both Asperger's and Tourette's syndromes,

⁶⁶ Martha Nussbaum, *Frontiers of Justice*, (Cambridge, Mass: Harvard University Press, 2006), 78.

⁶⁷ Ibid, 76.

⁶⁸ Ibid, 70.

meaning that despite his highly developed intellectual capabilities he cannot function in social settings and requires constant supervision; and Jamie Bérubé, the son of writer Michael Bérubé, has Down syndrome and high medical needs, but will most likely grow to hold a job and live relatively independently. Out of these cases, Sesha most closely resembles the severely impaired and medically fragile people caught in the debate over Fircrest School, who offer the major challenge to liberal inclusion.

The capabilities approach relies, at root, in concepts of human dignity. Nussbaum defines human dignity by these capabilities, which then allows both a more inclusive definition of personhood and the basis for why they should be entitled by well-ordered societies. The capabilities approach adequately includes and represents Jamie and Arthur. However, the list raises immediate questions for people like Sesha with more severe mental impairments. Nussbaum insists that to have a life “worthy of human dignity,” one must possess *all* of the capabilities on the list.⁶⁹ While Jamie or Arthur may be able to exhibit *Practical Reason* or *Control over Environment*, Sesha will never be able to perform such capabilities. Nussbaum’s theory moves away from liberal insistence on strict rationality and moral choice-making, but these capabilities still require an individual sense of the good which Sesha cannot develop.

Because of this, Nussbaum admits that Sesha will never live up to the human norm that she sets out and that “Sesha’s life is to that extent unfortunate.”⁷⁰ Here, Nussbaum fails the people she attempted to include. She claims Sesha has a “dignified and fruitful human life”⁷¹ through the proxy of her caregivers, but it remains unclear if this certifies Sesha as a person. Gaining her capabilities through her guardians, Nussbaum admits, “is not as good for Sesha as it

⁶⁹ Ibid, 166.

⁷⁰ Ibid, 192.

⁷¹ Ibid, 194

would be to have the capabilities on her own.”⁷² Nussbaum treats Sesha and her dependency as a special case, separate from the others – that she must achieve her valuable life from her caregivers, as opposed to others who achieve it themselves. Placing Sesha in a separate category of personhood does not include Sesha in any real way. Receiving her personhood through her caregivers is not good enough because it leaves Sesha in a less favored social position. Jamie and Arthur achieve personhood themselves, but Sesha does not. As shown above, the current problems in disability policy stem from the non-personhood and social exclusion of the severely disabled. Nussbaum’s solution fails to solve this fundamental problem because it fails to include Sesha at an equal social level or affirm her personhood. In Nussbaum’s writing, it remains unclear if Sesha, or anyone severely mentally and physically disabled like her, has a life worthy of human dignity.

Eva Kittay focuses her critique of liberalism on the work of John Rawls and the absence of dependency from the main structures of his Well-Ordered Society,⁷³ arguing that dependency remains largely absent from liberal theory, even though it forms a fundamental part of the human condition.⁷⁴ She also considers the problem of personhood and examines the theory proposed by Nussbaum. The problems of Nussbaum’s theory do not escape Kittay and she responds directly to Nussbaum in her article *Equality, Dignity, and Disability*. In this article, Kittay defends Sesha’s personhood, offers her own idea of a non-rational definition of personhood, and examines the issue of human dignity in the context of profound disability. She disagrees with Nussbaum that a person must have all of the capabilities on the list to have a life considered worthy of human dignity, that despite the innovations of Nussbaum’s work “it falls short of

⁷² Ibid, 193.

⁷³ Eva Kittay, *Love’s Labor*, (New York: Routledge, 1999), 105-106.

⁷⁴ The absence of dependency, particularly the absence of the home work done by women in society, is largely absent from liberal theory in general. This omission has been widely critiqued by feminist scholars, including Kittay, far beyond the small discussion of Rawls presented here.

finding a truly inclusive basis for human dignity.”⁷⁵ Nussbaum’s consideration of Sesha’s life as “to that extent unfortunate”⁷⁶ is unacceptable for Kittay. She argues, in response “that we not look for the basis of dignity in attributes we have as individuals, but in the relationships we bear to one another.”⁷⁷ She proposes an idea of human dignity and personhood based on the condition of being “some mother’s child.”

Some mother’s child is a conception of human dignity and personhood based on the idea that all people, no matter their circumstance, if they have lived past infancy, have received care from some mother.⁷⁸ This mother need not be biological or adoptive, need not be one person, and need not be female. Simply put, for one to reach adulthood, someone must take responsibility and must “enmesh” one’s existence with his or her own.⁷⁹ In Kittay’s view, this act of caring imparts dignity on the cared-for because of the particular nature of human care. A mother gives care because of its intrinsic worth, and in giving such care to another, the mother marks the recipient as worthy of that care. This human worth is the essence of human dignity, of a valuable life, and of personhood. All people have value because some mother has cared for them. They have rights and dignity out of societal respect for the care that mother imparted on them. This differs from Nussbaum’s idea of granting capabilities to Sesha through her caregivers because, under Kittay’s scheme, *all* people receive dignity and personhood from their mothers, not just those who cannot justify their human worth themselves. Kittay also uses her concept of everyone being *some mother’s child* to denote equality among all people. In this way, the idea covers many of the universal liberal ideals previously out of reach for people with severe

⁷⁵ Eva Kittay, “Equality, Dignity, and Disability,” *Perspectives on Equality*, Eds. Mary Ann Lyons and Fionnuala Waldron (Dublin: The Liffey Press, 2005), 109.

⁷⁶ Nussbaum, 192.

⁷⁷ Kittay, “Equality, Dignity and Disability,” 111.

⁷⁸ Kittay, *Love’s Labor*, 23-25.

⁷⁹ Kittay, “Equality, Dignity, and Disability,” 114.

impairments. Finally recognized as people, they can now have the dignity, equality, and the life-worth once denied to them.

What I propose here is a definition of personhood and dignity based on Kittay's idea of all people as *some mother's child*, along with an open capabilities list, one which does not require individuals to possess all capabilities on the list yet still encourages societies to promote all possible capabilities of individuals. This theory draws on both Kittay and Nussbaum to create an inclusive conception of personhood to not only include those classically excluded from political personhood, but also to give a foundation on which to measure a valuable life. Kittay's concept of *some mother's child* is an essential starting point for assuring the personhood of all people. Without a central grounding of personhood and human dignity, no inclusive or emancipatory project will succeed. Thus, a modified Nussbaumian capabilities approach, that reflects more of Sen's original conception of a variable list, outlines the basic goals of a valuable life that societies should promote while still valuing individuals who cannot achieve all capabilities on the list. While Nussbaum's insistence on the possession of all capabilities for valuable personhood is ultimately misguided and exclusionary, her list of human capabilities can be useful for determining the goals of a valuable life. The capabilities she includes are basic human goods that all people can understandably strive for. The capabilities approach provides a list of human goods that well-ordered societies should foster, the "core human entitlements that should be respected and implemented by the governments of all nations."⁸⁰ The list, beginning with *Life* and *Health* and ending with more complex goods like *Control over One's Environment*, provides a bare minimum of human goods. Because the capabilities on the list constitute many things that make human life enjoyable, we can understand them as goals for all people. Nevertheless, we cannot consider them the facets of all valuable life. As Kittay argues,

⁸⁰ Nussbaum, 70.

the intrinsic value of life comes from our relationships to one another, not from our capabilities. If an individual is incapable of exercising certain capabilities, such as *Practical Reason*, the individual still has a valuable life and can still be considered a person, worthy of human dignity, as *some mother's child*.

From this theory, new possibilities emerge for disability policy. While *some mother's child* lays a basis of personhood more inclusive than rationality, the capabilities list provides an account of basic human goods that societies should promote. In disability politics, advocates no longer need to promote the independence of people with severe impairments to prove their worth or personhood. As children of some mother, all people have value in their existence and relationships to one another. The value of a person *as a person* is assumed and need not be proven. Also, as a theory of human value that rests on care, Kittay's approach places care as a central human good. When society recognizes the important role of care in life, our policies can begin to value care in a way that they currently do not. As shown in the Fircrest example, current policy rhetoric often places ideals like "empowerment" and "choice" above quality care. Kittay's theory recognizes the flawed universality of these values and corrects them.

Second, the capabilities approach provides a list of human goods that societies should promote. While not all people should be required to possess every capability on the list, governments can create policies that foster them. Proper therapies and medical care can help improve quality of life for many people with severe impairments. With a new idea of personhood, the goals of such therapies need not to be to "fix" the people, but to help them live a better life.⁸¹ Likewise, governments and advocates can base housing and care policy on the quality of care needed and provided, not on the less important values of freedom or choice.

⁸¹ Adaptive therapies, and the "medicalization" of disability, have received criticism from disability theorists for attempting to "solve" disabilities. The theory introduced here allows therapies to improve quality of life for people

Here, we have a truly inclusive definition of personhood as well as a guiding principle for policy creation. All people have personhood, all people have dignity, and all people are included as valuable in political society as *some mother's child*. With a list of centrally human capabilities, and the definition of personhood in the care received from a mother, society can better include and serve all of its members. My goal in this project has been to create an alternative idea of personhood on which advocates and policy-makers could rely. As illustrated above, when disability advocates perpetuate values of liberalism, as in the case of Fircrest School, they ultimately promote false values and destructive policies. With a new definition of personhood, advocates can instead rely on the value of each person as *some mother's child* and promote policies in accordance with real care needs.

Conclusion

My thesis has focused on people like my sister, Amy, and the problematic political position they occupy in liberal society today. Because of Amy's severe mental and physical impairments, she cannot fulfill the criteria for liberal personhood. But, as Eva Kittay writes, "how can she be anything but a person?"

The liberal tradition requires rationality and independence for political personhood. These ideals have percolated into modern emancipatory movements, including the movement for disability rights. Able-minded activists argued for their inclusion and equality by highlighting their equal capacities for reason, rationality, freedom, and autonomy. However, these values have left out the most vulnerable members of the disabled population. Those with the most

without constructing disability as a problem to solve because it places human value on something other than one's abilities. (See Simi Linton, *Claiming Disability*, ch. 3 and Shelly Tremain's introduction to *Foucault and the Government of Disability*)

severe impairments do not have the capacity for rationality or autonomy, they do not (because they cannot) value their freedom to make choices.

Unfortunately, liberal values have continued to underpin our theories and policies for the disabled. As occurred in the controversy over Fircrest School, Washington State policy favored the promotion of choice and empowerment over high quality care. Cases like this show a strong need for a new conception of personhood in liberal society. I argue that when advocates value ideals like freedom and choice, they rely on the liberal logic of what makes a life valuable. In trying to promote the autonomy of severely impaired individuals, they attempt to put the liberal idea of personhood onto them; they attempt to make the severely impaired into valuable people in the liberal sense. The new definition of personhood proposed here will instead promote policies that recognize dependence and care.

I argue for a way to value people outside of rationality and autonomy, to denote personhood in more inclusive terms. Drawing on Sen and Nussbaum's idea of the capabilities approach, and Kittay's definition of personhood as *some mother's child*, I construct a theory of personhood that truly includes all people and provides a framework which places high quality care at its center. With care at the center of personhood and life-value, society can begin to construct policy that emphasizes care.

This thesis has raised other interesting ideas worthy of consideration in further research. First, the term "disability" is far too broad to serve any practical purpose, and too often refers exclusively to those with only physical impairments. In the Disability Rights Movement, most activists were mentally abled but physically disabled. The different outcomes of the movement for the physically and mentally disabled highlight the drastic differences between those with only physical impairments and those with mental (or mental and physical) impairments. In the context

of liberal theory, especially, the two groups occupy vastly different territories. Most importantly, people only affected by physical impairments can still argue for their personhood. They have a voice with which to fight for emancipation. The severely mentally impaired, however, have no such opportunity. Further research could be conducted into the social and political differences between these two groups, particularly in the creation of terms other than “disability” to describe people of such varying levels of impairment.

Second, a wider recognition of human dependency under the idea of a *spectrum of disability* could also address problems of care policy. As Kittay argues, all humans experience dependency, but most liberal theory ignores this fact and instead designates a binary between dependence and independence. The spectrum of disability recognizes the ubiquity of human dependency. Much disability theory has critiqued the binary made between abled and dis-abled persons. Contrary to ideas like the social construction model of disability, the spectrum of disability argues that *all* people are disabled and dependent in some way. Ideas that include all people in the disabled population could help our policy failings by removing the differentiation between abled and dis-abled, independent and dependent and therefore end the need to construct independence for people with severe impairments.

The central point of my thesis has been to find a definition of personhood that can include people like my sister, Amy. The social acceptance of people like Amy may very well be the last civil rights issue. As authors like Martha Nussbaum have shown by example, it is hard to find value in a life that few can conceive as possible. It is not that Amy cannot walk, but that she cannot understand how to operate her wheelchair. It is not that Amy cannot speak, but that she does not understand language. Many people want to assume that she has an internal world, that she is secretly observing and understanding, but I doubt this is true. Although Amy has a limited

understanding of the world around her, I consider her a *person*. I do not need to believe her capabilities are beyond what they are to consider her valuable in our family and in the world.

What I advocate, fundamentally, is a theory of personhood which accepts Amy as she is, no matter her dependency and no matter her care needs. And only when society accepts all lives as valuable, not tragic or unfortunate, will all people truly find inclusion.

Works Cited

- The ARC of King County. "Position Statement on Fircrest School." 17 Ap. 2008. 25 Nov. 2008.
<<http://arcofkingcounty.org/Fircrest/index.html>>
- The ARC of the United States. "A History of the ARC." About Us. 2008. 29 Jan. 2009.
<<http://www.thearc.org/NetCommunity/Page.aspx?pid=272>>
- . "Position Statement on Housing." About Us. 2008. 25 Nov. 2008.
<<http://www.thearc.org/NetCommunity/Page.aspx?pid=1373&srcid=217>>
- The ARC of Washington State. "History." 2007. 12 Dec. 2008.
<<http://www.arcwa.org/history.htm>>
- Charlton, James I. Nothing About Us Without Us. Berkeley: University of California Press, 1998.
- Clarridge, Christine. "Fircrest downsizing called 'truly cruel'". The Seattle Times. 28 Feb. 2004. 12 Dec. 2008.
<<http://community.seattletimes.nwsourc.com/archive/?date=20040228&slug=fircrest28m>>
- Brown, Sherrie. "Washington Debates the Future of Residential Habilitation Centers for People with Developmental Disabilities." Unpublished manuscript. Evans School of Public Affairs. University of Washington. 2 Aug. 2005.
- Drinkwater, Chris. "Supported Living and the Production of Individuals." Foucault and the Government of Disability. Ed. Shelley Tremain. Ann Arbor: University of Michigan Press, 2005.
- Durkan, Maureen. "Examine all the facts and keep Fircrest open." Seattle Times. 15 Jul. 2005. 12 Dec. 2008.
<<http://community.seattletimes.nwsourc.com/archive/?date=20050715&slug=fircrest1>>
- Fitten, Ronald K. "Working Their Way Out – Determination, Jobs Help Women Get Beyond Fircrest – And Society's Perceptions." The Seattle Times. 2 May 1991. 12 Dec. 2008.
<<http://community.seattletimes.nwsourc.com/archive/?date=19910502&slug=1280841>>
- Friends of Fircrest. "Fircrest School Residents Take DSHS to Court to Halt Eviction, Fircrest Closure." Press Release. 18 Dec. 2003. 12 Dec. 2008.
<www.fircrestfriends.org/Press/pressrelease12-18-03.pdf>
- . "About Friends of Fircrest" 2009. 24 Feb. 2009. <<http://www.fircrestfriends.org>>

- . "Guardians of Fircrest Residents Forced to Move Sue DSHS for Damages Caused by Transfer Trauma." Press Release. 12 Apr. 2006. 12 Dec. 2008
<<http://www.fircrestfriends.org/Press/GuardiansSueDSHS12Apr06.pdf>>
- Galloway, Angela. "Judge blocks transfer of residents from Fircrest." Seattle Post-Intelligencer. 21 Feb. 2004. 12 Dec. 2008.
<http://seattlepi.nwsourc.com/local.16150_fircrest21xx.html>
- . "State will close two Fircrest units." Seattle Post-Intelligencer. 7 Feb. 2004. 12 Dec. 2008.
<http://seattlepi.nwsourc.com/local/159775_fircest07.html>
- Heyamoto, Lisa. "Supporters of Fircrest sue DSHS." The Seattle Times. 19 Dec. 2003. 12 Dec. 2008. <<http://community.seattletimes.nwsourc.com/archive/?date=20031219&slug=fircrest19m>>
- Kamb, Lewis. "Group blasts new Fircrest report." Seattle Post-Intelligencer. 30 Jun. 2004. 12 Dec. 2008. <http://seattlepi.nwsourc.com/local/180139_fircrest30.html>
- Kant, Immanuel. Grounding for the Metaphysics of Morals. Trans James W. Ellington. Indianapolis: Hackett Publishing Company, Inc., 1993.
- . The Metaphysics of Morals. Trans. Mary Gregor. Cambridge: Cambridge University Press, 1991.
- Kittay, Eva Feder. "Equality, Dignity and Disability." Perspectives on Equality. Eds. Mary Ann Lyons and Fionnuala Waldron. Dublin: The Liffey Press, 2005: 95-122.
- . Love's Labor. New York: Routledge, 1999.
- . "When Caring Is Just and Justice Is Caring." Public Culture. 13.3 (2001):557-579.
- Kittay, Eva Feder with Bruce Jennings and Angela A. Wasunna. "Dependency, Difference and the Global Ethic of Longterm Care." The Journal of Political Philosophy. 13.4 (Nov. 2005): 443-469.
- Linton, Simi. Claiming Disability. New York: New York University Press, 1998.
- Locke, John. "An Essay Concerning Human Understanding." Modern Philosophy. Eds. Roger Ariew and Eric Watkins. Indianapolis: Hackett Publishing Company, Inc., 1998: 271-373.
- . Second Treatise of Government. Ed. C.B. Macpherson. Indianapolis: Hackett Publishing Company, 1980.
- Longmore, Paul K. Why I Burned My Book. Philadelphia: Temple University Press, 2003.

- Martin, Jonathan. "4 to be moved involuntarily from Fircrest." The Seattle Times. 25 Feb. 2004. 12 Dec. 2008.
<<http://community.seattletimes.nwsourc.com/archive/?date=20040225&slug=fircrest25m0>>
- . "Judge OKs transfer of Fircrest residents." The Seattle Times. 3 Mar. 2004. 12 Dec. 2008.
<<http://community.seattletimes.nwsourc.com/archive/?date=20040303&slug=fircrest03m0>>
- National Council on Disability. Olmstead: Reclaiming Institutionalized Lives. 19 Aug. 2003.
- Nussbaum, Martha. Frontiers of Justice. Cambridge, Mass: Harvard University Press, 2006.
- O'Hagan, Maureen. "State sued over Fircrest transfers." The Seattle Times. 13 Ap. 2006. 12 Dec. 2008.
<<http://community.seattletimes.nwsourc.com/archive/?date=20060413&slug=fircrest13m>>
- Olmstead vs. L.C. No. 98-530. Supreme Ct. of the US. 22 June 1999.
- Patterson, Liz. Email to the author. 25 Feb. 2009.
- . Email to Lori Flood. 28 Jan. 2004.
- Parsons, et al. vs. State of WA DSHS. No. 03-2-12424-9 SEA. Superior Court of King County, Washington. 2 March 2004. <<http://metrokc.gov/kssc/rulings/parsons.htm>>
- "person, *n*." OED Online. Dec. 2008. Oxford University Press. 23 Feb. 2009.
<http://dictionary.oed.com/cgi/entry/50176218?query_type=word&queryword=person&first=1&max_to_show=10&sort_type=alpha&search_id=jpfz-cXvtBc-3329&result_place=1>
- Rawls, John. Justice as Fairness. Ed. Erin Kelly. Cambridge, Mass: Harvard University Press, 2001.
- . Political Liberalism. New York: Columbia University Press, 2005.
- . A Theory of Justice – Revised Edition. Cambridge, Mass: Harvard University Press, 1999.
- Rosenbaum, Sara and Joel Teitelbaum. "Olmstead at Five: Assessing the Impact." June 2004. The George Washington University Medical Center.
<<http://www.kff.org/Medicaid/7105a.cfm>>
- Sen, Amartya. "Justice: Means versus Freedoms." Philosophy and Public Affairs. 19.2 (Spring 1990): 111-121.

Schapiro, Tamar. "What is a Child?" Ethics. 109 (July 1999): 715-738.

Schwartzberg, Susan. Becoming Citizens. Seattle: University of Washington Press, 2005.

Thompson, Margaret-Lee and Joanne Whitehead. "Fircrest closure will give residents a chance to flourish" Seattle Post-Intelligencer. 6 Jan. 2004. 1 Aug. 2004.
<http://seattlepi.nwsourc.com/opinion/155386_fircrestredux.html>

Tremain, Shelley. "Foucault, Governmentality, and Critical Disability Theory." Foucault and the Government of Disability. Ed. Shelley Tremain. Ann Arbor: University of Michigan Press, 2005.

Washington State Department of Social and Health Services. "Former Fircrest Resident Dies of Natural Causes In Bremerton Hospital" Press Release. 24 Nov. 2004. 14 Dec. 2004.
<<http://www1.dshs.wa.gov/medicareleases/2004/pr04311.shtml>>

---. Residential Service Guidelines. October 1998.

---. "Today's System of Supports for People with Developmental Disabilities." 11 July 2002. 1 June 2004. <<http://www1.dshs.wa.gov/cowofdd/supports.html>>

Wright, Sarah Anne. "250 rally against closure of Fircrest." The Seattle Times. 9 Mar. 2003. 12 Dec. 2008.
<<http://community.seattletimes.nwsourc.com/archive/?date=20030309&slug=fircrest09m>>

Zames-Fleischer, Doris and Frieda Zames. The Disability Rights Movement. Philadelphia: Temple University Press, 2001.

APP I

APPENDIX J

SURVEY PROCEDURES AND INTERPRETIVE GUIDELINES
FOR INTERMEDIATE CARE FACILITIES FOR
PERSONS WITH MENTAL RETARDATION

SURVEY PROCEDURES
INTERMEDIATE CARE FACILITIES FOR PERSONS WITH MENTAL RETARDATION

I. INTRODUCTION

This revised ICF/MR survey protocol is to assist surveyors to focus attention on the outcomes of individualized active treatment services. The Health Care Financing Administration (HCFA) intends the revised survey process to be less resource intensive for providers who consistently demonstrate compliance with the regulations. The survey process is based on the October 3, 1988 regulation and is applicable to all ICFs/MR, regardless of size.

In 1988, when the current ICF/MR regulation was implemented, it was viewed as a great step forward in promoting a focus on the actual outcomes experienced by consumers, rather than on the policies, procedures and paperwork of the facility. Since that time there has been an evolution on thinking in both the field of developmental disabilities (DD) and in the field of quality assurance (QA).

The field of DD is increasingly emphasizing supporting individuals in their own homes and communities, rather than placing people in facilities. In addition services in virtually all States are placing increased emphasis on person-centered planning and person-centered services that focus on the preferences, goals and aspirations of each individual and on supporting them in reaching their personal goals. The field of QA is placing increased emphasis on outcomes related to choice, control, relationships, community inclusion, and satisfaction with life, as well as satisfaction with services and supports. Many QA systems also include organizational self-assessment and continuous quality improvement components. These trends have contributed to the perception by providers and advocates that the ICF/MR regulation and oversight process is too prescriptive and cumbersome, and should be altered to reflect newer values of quality enhancement and continuous quality improvement.

This revised survey protocol gives facilities broader latitude to develop the processes by which it implements active treatment services. While the facility practice must comply with the requirements of 42 CFR 483, Subpart I, the survey is to center on the fundamental requirements that produce outcomes for individuals. When those outcomes occur, review of additional supporting requirements of process and structure is not indicated.

A survey which focuses on observations of staff/consumer interaction and on interviews with consumers regarding their participation and choice of services is sufficiently informative to determine the outcomes of active treatment. In the presence of problems, a more in-depth review of how the process unfolded for a particular individual(s) occurs.

A facility may receive reimbursement only for the cost of care of individuals classified as eligible for the ICF/MR level of care who are receiving active treatment. Determine facility compliance with Conditions of Participation and with standards in the context of individual experiences within the facility. When performing certification surveys to assess facility compliance, assess whether individuals are receiving needed active treatment services.

II. PRINCIPAL FOCUS OF SURVEYS

The principal focus of the survey is on the "outcome" of the facility's implementation of ICF/MR active treatment services. Direct your principal attention to what actually happens to individuals: whether the facility provides needed services and interventions; whether the facility insures

INTERPRETIVE GUIDELINES - INTERMEDIATE CARE FACILITIES FOR PERSONS WITH MENTAL RETARDATION

TAG NUMBER	REGULATION	GUIDANCE TO SURVEYORS
W122	<p>§483.420 Condition of participation: Client protections.</p>	<p>§483.420 COMPLIANCE PRINCIPLES: The Condition of Participation of Client Protections is met when:</p> <ul style="list-style-type: none"> o Individuals are free from abuse and neglect; o Individuals are free from unnecessary drugs and restraints; and o Individual freedoms are promoted (e.g., individuals have choice and opportunities in their money management, community involvement, interpersonal relationships, daily routines, etc.). <p>The Condition of Participation of Client Protections is not met when:</p> <ul style="list-style-type: none"> o Individuals have been abused, neglected or otherwise mistreated and the facility has not taken steps to protect individuals and prevent reoccurrence; o Individuals are subjected to the use of drugs or restraints without justification; or o Individual freedoms are denied or restricted without justification (e.g., systemic lack of privacy, of freedom of access to the community or to other individuals, in use of personal possessions and money, etc.). <p>§483.420 GUIDELINES: A citation of W127 or W150, which require that individuals are not subjected to verbal, sexual, or psychological abuse or punishment, is sufficient justification that the facility has failed to comply with the most fundamental of protections and, therefore, does not comply with this Condition of Participation.</p>
	<p>(a) Standard: Protection of clients' rights.</p>	<p>§483.420(a) GUIDELINES "Ensure" means that the facility actively asserts the individual's rights and does not wait for him or her to claim a right. This obligation exists even when the individual is less than fully competent and requires that the facility is actively engaged in activities which result in the pro-active assertion of the individual's rights, e.g., guardianship, advocacy, training programs, use of specially constituted committee, etc.</p>
W123	<p>(1) Inform each client, parent (if the client is a minor), or legal guardian, of the client's rights and the rules of the facility;</p>	<p>§483.420(a)(1) FACILITY PRACTICES: Individuals and their representatives, if applicable, are aware of the individual's rights and the rules of the facility. Information has been provided to the individual and their representatives, if applicable, in terms and language they understand. Individuals who are unable to understand their rights have family members, legal guardians or advocates who are involved in protection of their rights. §483.420(a)(1) GUIDELINES: The obligation to inform requires that the facility present information in a manner and form which can be understood, e.g., use of print materials, specialized programs to inform individuals who are deaf or blind, use of interpreters, etc.</p>

INTERPRETIVE GUIDELINES - INTERMEDIATE CARE FACILITIES FOR PERSONS WITH MENTAL RETARDATION

TAG NUMBER	REGULATION	GUIDANCE TO SURVEYORS
W125	<p>(3) Allow and encourage individual clients to exercise their rights as clients of the facility, and as citizens of the United States, including the right to file complaints, and the right to due process.</p>	<p>What does the facility do when individuals show consistent patterns of refusal of treatments or programs?</p> <p><u>§483.420(a)(3) FACILITY PRACTICES:</u> Individuals are taught and encouraged to claim and exercise their rights.</p> <p>A personal advocate or legally sanctioned surrogate decision-maker has been identified, when appropriate, and is encouraged to assist/support the individual in exercising these rights.</p> <p>Individuals and their representatives, if applicable, are aware of how to file a complaint and are free from reprisal when they do so.</p> <p>Individuals have the opportunity to register to vote and are taught skills to assist them in exercising this right.</p> <p><u>§483.420(a)(3) GUIDELINES:</u> The facility must ensure protection of the individual from any form of reprisal or intimidation as a result of a complaint or grievance reported by an individual.</p> <p>As long as there are no decisions or circumstances which require action by a legally- appointed surrogate, a spokesperson or advocate could assist the individual in exercising his or her rights as a citizen of the United States and as a person residing in the facility. Some examples might include assisting the individual to express his/her needs, wants and interests, to utilize community resources or to file a complaint. A spokesperson might also express opinions regarding situations in which consent by the beneficiary, parent of a minor, or legal guardian is required in order to bring to the attention of the facility potential concerns or problems.</p> <p>The extent to which any person can act on behalf of another individual who has been assessed as needing a guardian, however, is entirely dependent upon the needs of the individual client and upon the laws and regulations of the State in which that individual resides. The facility and surveyor must be familiar with the laws and regulations of the State in which the facility is located. It is inappropriate for the facility to unofficially delegate the individual's rights to others (e.g., parents, family, advocacy groups, etc.) To the extent that the individual is able to make decisions for himself or herself, it is inappropriate to delegate the person's rights to others.</p> <p>Individuals who need guardianship or advocacy, and do not have this need addressed, are not prepared to exercise their rights as citizens of the United States. The facility's failure to ensure guardianship or advocacy for those who need it should be cited. Further deficiencies may also be cited under W123, W124, W143, and W263, depending upon the survey findings.</p>

INTERPRETIVE GUIDELINES - INTERMEDIATE CARE FACILITIES FOR PERSONS WITH MENTAL RETARDATION

TAG NUMBER	REGULATION	GUIDANCE TO SURVEYORS
		<p>§483.420(a)(3) PROBES: How are individuals prepared to exercise their rights?</p> <p>Are provisions made for all individuals to assert their rights including those with mobility, sensory and communication impairments?</p> <p>Can staff explain individual rights and how they facilitate individual exercise of rights?</p> <p>Do individuals use advocacy systems?</p> <p>Are there established individual grievance procedures?</p> <p>Are advocates given access to the individual and his/her records, as appropriate, consistent with the Developmental Disabilities Assistance and Bill of Rights Act, as amended?</p> <p>Are rights that are modified or limited specific, general, or blanket? Are they reviewed to ensure continued appropriateness to the individual?</p> <p>What ways show that individuals assert their rights (e.g., do they vote, self-advocate, participate in self-governance council, participate in citizenship training, participate in community political activities)?</p> <p>What type of complaints do individuals report (if any) and how well does the facility respond?</p> <p>When interviewing individuals, do they describe situations which demonstrate the exercising of their rights?</p> <p>On what basis does the facility accept, or not accept, an individual's informed choice?</p> <p>In what manner is due process ensured? How does the team fit into this process?</p>
W126	(4) Allow individual clients to manage their financial affairs and teach them to do so to the extent of their capabilities;	<p>§483.420(a)(4) FACILITY PRACTICES: Individuals receive instruction (either as part of a formal program or a more general, informal series of activities) on handling their money which is geared to the individual's functional level.</p> <p>Individuals have opportunities to hold and manage their own money to the maximum extent of their capabilities.</p> <p>§483.420(a)(4) GUIDELINES: Since the use of money is a right, determine if the facility demonstrated, based on objective data, that the individual was unable to be taught how to use money before the decision was made to restrict that right.</p>

APP J

SAMPLE ASSESSMENT TOOL FOR COMPETENCY-BASED APPROACH

COMPETENCIES	EVIDENCED BY	EVALUATION METHOD
<p>Advocates for others. Promotes the wants, desires, and needs of another to persons with the authority and power to grant and/or provide the objects, items, and services wanted, desired or needed.</p>	<ul style="list-style-type: none"> • Negotiated relevant services and education systems on behalf of clients. • Helped others gain access to needed resources. • Identified barriers to the well-being of individuals and vulnerable groups. • Developed an initial plan of action for confronting these barriers. • Identified potential allies for confronting the barriers. • Identified environmental factors that impinged upon clients' development. • Alerted community or school groups with common concerns related to the issue. • Provided and interpreted data to show the urgency for change. • In collaboration with other stakeholders, developed a vision to guide change. • Analyzed the sources of political power and social influence within the system. • Developed a step-by-step plan for implementing the change process. • Developed a plan for dealing with probable responses to change. • Recognized and dealt with resistance. • Assessed the effect of advocacy efforts on the system and constituents. 	

APP K

Media coverage highlighting the increasing need for more effective federal and state protections in the ever-expanding community system of care for people with mental retardation

Washington, D.C.

Associated Press, December 15, 2008

Woman at D.C. group home is homicide victim

Authorities say a woman's death at a group home in Northeast D.C. has been ruled a homicide. D.C. Council member Muriel Bowser says police responded about 4 p.m. Sunday at the home for the mentally disabled in the 5400 block of Blair Road NE. Bowser says the home is operated by a contractor, and she is unaware of any complaints about the home. Authorities have not revealed the cause of death. Police Inspector Rodney Parks said Sunday evening that the case had been closed. The District's care of its disabled citizens as been in question since December 1999 when reporter Katherine Boo's Pulitzer Prize winning investigative series, "Invisible Deaths: The Fatal Neglect of D.C.'s Retarded" (see below).

Washington, D.C.

Washington Post, October 22, 2008

Disabled Man Died Before Needed D.C. Aid Arrived

"Mr. Johnson" badly burned himself while trying to cook. There were roaches on him when he showed up for medical appointments. He had difficulty using the toilet and rarely took his medication. But for years, the 65-year-old was deemed ineligible for help by the District agency that cares for mentally and physically disabled residents. For bureaucratic reasons, he officially did not exist.

In February, the District finally approved funding for him. It was for his burial.

That detail made the District's acting attorney general, Peter Nickles, call it "a sad story, the ultimate sad story," and a case that "fell through the cracks." City officials yesterday acknowledged mishandling the case and vowed to investigate.

Mr. Johnson, the pseudonym used by lawyers who took up the man's case in recent years, was hit by a bus when he was a toddler, in the 1940s. Doctors concluded that he was left mentally disabled, and for decades he remained at home under his mother's care. When the mother died 15 years ago, the man's well-being fell to a volunteer who cleaned, shopped and tried to arrange medical care from the city's agency for the mentally disabled. But the volunteer's efforts could not keep the man from living in squalor, hurting himself, skipping his medication and ultimately dying in a diabetic coma.

The legal advocacy group said it wrote the report to shine a light on a bureaucracy's fatal focus on paperwork protocol that kept a person in need from getting help. "We have other clients like him who have been waiting around for services, and they are denied services simply because they don't have the right records, usually documents from D.C. public schools," said Mary Nell Clark, managing attorney for University Legal Services.

The group represents abuse victims in a 30-year-old lawsuit against the District over quality of care in group homes for the mentally and physically disabled.

Illinois

Associated Press, March 21, 2008

Disabled pregnant woman used as target practice

Banished to the basement, the 29-year-old mother with a childlike mind and another baby on the way had little more than a thin rug and a mattress to call her own on the chilly concrete floor. Dorothy Dixon ate what she could forage from the refrigerator upstairs, where housemates used her for target practice with BBs, burned her with a glue gun and doused her with scalding liquid that peeled away her skin. Her attackers / housemates included Michelle Riley, 35, who they said befriended Dixon but pocketed monthly Social Security checks she got because of her developmental delays, Judy Woods, three teenagers (including Riley's 16-year old daughter), and Riley's 12 year old son. They torched what few clothes she had, so she walked around naked. They often pummeled her with an aluminum bat or metal handle. Dixon -- six months pregnant -- died after weeks of abuse. Police have charged two adults, three teenagers and a 12-year-old boy with murder in the case that has repulsed many in this Mississippi River town. Riley and Dixon, police said, had lived in Quincy, a Mississippi River town about 100 miles north of St. Louis, Mo. Quincy is where Riley worked as a coordinator for a regional center that helps the developmentally disabled with housing and other services. Dixon was a client. "The idea that someone would say, 'Have the handicapped people do it' is very disturbing," he said. "They just cut the grass and do the weeding. They work so hard."

Washington, D.C

Washington Post (column), March 16, 2008

Putting Mentally Disabled at Risk Is No Way to Cut Corners

Demolishing a building that dates back to the days of asbestos is a complicated business. You need to examine the construction method and, often, call in the men in white suits. When the Federal Aviation Administration decided to knock down an old guard shack last year on the grounds of the Washington Air Route Traffic Control Center in Leesburg, no such precautions were taken. Instead, managers called in a crew of mentally disabled people and put them to work at the site, which had been found in 1993 to contain asbestos. Now, the FAA says, the agency's inspector general, federal prosecutors in Alexandria and a grand jury are investigating whether the decision to give part of the job to people with severe disabilities was a purposeful attempt to circumvent procedures. A crew of about half a dozen workers from Echo Inc. (Every Citizen Has Opportunities), a Leesburg-based charity that trains and provides jobs for mentally retarded and other disabled people in Loudoun and Fairfax counties, has handled groundskeeping duties at the FAA facility for three decades, Echo Executive Director William Haney said. Haney said that when he heard about the asbestos incident, he asked the FAA for a written report on what role his workers had played but "never got anything." Haney was told that the workers' role in the demolition was "incidental," but, he said, "I just don't know what went on."

South Carolina

The Item, March 9, 2008

DSN under the microscope

Allegations of abuse, financial fraud have cast a shadow over a county agency whose clients are among the most "fragile and vulnerable." The director of the Sumter County Disabilities and Special Needs Board has been removed from his position and charged with five counts of criminal sexual conduct and two counts of kidnapping. He and the local board are defendants in a lawsuit brought by former employees alleging a hostile work environment and improper termination. In an unrelated incident, an employee of the Sumter County DSN Board has been charged with breach of trust with fraudulent intent after allegedly bilking the organization of

\$75,000. Whether coincidental or systemic, the nature and number of charges connected to the special needs agency are significant enough to warrant a closer look.

Even before the most recent charges, a group of lawmakers had decided there was sufficient cause to seek an audit of the entire department by the Legislative Audit Council. The state audit is expected to be finalized later this year.

The state Department of Disabilities and Special Needs serves those residents who have development disabilities, autism, head or spinal cord injuries or mental retardation. The state department, which opened in 1967 as the Department of Mental Retardation, acts as an umbrella to 39 local disabilities and special needs boards that serve the state's 46 counties, including Sumter County. The Sumter County board employs about 275 full- and part-time workers and serves about 600 clients. The board provides a variety of services, such as early intervention to help families assess children from birth to age 6; individualized rehabilitation to help clients have greater independence; helping clients find jobs; supervised living for adults able to live on their own; and community training homes for those who need a little more assistance. The board also hosts camps during the summer months. The Sumter agency was established by state law and county ordinances and is governed by a seven-member board, whose members are appointed by the governor upon recommendation of the local legislative delegation.

North Carolina

News & Observer, February 24 – March 2, 2008

Mental Disorder: The Failure of Reform

The series focuses on the aftermath of the 2001 mental health reform including aggressive deinstitutionalization, including findings of extensive financial fraud, astronomical community costs, and compromised treatment. It was predictable – people were displaced from psychiatric hospitals before community services were in place, costs were underestimated, privatization opened the door for opportunistic providers who took advantage of every loophole (and there were many). As a result treatment suffered and costs skyrocketed. According to the *News & Observer*, in January 2005, the state told the federal government those two services, community support for children and community support for adults, would cost less than \$5 million a month. By February 2007, when the Health and Human Services accountability team started an audit, the monthly bill was \$93.5 million. The full series can be found at:

<http://www.newsobserver.com/2789/story/962049.html> and includes these articles: **Part 1:** Reform wastes millions, fails mentally ill; **Part 2:** Companies cash in on new service; **Part 3:** Serious mental therapy fades; **Part 4:** Hospitals, nearly forgotten, teem with abuse; **Part 5:** Patients die from poor care.

Oregon

The Oregonian, November 4 – 10, 2007

After Fairview: How Oregon fails disabled adults

In the seven years since Fairview Training Center closed, more than 2,000 developmentally disabled adults have been robbed, beaten, raped, neglected or cursed, most often by their state-paid caregivers. Clients have choked on food, suffered violent injuries or become ill with treatable health problems that caregivers ignored or missed. In half the deaths investigated by the state, *The Oregonian* found that caregivers didn't recognize clients' serious health problems or act quickly enough to call 9-1-1. Their stories, archived in a state database and detailed in hundreds of confidential files obtained by *The Oregonian*, show that one of every five clients in state-licensed foster or group homes have been victims of at least one serious instance of abuse or neglect during the past seven years. The officials who oversee Oregon's 8,000 caregivers and 1,200 adult group and foster homes say they are working to protect clients. But the state has failed to close troubled homes, even after clients were raped or died. Officials also have been slow to adopt reforms in areas they acknowledge would make the system safer. See <http://blog.oregonlive.com/oregonianextra/2007/11/grouphomes.html> for full series.

California

CBS 5 Investigates, November 8, 2007

Bay Area Homes For Disabled

A CBS 5 Investigation raises questions about the quality of care in some for-profit group homes for the developmentally disabled. Our investigation begins with an incident in 2004 that happened at one Bay Area group home. Inside that home, Theresa Rodriguez, a woman with mental and physical disabilities had been badly burned. The home was run by RCCA Services. As a result of the scalding, the house was cited and fined by the state. And CBS 5 Investigates found that home was just one of three RCCA facilities in San Mateo County cited by the state for failing to meet federal standards. Two of those were cited for insufficient staffing, among other problems, and one was forced to shut down. CBS 5 Investigates also discovered the state recently found deficiencies at two other RCCA homes in San Jose. In January 2007, inspectors cited one of them, a home called Purple Hills, for failing to provide "continuous active treatment" for fully half of its clients.

Washington, D.C.

The Washington Post, September 15, 2007

Promises, Promises: The District has three months to show it can help its developmentally disabled residents.

The Washington, D.C. government has made a lot of big promises about improving the treatment of the mentally retarded men and women in its care. Over the years, it has broken most of those promises, and the result has been the neglect, mistreatment and even the deaths of many vulnerable people. Now a judge is demanding that the District keep some little promises. If it fails, it will be clear that the District is simply incapable of providing proper care, and the court should feel compelled to take over the system. U.S. District Judge Ellen S. Huvelle, presiding over the 31-year-old class action lawsuit involving onetime residents of the notorious Forest Haven facility, has made no secret of her aggravation over the lack of progress in protecting the health and safety of developmentally disabled residents. Decrying "the tortured history" of the case, Judge Huvelle in March found D.C. officials in "systematic, continuous, and serious noncompliance with many of the court's orders." Still, she has resisted placing the Department of Disability Services in receivership. This week, she issued an order that refreshingly focuses on tangible steps to improve the health and safety of the some 650 surviving members of the plaintiff class. The beauty of the judge's approach is that it compelled the city and the plaintiffs to come up with specific goals that can be accomplished in the next 90 days. There's nothing pie in the sky about the list that Judge Huvelle accepted this week. It includes recruiting five providers of high-quality residential care, expanding a medical clinic program, figuring out which homes really are substandard, and identifying and treating the 25 most medically fragile residents. Key to recruiting and retaining qualified providers is the District's promise to increase the rates it pays. Cost-of-living increases inexplicably were frozen for five years. That D.C. Mayor Adrian M. Fenty (D) is agreeing to come up with the \$4.7 million city share (Medicaid and Medicare would pick up the rest of the \$15.6 million tab) is a hopeful sign of his administration's commitment to reform.

California

The Orange County Register, February 7, 2007

Taped Attacks Spur Outcry

A caregiver worked at a dependent-care facility for at least five months before a cellular phone surfaced that contained videos police said show him beating and taunting developmentally disabled men who cannot speak. "This isn't an isolated incident," Anaheim police Detective Cherie Hill said. "I think there's a lot more going on than we already know." State-licensed care facilities are required to run background checks on potential employees, but many aren't licensed and aren't required to do such checks, Hill said. "What else happened that wasn't taped?" Anaheim police Sgt. Rick Martinez asked. "Nobody would've ever known had it not been for that video."

Kentucky

The Lexington Herald-Leader, January 7, 2007

Deaths largely not investigated - Critics see gaping hole in care of state's mentally disabled

The woman, whose name was not released, is one of thousands of mentally disabled people who received care in group homes paid for by Medicaid. And she is one of 146 people who died over the past five years in the Supports for Community Living Home and Community-Based waiver program, a network of 137 agencies that provides community-based services such as housing and counseling to 2,874 mentally disabled Kentuckians. Since 2001, the state has initiated on-site investigations in only 18 of the 146 deaths in the community living program, a Herald-Leader investigation found. Long-term mortality rates for mentally disabled people in community facilities are unknown. The department only started tracking deaths of the mentally disabled in the community in 2001. Thirty-eight of the 146 deaths since then were unexpected or sudden, according to the reports providers sent to the department. If any of those 146 people had died in a state institution in Kentucky their deaths would have been investigated by the Office of Inspector General with the Cabinet for Health and Family Services, and Kentucky Protection and Advocacy would have been notified. A mortality review board, made up of doctors and other specialists, also reviews all deaths in institutions. But the same review process doesn't apply when deaths occur in Kentucky's privately run, community-based care facilities. In those cases, only deaths deemed suspicious trigger an on-site investigation. The lack of in-depth investigation of deaths in the community is a gaping hole in Kentucky's protection of the mentally disabled, said Marsha Hockensmith of Kentucky Protection and Advocacy.

California

The Sacramento Bee, January 1, 2007

Conflict is boiling over care: The death of a severely retarded man is the latest flashpoint in a battle between families and the state over its developmental centers

Donald Santiago's mother and sister didn't want the state to move him out of the Agnews Developmental Center in San Jose, the state hospital where he had lived for nearly four decades. But state officials got a court order to move him into Justin's Home in Union City in 2005 over his family's objections. Santiago, 63, died of pneumonia in a Fremont hospital three weeks ago. The death of Donald Santiago -- being investigated by the California Department of Health Services -- is one more flashpoint in a wrenching battle between some parents of Agnews residents and the state, which has been under legal pressure to close its institutions and integrate residents with disabilities into their communities. Following changes in state law, the number of people living in developmental centers in California has dropped from a high of more than 13,000 in the 1960s to about 2,900 today. Three developmental centers have been shut down. Agnews, one of five remaining state centers for people with developmental disabilities, is slated to close in 2008. Only 261 residents remain. Some family members say they fear the state is hastily moving people into existing community homes that are ill-prepared to care for the severely disabled and don't have medical staff on-site, as Agnews does. Donald Santiago had the mental capacity of a 2-year-old and a vocabulary of only a few words, according to his sister, Angie Abrue of Placerville. But the state argued that Santiago had expressed a desire to leave Agnews in a 2005 court hearing before a Santa Clara Superior Court judge. Brian Boxall, president of the Association for the Mentally Retarded at Agnews, a group representing families, said the court system never should have ordered the move in the first place. "My sense of anger is most focused on the judge, the (district attorney) and the public defender who all orchestrated his placement knowing that his group home operator had these kinds of citations," Boxall said. "In that respect, Donald really was a victim of the system." Eileen Goldblatt, whose organization has assisted others in getting court orders but was not involved in Santiago's case, sees it differently. "It was our understanding that he got to court because he really wanted to move," she said. "It's tragic that he then died. It's also nice that he got to

Missouri

St. Louis Dispatch, December 20, 2006

Gov. Blunt orders Department of Mental Health to tell parents of sex offenders

The Post-Dispatch reported Monday that the state was placing people convicted or accused of sex offenses into privately run group homes and state-run facilities with other mentally retarded residents and was not notifying parents of the other residents. Gov. Matt Blunt said Tuesday that he was concerned about the report and that he had ordered the department to notify parents or guardians of others who share the group home with convicted offenders. He also ordered the department to ensure that all convicted offenders are registered with local police, as required by law. But the department will continue to keep secret the placement of people accused of sex offenses but not prosecuted because of their disability, saying state and federal law prohibit them from saying anything. Ron Nicholson, whose son was in a group home with a man accused of molesting a girl, said the new policy continues to put residents at risk. The man in the group home with his son had been determined to be incompetent to stand trial, so parents would not be notified of his presence under the policy. "I think it's atrocious. I think it's indefensible and unconscionable," he said. "They're knowingly and secretly putting known risks into group homes with non-risk individuals." The debate centers on about 50 people, and 31 of those are convicted sex offenders, department spokesman Bob Bax said. In three cases, the department discovered this week that it hadn't told police of the offender. In the rest of the cases, the department had notified police, although police didn't always list the offender on registries, Bax said. He said he thought that was because not all sex offenders are required to register. The debate comes as the Department of Mental Health already is undergoing major changes in how it reports and investigates abuse and neglect of residents, after a June series in the Post-Dispatch that found widespread mistreatment of residents and inadequate investigations of allegations.

Florida

The News-Press, September 20, 2006

Group Home Closed for Violations

Rodents and roaches. Chemicals left in unlocked cabinets. Electrical cords with wires exposed. A syringe in a kitchen drawer. Florida state inspections turned up those problems and others over nine months at 10 Professional Group Home, Inc. residences. The deaths of four residents and health and safety violations prompted the Florida Agency on Persons with Disabilities to shut down the Miami-based chain. The agency is required by law to monitor group homes once a year, but it does so at least once a month, officials report. Group homes are licensed by the agency and receive money through reimbursements from a Medicaid program for people with disabilities. There are 1,263 providers statewide. The homes are part of the state's emphasis on deinstitutionalization, taking people out of large institutions such as Gulf Coast Center. In one case, a Professional Group Home resident died just six weeks after he was moved from Gulf Coast center, where he had lived since 1994."

North Carolina

The News & Observer – August 13, 2006

53 Deaths in Five Years Tied to Adult-Care Violations

More than 50 people living in adult-care homes in North Carolina died recently after preventable mistakes. State records say that inattentive care, medication errors and poor maintenance of the homes contributed to the deaths over a five-year period. Residents of these assisted-living facilities, rest homes and family-care homes have choked to death, frozen, been scalded and wandered into traffic, according to reports on file with the state Division of Facility Services. One suffered a fatal stabbing by a fellow resident. Another received the blood thinner Coumadin for five days instead of Claritin, an allergy medicine. In each case, the deaths arose out of "something the facility did or failed to do," said Jeff Horton, the division's chief operating officer. For about

27,000 North Carolinians living in adult-care homes, the death rate after these preventable incidents is more than six times that of state residents over age 65 who die from health-care complications such as surgery gone wrong. These cases, in which people died after the staff or home committed serious violations, are just the ones reported to the state. Advocates for residents say more occur without notice. Outside of family and government, the deaths rarely get attention. A change in state law last year resulted in reduced public access to investigations and information about penalties in the cases. Since 2000, the state has dealt with 67 cases of preventable deaths in adult-care centers. The N&O analyzed 53 cases for which complete data were available and the most serious level of violation occurred, according to state records.

Washington, D.C.

Washington Post – August 5, 2006

D.C. Cleansed Group Home Death Reports; Court, Council Didn't See Unfavorable Information

The District government has altered reports concerning deaths of mentally retarded residents of the city's group homes, deleting damaging information before the documents were turned over to court officials and others who review the cases. The deletions, discovered by a federal court monitor, included information that described serious case-management failings; delays in obtaining consent for medical procedures; concerns about health care; concerns about autopsy findings and procedures; and problems getting information needed to complete the death investigations. One report was changed to remove several sentences critical of a case manager's oversight, including a complaint that he had visited the resident only once in eight years. The case manager still works for the Mental Retardation and Developmental Disabilities Administration, according to the court monitor, Elizabeth Jones. Jones frequently has faulted the city for the care and oversight of roughly 2,000 mentally retarded wards, most of whom live in group homes. In November, she said a pattern of neglect led to four deaths since late 2004, and she warned that other lives were in danger. In her latest report, Jones says the city also deleted some recommendations from the investigative contractor, the Columbus Organization that urged the mental retardation agency to change policies or practices to avoid future harm to group home residents, many of whom also have physical disabilities.

California

Inside Bay Area, July 3 – 5, 2006

Broken Homes

Some 26,000 of California's 200,000 developmentally disabled residents — people who are mentally retarded, have Down syndrome, are autistic or have other disabilities — get some type of community-based care, state data show, and many of them are in licensed care homes like The Circle-Los Altos, which are in residential neighborhoods all over the state. Many have been placed in care homes over the past dozen years, as the state emptied its institutions. Two state institutions for developmentally disabled people closed in the late 1990s and a third, Agnews Developmental Center in San Jose, is slated for closure in the near future. Many people are getting good services and leading happy lives in the community, those who work with them say. But others are being poorly cared for, according to the investigation of 300 care homes in Alameda, Contra Costa and San Mateo counties, which included more than 100 interviews and analysis of thousands of pages of public licensing reports and other documents spanning back to 1999. The investigation shows a care system whose low standards, poor funding and limited oversight spell trouble for the more severely disabled people it is now expected to serve — people the system was never set up for in the first place. And it shows that the state agency ultimately responsible for the welfare of the developmentally disabled — some of the state's most vulnerable people - has little direct involvement in their care. See, <http://www.insidebayarea.com/brokenhomes>

Missouri

Broken promises, broken lives, June 7 – 13, 2006
The St. Louis Post-Dispatch

A Post-Dispatch investigation has found abuse and neglect of mentally retarded and mentally ill residents in state centers and in private facilities the state supervises. Since 2000, there have been more than 2,000 confirmed cases of abuse and neglect with 665 injuries and 21 deaths.

<http://www.stltoday.com/stltoday/news/special/abuse.nsf/Front?OpenView&Count=2000>

Washington, D.C.

The Washington Post, June 24, 2006
Group Home Failures Persist - Care Still Lacking, D.C. Report Says

The District government continues to provide dangerous, substandard care to disabled residents at some of its group homes and has recently hampered oversight efforts by failing to provide full and timely information on critical operations, a federal court monitor has found. In her latest quarterly report, court monitor Elizabeth Jones describes numerous and chronic problems with the city's Mental Retardation and Developmental Disabilities Administration. She also questions whether she is getting complete reports on death investigations, saying that at least one document she received from the District was edited to remove information critical of the city. A review of five deaths between late 2004 and late 2005 showed that recommendations issued after death investigations weren't always shared with direct care providers, putting group home residents at risk, she said. "The continuing failure to remedy critical systemic issues of substandard care, treatment and oversight means that other clients will experience needless pain, delayed or non-existent attention to high risk situations involving health and safety, and unnecessary threats to their very existence," she wrote. "The urgency to remedy these systemic failures could not be greater."

Connecticut

Hartford Courant, June 12, 2006
Agency criticizes agency responsible for mentally retarded

A state agency, reviewing deaths of mentally retarded clients, is critical of the quality of health services provided by the state Department of Mental Retardation. The Fatality Review Board for Persons with Disabilities has concluded that the DMR contributed to the deaths of dozens of mentally retarded people in its care because it failed to provide them with adequate health care services. The report, released Friday, pointed to what it said were key weaknesses in the DMR's health care services including inadequate coordination of services for people living in the community, the discharge of hospital patients into shoddy nursing homes and insufficient nursing care. The report summarizes the board's review of DMR client deaths from July 2003 through June 2005. The board reviewed the deaths of 361 clients, ranging from people who live in state institutions to those living independently or with family, and conducted 35 in-depth investigations. The board found abuse or neglect in many of the cases. The mental retardation agency is reviewing the findings of the board and plans to use them to enhance the agency's existing efforts to improve its health and safety programs, according to a statement the DMR released Friday. It said it has already enacted some of the board's previous recommendations.

Virginia

Times-Dispatch, December 18, 2005
New stakes for study of group homes

A legislative study of group homes is expected to produce proposals for new laws to toughen the regulation of group homes in Virginia and require a closer look of how public money is spent on the care of troubled youths.

For state and local policymakers, there is evidence that Virginia isn't doing a good enough job in making group homes accountable for the care they provide at public expense under the Comprehensive Services Act, or CSA.

"The state has a laissez-faire approach to regulation and monitoring," he said, "resulting in a system that is extremely costly and not necessarily providing the quality of care that the kids deserve."

A legislative subcommittee plans to introduce legislation that would:

- Make the state put the new law into effect immediately.
- Tighten the standards for licensing and regulating group homes.
- Order a study by the Joint Legislative and Audit Review Commission of the rates charged under the Comprehensive Services Act, which pays for treatment of children primarily through a combination of state and local funds. The federal Medicaid program also contributes money for care under the system.

The state licenses and regulates group homes, as well as other kinds of treatment facilities, through four different agencies that in some way handle children with problems. The system includes children in foster-care, special-education and mental-health programs, and the juvenile-justice system.

[Internet: <http://www.timesdispatch.com>]

Washington, D.C.

The Washington Post, November 29, 2005

4 Deaths in D.C. Group Homes Raise Concerns About Neglect

The District government is failing to provide adequate care for mentally and physically disabled residents in its group homes, according to a court monitor who found that a pattern of neglect led to four deaths in the past year. One woman and three men "are dead because they did not receive timely and competent health care," court monitor Elizabeth Jones said in a newly released report. Jones expressed "grievous concerns" about the health and safety of hundreds of disabled people who live in the group homes, especially those with special health risks. The deaths, she warned, "reflect the lack of meaningful safeguards in the system." The four deaths might have been prevented if the city's Mental Retardation and Developmental Disabilities Administration had followed up on earlier recommendations for improving care in the homes -- and if the agency's case managers had been more vigilant in addressing critical problems, wrote Jones, whose staff reviewed medical records and death investigations. Sandy Bernstein, legal director for University Legal Services, which represents the plaintiffs in the suit against the District, criticized what she called "short-term approaches" to dealing with such serious failings by the city. The suit covers about 700 plaintiffs, all former residents of Forest Haven, a now-defunct institution for the mentally retarded. Another 1,300 plaintiffs are special-needs clients of the agency.

Washington State

Seattle Post Intelligencer, Nov. 16 – 18, 2005

Public Protection, Private Abuse (Mentally disabled preyed upon in state system)

11 articles in a three part series look at for-profit companies, contracted by the state, to closely supervise dangerous developmentally disabled people in the community. While the costly program does protect the public in many cases – most of the clients are sex offenders – it has left other vulnerable adults with developmental disabilities at risk of abuse and neglect.

The investigation of the Community Protection Program was based on multiple public disclosure requests to the Department of Social and Health Services which led to the release of more than 12,000

pages of documents. That included incident reports, recertification reviews of residential providers, financial reports and policy documents. <http://seattlepi.nwsourc.com/specials/protect/>

South Carolina

The State, October 28, 2005

State needs investigators to handle abuse and neglect cases, group says

Reports of abuse and neglect of disabled South Carolinians are too often mishandled and those responsible are rarely held accountable, according to a watchdog group. Protection and Advocacy for People with Disabilities Inc. released a report on a two-year study Thursday, highlighting 50 cases that included physical and sexual abuse and deaths in state-funded community-based residential facilities. The authors, who focused the study on the state Department of Disabilities and Special Needs, say the report portrays a broken system that provides little protection for those who cannot protect themselves. The report found flaws in the way many of the cases were handled, stemming largely from the practice of allowing facility administrators to conduct their own investigations into abuse claims rather than alerting law enforcement immediately. The state should create an independent agency, preferably within the State Law Enforcement Division, to investigate all abuse claims immediately, the report says. The agency would include specially trained investigators who know how to work with mentally disabled adults. The issue of abuse at state-funded care facilities came to the fore in recent years when a series of audits of the Babcock Center uncovered cases of abuse, neglect and exploitation of its residents. [Internet: <http://www.thestate.com>]

National

The Wall Street Journal, September 20, 2005

Difficult Choices: Needing Assistance, Parents of Disabled Resort to Extremes

Nationwide, an estimated 80,000 developmentally disabled people are waiting for in-home help or an opening in a group home. Some have been on waiting lists for more than a decade. In Texas, there are 46,000 people waiting for such help -- or about four times the number of people actually receiving assistance. Requests are increasing as the nation's 4.6 million developmentally disabled, like the rest of the population, are living longer. Meanwhile, their parents are aging too, making it harder to keep up with caretaking.

Long waits for help have prompted lawsuits in two dozen states, charging violations of a 1999 Supreme Court decision requiring states to make diligent efforts to serve disabled individuals in their community. Florida settled one suit in 2001, promising services to 17,000 people on waiting lists. By increasing spending, it did. Since then, the waiting list has ballooned again, to more than 15,000.

Indeed, even though public spending to provide community services to people with developmental disabilities grew by 17% between 2000 and 2002 -- to about \$27 billion -- demand for those services continues to outpace availability. Federal funds, primarily Medicaid, provide 50% of that \$27 billion, with states kicking in 46% and local funds the remaining 4%.

"Unless you're in a crisis, you don't get services. I'm sure that's the case in most states," says Tony Paulauski, executive director of ARC of Illinois, part of a national, nonprofit organization for the developmentally disabled.

National

The Wall Street Journal, September 13, 2005

Safe Place: Disabled People Find Group Homes Can Be Broken too -- Patients Gain Independence, But Oversight is Spotty; Challenges of Monitoring

Over the past three decades, there has been a concerted effort to move people with developmental disabilities out of large institutions, which had been long criticized for being overcrowded and isolated. A widely lauded effort to move people into smaller group homes has succeeded in bringing the developmentally disabled into communities where they can learn new skills, get jobs or attend special schools. But this progress has come at a price. It has strained the systems that support people living in the smaller settings and created big gaps in oversight.

Twenty-five years ago, people with developmental disabilities lived in about 16,000 publicly funded homes. Today, they are scattered in about 140,000.

"The systems of quality monitoring have really been taxed beyond what they can manage," says Charlie Lakin, who heads a University of Minnesota program that tracks services to the developmentally disabled. "By and large, a lot of it is pretty loosely organized and pretty loosely monitored."

Only a half-dozen states require that residential programs serving the developmentally disabled be accredited by an independent third-party organization. Developmental disabilities, which affect about 4.6 million people in the U.S., include a range of mental and physical impairments, such as cerebral palsy, autism and mental retardation. Babcock (South Carolina community provider) offers a stark look at the flawed monitoring of group homes, which sometimes leaves family members and other advocates feeling they need to police the care themselves.

The U.S. Department of Health and Human Services -- which pays about half of the \$27 billion spent annually on community services for the developmentally disabled -- is ultimately responsible for their protection. But the federal agency assigns the creation and enforcing of rules over such homes to each state. As a result, laws and monitoring vary by state. States aren't required to report all incidents of abuse or neglect to the federal agency. The federal government typically only gets involved if families, advocates or employees of homes provide credible concern about the thoroughness of a state investigation. HHS, which oversees the Centers for Medicare and Medicaid Services, is drafting new procedures following a 2003 report from the General Accounting Office, saying states should be required to report more information about how they protect people with developmental disabilities.

Thousands of nonprofit group homes offer well-supervised programs for the developmentally disabled. But problems exist to some degree in nearly every community, says Curtis Decker, executive director of the National Disability Rights Network, a nonprofit group. Investigators may overlook flaws, he says, because of a lack of other housing options. "They don't know what to do with these folks if they closed a place down." The number of abuse and neglect cases among the developmentally disabled isn't collected nationwide. Many states don't keep central databases on employees involved in such cases, allowing workers to move from one agency to another. "You put people in tough jobs, who are underpaid, not well-trained or supervised, and the potential for abuse is big," says Mr. Decker. "It's endemic to the country."

Missouri

Missouri State Auditor, September 2005

Report No. 2005-62: State mental health clients not fully protected from abuse and neglect due to problems with incident investigations and abusive workers still employed

This audit reviewed how well the Department of Mental Health tracks, investigates and handles incidents and investigations of individuals committing abuse or neglect against its 140,000 clients. All such allegations, including client deaths are tracked in the department's Incident and Investigation Tracking System, which reported 5,689 incidents from July 2003 through August 2004. This audit also followed up on recommendations from a 2001 audit and found systemic problems with abuse investigations. The audit found continuing problems in several areas, including continued employment of known felons and abusers, leading to more abuse, and

overall lack of independence and consistency in abuse investigations. [Internet: <http://www.auditor.state.mo.us/press/2005-62.pdf>]

Maryland

The Baltimore Sun, April 10-17, 2005

A failure to protect – Maryland's troubled group homes.

In an investigation of state oversight of group homes going back a decade, The Sun found that:

- Mistreatment of children has gone unpunished.
- People with criminal convictions can -- and do -- work at group homes.
- Taxpayers' money is often wasted on poor care, denying youths a range of services.
- Maryland subsidizes high salaries and perks.

The Sun examined the regulation of care, spending and staffing at 25 companies that ran 120 homes for children. Reporters studied 15,000 pages of inspection reports, case files and other records obtained under the state's Public Information Act and conducted more than 150 interviews.

[Internet: <http://www.baltimoresun.com/news/local/bal-grouphomes,1,270369.special?ctrack=1&cset=true>].

Florida

The Miami Herald, March 26, 2005

Deaths at group homes being probed

In light of cost-cutting changes in nursing care, an investigation is under way into the deaths of four disabled Floridians at group homes. A federally-funded watchdog group is investigating the recent deaths of four disabled Floridians amid an aggressive state campaign to cut millions of dollars from programs that provide medical care for disabled people in community settings. In 2001, the state hired a private company, Maximus Inc., to look for ways to save \$24 million annually. The company's actions have been upheld in 97 percent of the appeals to state officials. Advocates for the disabled insist the quality of medical care for disabled people in group homes has suffered since September when Maximus and the state began requiring group homes to pay for nursing care from the state's Medicaid plan. That plan covers rotating nurses, not the more stable nursing care provided under a previous plan for disabled people. [Internet: <http://www.herald.com>]

National

People with Mental Retardation & Sexual Abuse

The Arc of the United States

(author: Leigh Ann Reynolds, M.S.S.W., M.P.A., Health Promotion & Disability Prevention Specialist)

More than 90 percent of people with developmental disabilities will experience sexual abuse at some point in their lives. Forty-nine percent will experience 10 or more abusive incidents (Valenti-Hein & Schwartz, 1995). Other studies suggest that 39 to 68 percent of girls and 16 to 30 percent of boys will be sexually abused before their eighteenth birthday. The likelihood of rape is staggering: 15,000 to 19,000 of people with developmental disabilities are raped each year in the United States (Sobsey, 1994). [Internet: <http://www.thearc.org/faqs/Sexabuse.html>]

North Carolina

The Charlotte Observer, January 16, 2005

Millions Wasted – The Cost of Kids' Lives

Since 2001, the state has wasted tens of millions of dollars paying group homes for workers who were never hired, making the industry so lucrative that hundreds of new homes opened – so many that the state couldn't regulate them. The error helped create a system that's failing some of the state's most vulnerable youngsters and cheating taxpayers who pumped more than \$165 million into homes last year. In the past three years, as group homes multiplied and regular inspections ceased, many group home owners exploited the system's weaknesses. Many ignored even the state's minimal standards, putting children at risk. [Internet: <http://charlotte.com>].

California

California Department of Developmental Services (DDS), October 27, 2004 California Releases Mortality Studies

During the late 1990s, a series of epidemiological studies of death rates in California mental retardation institutions compared community residential settings was issued by the University of California Riverside. These reports found risk of mortality to be 83% higher in community settings than in institutions (see, <http://www.lifeexpectancy.com>, link Articles, Comparative Mortality). These studies prompted the California Department of Developmental Services to commission two follow-up studies. Comparing quality of care provided by developmental centers, community care facilities, intermediate care facilities and other settings, the report indicates, "there were few statistically significant differences in the quality of care, "though it was noted that the developmental centers provided a 'higher quality of care.'" One problem in determining the adequacy of health care for this study was the lack of documentation. Except for developmental centers, the lack of documentation was an issue for all other types of facilities. Another issue pointed out by the authors of the report is the need for health education appropriately geared for the developmental level of the consumer. An earlier report (1994) noted that "residents at developmental centers were significantly less likely to die from preventable causes than those residing [in] skilled nursing facilities, intermediate care facilities, or community care facilities." The preventable deaths were primarily due to "inadequacies in the quality of care" followed by "inadequacies in the medical management of common health concerns."

The three reports can be found on the Department of Developmental Services website:

http://www.dds.cahwnet.gov/mortality/mortality_home.cfm

http://www.dds.cahwnet.gov/mortality/PDF/CSUS_Final94_Report.pdf

http://www.dds.cahwnet.gov/mortality/PDF/CSUS_Final99_Report.pdf

Maryland

The Baltimore Sun, August 1, 2004

Safeguards meant to protect the disabled in Maryland group homes failed this time

Toby Adele Heller died of colon cancer 11 months after caretakers failed to follow a physician's advice to see a gastroenterologist. Toby's case exposes holes in the state system of care for 5,000 people with developmental disabilities living in licensed group home facilities. Employee turnover is high – 42 percent a year among aides – and wages are low. Even with the recent state-imposed increases, caregivers on average make less than \$10 an hour. Quality of care varies with their skills and compassion. And regulators rely heavily on the facilities and families of residents to report problems. But, with nearly 7,000 people on a waiting list for residential services, relatives are often afraid to complain, fearing that their loved ones would have nowhere else to go. Still, Toby's family, like other families, had every reason to expect that she was getting good care: The state was paying top dollar for her to receive round-the-clock staffing at a cost of \$127,672 a year. Her provider, Autumn Homes, received \$2.6 million from the state to provide services for 32 clients in 2003.

[Internet Access: <http://www.baltimoresun.com>]

Virginia

The Washington Post, May 23 – 27, 2004

Assisted Living in Virginia

In a series of articles this week, The Washington Post reported that residents at the facilities have suffered thousands of incidents of harm, including death, abuse, neglect and serious injuries. The state is home to 627 facilities licensed to care for more than 34,000 residents who need supervision and care but who are not sick enough to qualify for a nursing home. The problems stem from several causes, including poor staff training, insufficient resources and relatively weak enforcement by state regulators, according to records and interviews. [Internet Access: <http://www.washingtonpost.com>]

Michigan

The Detroit News, May 5, 2004

Group home abuses escalate

The March 29 beating joins a growing number of complaints about abuse at Michigan group homes, where many of the state's most vulnerable citizens are cared for by employees with low wages and limited training. Last year, the state of Michigan fielded 1,898 complaints about adult group home conditions. That represents a sharp rise compared to 2002, when there were 1,300 total complaints statewide. An estimated 35,000 people live in more than 4,200 state-licensed adult foster care facilities in Michigan. In general, the staff members are paid fast-food wages and given about two weeks of training before they take over the care of the mentally ill and developmentally disabled adults in the homes. [Internet Access: <http://www.detnews.com/2004/metro/0405/05/a01-143514.htm>]

Massachusetts

The Patriot Ledger, March 20 – 23, 2004

Special Report: Retarded at risk; System failures

When it comes to medical care, some of the state's most vulnerable residents, the 8,700 adults who live in group homes for persons with mental retardation, are treated as second-class citizens. Since 2002, three group home residents died because of medical neglect and nine other deaths are under investigation. Since 1999, more than 260 cases of physical abuse and medical error involving the disabled have been substantiated each year. Often, when something goes wrong, on one is held accountable.

[Internet Access: <http://www.southofboston.net/specialreports/retardedatrisk>]

Virginia

The Virginia Pilot, February 29, 2004

Special Report: Virginia's treatment of the mentally disabled

Was it truly their time to die, or could their deaths have been prevented? The answers are difficult to find, mostly because the state, which used to be the primary caregiver for the mentally disabled, has surrendered much of that role to a patchwork system of community-based programs, such as group homes. The homes, 106 of them in South Hampton Roads, operate with low-paid, minimally trained workers. They churn along with a steady stream of money from the state and federal government, but with little oversight from either. The state employees 12 inspectors to monitor 2,468 mental health, mental retardation and substance abuse service locations, including group homes. That's an average caseload of 206 locations per inspector. A single inspector has responsibility for all of South Hampton Roads, except Portsmouth. Accidents and injuries are supposed to be self-reported by the provider, but may go unreported. Deaths do not have to be reported to the medical

examiner. State records that do exist show problems. Of 34 group home providers in South Hampton Roads, 18 have been cited for state licensing violations and 11 for client abuse or neglect in the past three years. The state has legal authority to fine violators but never has done so. Only one provider's license has been revoked in the past three years. [Internet Access: <http://www.hamptonroads.com/pilotonline/>]

Indiana

The Times Newspapers of Northwest Indiana/S. Chicago, January 25, 2004

Caring for our invisible citizens; Developmentally disabled caregivers often overworked, undertrained, unqualified

A severe shortage of direct care providers across the country has stemmed from a mass exodus of state institutional care. The result is an annual turnover rate ranging from 50 to 75 percent due in part to low wages. Indiana had no state standards for direct care providers until late 2002. These standards, however, still allow the hiring of individuals regardless if they have employment experience or training of any kind. In addition, no required registry exists for these employees if they are fired from one agency for alleged neglect or abuse and then hired at another agency. Critics said the old threat of state-run institutionalized care has been replaced by a new danger - the big business of private care. That machine is fed by money from the Medicaid waiver program, a financing arrangement that relieves clients from traditionally strict care regulations. In 2003, Indiana's Family and Social Services Administration received 467 formal complaints against some of the approximately 850 approved private providers. Some complaints were minor, some more significant, resulting in corrective actions.

New Mexico

The Albuquerque Journal, November 18, 2003

State Probes Abuse of Disabled

Gov. Bill Richardson has ordered an independent inquiry to track down former residents of the now-closed Los Lunas Hospital and Training School. Richardson's order follows publication of news stories about three developmentally disabled women who were discharged from the Los Lunas facility more than 20 years ago and placed in the unlicensed home of a staff housekeeper and her husband. The goal of the investigation announced Monday is to find whether any more of the former residents may have "slipped through the cracks," receiving no state services and no monitoring. [Internet Access: <http://www.abqjournal.com>]

New Mexico

The Albuquerque Journal, November 3, 2003

Judge Won't Halt Disability Suit: State's Request for Stay Rejected

The Jackson class action lawsuit, filed in 1987, resulted in the closure of Los Lunas and Fort Stanton State Developmental Centers and the court-ordered transfer of residents into group homes and other community settings. In 1997, the parties reached an agreement intended to be a blueprint for ending the lawsuit once certain benchmarks were reached. Oversight has since ended in about two-thirds of the areas. The state's motion to dismiss the case, arguing that all requirements have been met, failed in light of evidence that there remained pronounced shortcomings in providing safety for New Mexicans with severe disabilities. Attorney for the plaintiffs, Peter Cuba, told the judge that there had been more than one death of class members per month over the past 20 months. The state lacks an effective system for dealing with neglect and abuse when it occurs and for preventing its recurrence, plaintiffs argued. Arc attorney Maureen Saunders cited instances where guardians for clients had learned of problems at group homes operated by contract providers and had informed both providers and the state about them. She said she received no response or one that was delayed for months. [Internet Access: <http://www.abqjournal.com>]

Illinois

The Chicago Tribune, September 1, 2003

Report blasts group homes – Dirty, unsafe conditions cited

Developmentally disabled residents of six Chicago-area group homes endured filthy and unsafe living conditions, frequently going without toilet paper, while the homes' owners spent thousands of dollars on leased cars and other perks, a disability-rights watchdog group said in a new report. Surprise inspections at the homes, operated by These are God's People Too, found dark, "foul-smelling" homes, walls smeared with feces, bathrooms without toilet paper and "unkempt yards strewn with garbage," said the report by a non-profit group that the state has designated to "protect and advocate" for the disabled. The investigation, conducted from March 2002 to June 2003, also found safety hazards, such as blocked exits and easily accessible cleaning products, as well as staff members unfamiliar with proper techniques for restraining unruly residents, the report said. [Internet Access: <http://www.chicagotribune.com/>]

National

Policy Research Brief (University of Minnesota), September 2003

Medicaid Home and Community-Based Services: The first 20 years

HCBS and other community services for persons with mental retardation and developmental disabilities have grown at an extremely rapid rate during the past decade. This growth and the nature and flexibility of HCBS have brought enormous challenges in monitoring of service quality and protecting persons receiving them. States have not been able to expand quality assurance (QA) systems commensurate with this growth. But even if they had, they would have had to adjust to new expectations. What was considered "quality" in community services in 1982 or even in 1992 no longer satisfies contemporary values. Today, definitions of quality in human services require attention to dimensions of quality of life in addition to protection of health and safety. A few states have established systems for quality review that attend to the new concepts of quality (see Bradley & Kimmich, 2003; www.qualitymall.org) and over the past decade there have been persistent concerns about whether they attend sufficiently even to the basics of health and safety. A March 19, 1993, House hearing called by Rep. (now Senator) Wyden examined the quality of community services and concluded, "State public officials charged with their oversight had little or no knowledge of the conditions within their homes...or at best found out only after terrible events had occurred." The Wyden hearing was followed by newspaper stories of the inadequate, life-threatening, sometimes life-ending quality in community services published in several major newspapers in the late 1990s and early 2000s (e.g., Washington Post, San Francisco Chronicle, Minnesota Star Tribune, Hartford Courant). They stimulated emotional reactions, defensive responses, and promises to do better. But, in June 2003 the General Accounting Office (GAO) issued a new report critical of QA in Medicaid HCBS. Although focused primarily on HCBS for elderly people, it recommended that the federal government: "1) establish more detailed criteria regarding necessary components of HCBS QA systems; 2) require states to submit more specific information about QA approaches prior to approval; 3) ensure that states provide sufficient and timely information in their annual reports on efforts to monitor quality; 4) develop guidance on the scope and methodology for federal reviews of state programs; 5) ensure allocation of sufficient resources for conducting thorough and timely reviews of quality in HCBS and hold regional offices accountable for such reviews" (GAO, 2003, p. 5). Clearly, addressing challenges of creating effective quality assurance systems will require leaders that believe that the safety, well-being and quality of life of people with mental retardation and developmental disabilities deserves public investment in a time when other substantial needs are competing for that investment. [Internet Access: <http://ici.umn.edu/products/prb/143/>]

Colorado

The Denver Post, August 11, 2003

State Medicaid program a mess, participants say; Oversight at issue in waiver care

Medicaid clients and advocates report failures by state officials to adequately monitor the care patients received through the state home and community-based waiver program. State regulators have known about holes in quality oversight since a scathing report two years ago, but say that policing home care is tough with the little power state legislators have given them. Complaints range from theft and negligence by in-home caregivers to allegations that aides forced patients to sign false time sheets and that caseworkers kept people from qualifying for service. Some clients say they've waited for years for the state to address complaints about shoddy service or forgotten care – with no response. A report issued by the Colorado state auditor in June 2001 found that investigators of Medicaid waiver-related complaints sometimes waited months to follow-up, spent far less time investigating complaints than other states did, kept inadequate records of investigations, and were far less likely than investigators elsewhere to cite health providers with deficiencies even after multiple complaints.

National

U.S. General Accounting Office, July 2003

Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened (Report No. GAO-03-576)

Despite a growing number of home and community-based waiver beneficiaries (up to almost 700,000 as of 1999), State waiver applications and annual reports for waivers contain little or no information on state mechanisms for assuring quality in waivers, thus limiting the information available to the federal government. GAO's analysis of available federal and state oversight reports for waivers serving beneficiaries identified oversight weaknesses and quality of care problems. More than 70% of the waivers that GAO reviewed documented one or more quality of care problems. The most common problems included failure to provide necessary services, weaknesses in plans of care, and inadequate case management. The full extent of such problems is unknown because many state waivers lacked a recent CMS review, as required, or the annual state waiver report lacked the relevant information. GAO recommends strengthened federal oversight.

[Internet Access: <http://www.gao.gov/cgi-bin/getrpt?GAO-03-576>]

Georgia

The Atlanta Journal-Constitution, February 24, 2003

Agency failed clients; Poor service may be linked to 6 deaths

Mismanagement by a state-funded community service board in northwest Georgia might have contributed to the deaths of six disabled people, according to a written state review. A scorching report on the performance of the Highland Rivers Community Service Board also found payments to employees who might not exist; long delays in serving mentally ill and mentally retarded patients; and high staff turnover. The state Department of Human Resources has given Highland Rivers until the end of February to come up with a plan for fixing 12 "critical" problems cited in the report. Highland Rivers has another month to address the other issues noted in the 30-page report.

Massachusetts

The Boston Globe, February 4, 2003

Audit alleges misuse of \$1 million

Since 1997, the state Disabled Persons Protection Commission has investigated 19 complaints of client injury at Community Group, Inc., facilities and substantiated three cases involving neglect. Another six cases are

pending. Officials said they were concerned about the well-being of many of the 85 clients the firm was caring for at 21 group homes in Eastern Massachusetts. The for-profit company was hired by the state to provide housing and job training for people with mental retardation. In addition to the accusations relating to poor care, a state audit recently found that the company had secretly raised more than \$1 million selling products made by its clients with disabilities and used the money for a Mercedes-Benz, country club membership, and other perks for company management. Community Group, Inc. of Wakefield also kept \$673,000 in profits from group homes and support services – three times the amount allowed by its approximately \$4 million contract with the state. The state Department of Mental Retardation fired the company last fall, accusing it of providing poor care, in addition to the alleged financial misdeeds.

Connecticut

The Hartford Courant, January 4, 2003

Study: DMR Clients Died Needlessly

A legislative committee has concluded that some mentally retarded residents of group homes in Connecticut needlessly died “tragic” deaths, which were then not investigated properly because of poor oversight by state agencies. In a voluminous report on group home deaths, the Program Review and Investigations Committee also found that the state Department of Mental Retardation created a conflict of interest by investigating deaths itself, and said it should transfer that responsibility to another state agency. The legislature late last year asked the committee to review deaths in DMR group homes after a Courant investigation found evidence of neglect, staff error or other questionable circumstances in one out of every 10 deaths over the past decade. As part of the lengthy report, the committee reviewed the 36 cases identified by The Courant and 177 others chosen randomly to see if there were any patterns of neglect. The committee report concluded: “Tragic things happened that but for a different set of circumstances might not have.” It also pointed out that systems were in place to address the risks to DMR clients, but for one reason or another were not carried out.

[Internet Access: <http://www.ctnow.com>].

Wisconsin

Milwaukee Journal Sentinel, December 13, 2002

Assisted living sites go without inspection; Audit finds citations rose 140% in 3 years

Nearly half of the 2,114 assisted living facilities that care for the elderly and people with disabilities went more than a year without a visit from a state regulator, an audit report revealed Friday. The lack of state scrutiny came at the same time that complaints and citations against such assisted living homes and apartments in the state were increasing, according to the report from the Legislative Audit Bureau. State legislators requested the review in October 2001, after a series detailed how residents in assisted living facilities had died or been injured because of inadequate care or supervision. The series also showed that the state’s regulation had fallen behind the growing industry, which expanded from 1,824 facilities to 2,114 from 1998 to 2001. The capacity of the facilities grew even faster, jumping 35% over the three-year period. At the same time, the number of field inspectors assigned to scrutinize assisted living facilities by the state Bureau of Quality Assurance has declined from 23 to 26. [Internet Access: <http://www.legis.state.wi.us/lab/Reports/02-21full.pdf>].

Ohio

Cincinnati Enquirer, September 2002

Ohio’s Secret Shame

In two previous installments of Ohio’s Secret Shame, the *Enquirer* revealed that the state mental retardation system is so chaotic that it routinely fails to prevent deaths, correct problems or enforce minimum standards of care. The well-being of 63,000 mentally retarded people depends on the system, which taxpayers fund with \$1.8 billion every year. Among the newspaper’s findings thus far: 80 to 120 mentally retarded people die each year from choking, drowning, abuse, neglect or other avoidable causes. That’s one of every seven deaths in the

system; Reports of neglect, abuse, and other serious incidents have quadrupled in the past four years. Yet there's little public accounting; and Caregivers who abuse and neglect mentally retarded people rarely are punished. [Internet Access: <http://enquirer.com/mrdd>].

Washington State

Seattle Post-Intelligencer, July 27, 2002

Audit blasts DSHS services for disabled

A \$250 million-a-year state program serving about 11,700 developmentally disabled Washingtonians is so poorly run that it jeopardizes the health and welfare of its client and violates federal law, a federal audit has found. The report concluded that Washington provided services through the federally subsidized program to more than 5,000 ineligible people over 4 ½ years — and the feds want millions of dollars back. The report also found that the state unfairly denies services and inappropriately handles appeals of service denials. The state further provides shoddy financial accountability. The review was conducted by the Centers of Medicare and Medicaid Services and looked at the Department of Social and Health Services' operation of the waiver program which is intended to offer community-based alternatives to institutionalization for people with mental retardation, cerebral palsy, epilepsy, autism and similar conditions.

[Internet Access: http://seattlepi.nwsourc.com/local/80326_audit27.shtml]

[CMS Report: <http://www.wa.gov/dshs/mediareleases/pdf/CAPWaaupdf>]

Maryland

Baltimore Sun, July 21, 2002

Violence raises concerns over group homes

The killing of a caretaker this month at an Ownings Mills group home for the mentally ill — the latest in a series of violent incidents at assisted-living centers — has renewed concerns about the state's ability to regulate such facilities. In several incidents this year, a state review uncovered serious problems, including inadequate staff training and supervision. And although state officials acknowledge that as many as 1,000 unlicensed group homes may be in operation, there are no inspectors dedicated to finding them. In every case of violence, officials found problems. There were too few staff members supervising the group homes, not enough training for caretakers, and inadequate screening of residents and staff for histories of violent or criminal behavior. The number of hospital beds for the mentally ill has steadily declined as a result of recent cuts in state funding for mental health and deinstitutionalization, a movement to transfer such patients from long-term institutions to community settings. [Internet Access: <http://www.sunspot.net/news/local/bal-md.home21jul21.story>]

New Jersey

The Bergen Record, June 23, 2002

N.J. finds dangers in group homes

State inspectors uncovered violations that jeopardize the health and safety of disabled people in more than half of the 86 group homes in Bergen and Passaic counties. Inspection reports reviewed by The Record found dozens of instances where residents were given improper medication or failed to receive prescribed treatments. The 136 reports, which covered a four-year period, also cited homes for employing untrained staff and failing to keep complete records. An increasing number of people with autism, cerebral palsy, and other disabilities are living in group homes. In 1992, about 1,590 people lived in 260 group homes statewide. Today, 742 homes, run by 106 private agencies, house nearly 3,400 people. The agencies receive state funds to operate the homes. [Internet Access: <http://www.northjersey.com>]

Kentucky
State Audit Report, May 2002

Kentucky can better serve mentally retarded/developmentally disabled persons, State Auditor Ed Hatchett announced today that a performance audit of Kentucky's community-based services for people with mental retardation and developmental disabilities has raised questions about the failure to report abuse, the quality of care provided, and the number of persons served. The audit examined 210 incidents of alleged abuse, neglect, or exploitation and found that Kentucky's Cabinet for Families and Children (CFC) had reported only 19 to law enforcement. In addition, one of these cases were reported to the Attorney General's Office in spite of a contractual agreement obligating the Cabinet to refer all cases "which exhibit substantial potential for criminal prosecution . . ." The audit also revealed that SCL providers as well as the Cabinet for Health Services have frequently failed to inform the Cabinet for Families and Children of incidents of neglect and abuse.

[Internet Access: http://www.kyauditor.net/Public/Audit_Reports/Archive/2002MRDDPerformance-PR.htm]

Maryland
Washington Post, May 8, 2002
Md. concedes failings of group home system

Maryland health and child welfare officials acknowledged this week that they have not adequately monitored the patchwork of complaints that run more than 300 group homes for troubled youth, including a Wheaton home where a 14-year-old girl committed suicide. Last fall, mounting evidence that several group homes were leaving unstable children in the custody of untrained, poorly paid workers prompted Gov. Parris N. Glendening (D) to convene a task force to propose an overhaul. But months later, he rejected the key steps the pane had offered in an October report because the state could not afford the added \$3.8 million in costs, one of his aides said. In meetings with the task force last year, advocates complained that no central agency is monitoring complaints about group homes. Homes that were cited by the Department of Health and Mental Hygiene may still have clean records with the Department of Human Resources or the Department of Juvenile Justice.

[Internet Access: <http://www.washingtonpost.com>]

New York
The New York Times, May 29, 2002
Here, life is squalor and chaos

Federal prosecutors in Brooklyn and Manhattan said yesterday that their offices were investigating adult homes for the mentally ill in New York City to determine whether poor conditions in the homes resulted from criminal conduct by their operators and health care providers. F.B.I. agents have begun interviewing current and former workers at the homes, and prosecutors said they would focus on whether the operators or health care providers had defrauded federal aid programs, siphoning off money that should have been spent on care for the residents. Their action came after a three-part series in The New York Times that laid out neglect and misconduct in private, profit-making homes, which are regulated by the state.

Ohio
Dayton Daily News, February 3, 2002
There are deaths that are preventable

As it stands on the brink of its most sweeping overhaul since deinstitutionalization began three decades ago, Ohio's \$1.85 billion system to protect 63,000 people with mental retardation is riddled with gaps that have deadly consequences. Since 1997, at least 30 people with mental retardation in Ohio have died from neglect while in the care of others. These people died from chokings, drownings, bowel obstructions, accidents, malnutrition or other causes that experts say are preventable or can be successfully treated. The system is so

enshrouded in secrecy that fatal mistakes are often hidden from the public. But an 18-month Dayton Daily News examination, which included more than 200 interviews and a computer analysis of 400,000 Ohio death records from 1997 - 2000, found a pattern of neglect toward the state's most vulnerable citizens. [Internet Access: <http://www.activedayton.com/ddn/local/0203mrdd.html>].

Ohio
Cincinnati Enquirer, February 2002
Ohio's Secret Shame

At least 12 Ohioans with mental retardation, and probably more, have died in questionable circumstances in the past four years. Deaths from all causes jumped 78 percent, and reports of neglect and other serious incidents quadrupled. Yet there's little public accounting. Some county caseworkers are supposed to watch over 125 people at once, five times the state's recommended number. Taxpayer support is so uneven that one Ohio county spends \$43,800 a year on each person with mental retardation, while another spends just \$2,800. Articles in the investigative series include, "Twelve who died," "Unequal System," "Who is accountable," "Slow reform," "Take control," and "Taft to review plight of retarded in response to report on questionable deaths." [Internet Access: <http://enquirer.com/mrdd/>]

Service Employees International Union (SEIU)
Widespread Problems in Quality of Care
January 28, 2002

A new online service launched today provides important information for family members of people with mental retardation/developmental disabilities (MR/DD), advocates, state regulators and purchasers of MR/DD services. The service, <http://www.rescarewatch.org>, tracks issues regarding quality of care provided by ResCare, Inc., and its subsidiaries in the United States. The online service is not affiliated with ResCare, Inc. Copies of inspection and investigative reports for problem programs in California, Indiana and other states. [Internet Access: <http://www.ctnow.com/news/specials>]

Wisconsin
Milwaukee Journal Sentinel, January 25, 2002
Charges allege care center abused patients

A North Carolina-based corporation was charged in a groundbreaking prosecution Friday with 10 criminal counts alleging physical and sexual abuse of developmentally disabled patients at its care center in Milwaukee. Personnel at the Jackson Center Nursing Home, where "use of alcohol and drugs by staff" is a "regular" occurrence, were responsible for "numerous acts of abuse," ranging from ear twisting to forced hot sauce feeding to sexual assault on an elevator, the criminal complaint filed by the state attorney general's office charges. Neglect led to an unattended patient falling out a third floor window and another nearly drowning in a whirlpool, the complaint says. Benchmark Healthcare of Wisconsin Inc., was charged in the complaint with six counts of intentional abuse of a patient, three counts of intentional neglect of a patient and one count of second-degree sexual assault. The charges carry fines totaling up to \$91,000. Assistant Attorney General William E. Hanrahan, who drafted the criminal complaint after an investigation by the Medicaid fraud control unit of the state Justice Department, said the unusual step of charging a corporation with crimes was taken because "the primary responsibility for the patients' care lies with the corporation." The facility in question is a large community-based facility. [Internet Access: <http://www.jsonline.com/news/state/jan02/15528.asp>]

Connecticut
Hartford Courant, December 2-4, 2001
Fatal Errors, Secret Deaths

Despite a history of official insistence that untimely deaths are virtually nonexistent in Connecticut's 774 group homes for people with mental retardation, a *Hartford Courant* investigation of group homes found evidence of neglect, staff error and other questionable circumstances in one out of every 10 deaths over the past decade. The series spans five articles, including "The Toll: Suffocation, Drowning, Choking and Burns," "How did they die? The State Won't Say," and "Lawmakers Call for Inquiry into DMR."

[Internet Access: <http://www.ctnow.com/news/specials> (link: Fatal Errors, Secret Deaths)]

Georgia
Atlanta Journal-Constitution, December 2-4, 2001
Dying in Darkness

At least 163 of Georgia's most vulnerable residents have died under the state's watch in the last four years, in circumstances largely shrouded in secrecy. Some who died were malnourished, bruised, scalded, and dehydrated. *The Journal-Constitution's* investigation into deaths of people with mental retardation began as an assignment to see how former residents of the Brook Run retardation center were faring after the facility closed in 1997. Many of the 60 families interviewed expressed concerns over injuries and deaths of residents who had been moved into smaller residential settings around the state. The Journal found that "Group home deaths reveal ugly picture of state care." The series spans 7 articles.

[Internet Access: <http://www.accessatlanta.com/ajc/metro/brookrun/1202about.html>]

National
Children and Family Research Center, November, 2001
Abuse of Developmentally-Disabled Children Bibliography

This resource lists 72 peer reviewed studies about the abuse of children with developmental disabilities (8 pages). [Internet Access: <http://cfcwww.social.uiuc.edu/respract/biblio.pdfs/abuseofdisabled.pdf>].

Minnesota
Minneapolis Star Tribune, October 25-31, 2001
Voiceless and Vulnerable

Since 1995, at least 20 Minnesotans with mental retardation and other problems have died in cases in which maltreatment or questionable care was identified, a *Star Tribune* investigation found. The deaths involved neglect, starvation, physical restraint, medication overdose, drowning or other circumstances. At least 15 died in group homes where authorities or workers raised questions about proper training. The state's watchdog, the Office of the Ombudsman for Mental Health and Mental Retardation, has a backlog of about 500 deaths of mentally retarded and other vulnerable people that have yet to be reviewed. In addition, in 1994, the ombudsman stopped requiring intensive review of injuries, despite having broad authority to do so. More than 4,000 mentally retarded people have suffered serious injuries since then, the newspaper found. The injuries, which were reported to the ombudsman's office, ranged from serious head injuries to fractures to burns to frostbite. The number of serious-injury reports has increased each year since 1998, with 424 reported that fiscal year and 672 in fiscal year 2001. The *Star Tribune's* investigation provides the first public examination of deaths of mentally retarded people in Minnesota. Their files had been kept confidential by the ombudsman's office until the *Star Tribune* sued to have them opened. Three national experts reviewed death files for the *Star Tribune*. All three concur that Minnesota's system is broken, dangerous and operates with little accountability.

[Internet Access: <http://www.startribune.com>]

[Direct Internet access: <http://www.startribune.com/stories/1600>]

Pennsylvania Auditor General Audit, October 9, 2001

Casey audit finds serious deficiencies in state's oversight of Personal Care Homes; Offers over 30 recommendations to better protect residents' health and safety

The Pennsylvania Department of Public Welfare (DPW) was seriously deficient in its oversight of personal care homes, according to a performance audit released today by Auditor General Robert P. Casey, Jr. During the two-year period covered by Casey's audit, DPW renewed licenses without verifying that serious violations were corrected, licensed new homes without ensuring that administrators and staff were qualified, failed to impose fines and penalties as required by law, and investigated almost half of the complaints it received late. The commonwealth currently annually inspects about 1,900 personal care homes which, by definition, provide "safe, humane, comfortable and supportive residential settings" for older or disabled adults "who require assistance beyond the basic necessities of food and shelter but who do not need hospitalization or skilled or intermediate nursing care." In the two-year period covered by Casey's audit -- July 1, 1998, through June 30, 2000 -- bed capacity at Pennsylvania personal care homes increased 34 percent. During this time, however, DPW was not adequately staffed to oversee these homes. Casey's audit found that there were just 34 DPW employees monitoring more than 1,800 personal care homes with nearly 50,000 residents and a licensed capacity of nearly 75,000. [Internet Access: <http://www.auditorgen.state.pa.us/Department/Press/PCH-PR.html>]

Washington, D.C.

The Washington Post, September 9 - 12, 2001

The District's Lost Children

This four day investigative series (9 articles) reveals a decade of deadly mistakes that resulted in the deaths of 229 children from 1993 through 2000. One in five lost their lives after government workers failed to take key preventive action or placed children in unsafe homes or nursing homes. Seventeen of the deaths were homicides, most of them in homes. Many of these children were severely disabled. In the District, there are few long-term alternatives for severely disabled children whom nobody wants: some group homes, out-of-state institutions and foster homes.

Kansas

The Wichita Eagle, September 5, 2001

Malpractice verdict: \$4 million

The family of a developmentally disabled woman who died in a western Kansas rehabilitation center won one of the state's biggest malpractice awards Tuesday: \$4 million. The verdict included \$2.5 million in punitive damages against Golden West Skill Center of Goodland and its parent company, Res-Care Kansas Inc. It was the largest jury award in Kansas for medical malpractice in three years, culminating an eight-week trial before U.S. Magistrate Judge John Reid at the federal courthouse in Wichita. The case involved the treatment of Christine Zellner, 23, of Denver, who died 13 days after entering the Goodland facility in January 1996. An autopsy never determined the cause of death, but the woman was found face down with marks on her wrist indicating she'd been tied up.

Wisconsin

The Milwaukee Journal, August 25 - 30, 2001

Caring for the Elderly, Disabled: Overwhelmed and Broken Down

A six-month examination of long-term care in Wisconsin finds caregivers overwhelmed, families torn apart and businesses barely surviving. The elderly and disabled wait interminably for care, and at times, they are harmed by the care they finally receive. And the future looks bleak.

[Internet Access: <http://www.jsonline.com/news/state/aug01/care26082501a.asp>]

The Tennessean, August 2, 2001
Tennessee may lose disability funding

Tennessee has failed to protect the health and welfare of people with mental retardation who live in supervised homes, a federal report has concluded. The federal government placed a moratorium on moving any more residents of state-run developmental centers into the community until the state takes "corrective action." Findings include, numerous medication errors; inappropriate medical care; many homes did not have adequate food supplies and/or the food in the homes was inappropriate for the clients' diets; staffers often have their children with them while on duty, even when clients' care plans indicate they should have (one-on-one) care; care plans are often outdated or not followed; and community agencies have refused to send records to family members, even when releases have been signed. The report also noted that substantiated cases of abuse and neglect have ranged from 25 incidents for every 100 individuals in homes in the community to 42 incidents per 100. In comparison, the rate for the state's developmental centers last year was 14 substantiated incidents of abuse or neglect for every 100 residents, according to a separate report released in January. The federal government began investigating last year after receiving complaints from family members that the state did not seem to be able to correct the problems.

[Internet Access: <http://www.tennessean.com>]

[Direct Access: http://www.tennessean.com/local/archives/01/04/07124262.shtml?Element_ID=7124262]

[See also: <http://www.gomemphis.com/newca/local/080201/e2mental.htm>]

Maryland
The Herald Mail, July 23, 2001
State reports cited agency for poor living conditions

The now defunct Hagerstown-based agency that served 25 developmentally disabled people last year received nearly 40 pages of citations from the state, some of which alleged poor living conditions, improperly trained staff and lack of medical supervision. The citations for Consumer Driven Services Inc. are listed in a 37-page May 2000 report put together by the state's Office of Health Care Quality. A 24-page follow-up report completed in December 2000 alleges that the agency did not fix many of the conditions for which it had been cited in the first report. The report states that many staff members of Consumer Driven Services were not properly trained in CPR, first aid and treatment for seizure disorders. An inspection of the group homes run by the agency turned up alleged safety and health hazards. An inspector of one of the homes wrote in the May report: "There is a strong smell of urine coming from one of the bedrooms that can be detected from the hallway. The bedroom bath has a very stained toilet and the shower door is broke. The cover is off the temperature control in the hallway. Curtains are off the window in one individual's bedroom and the dresser door swings open. A pot of stew, left over from the previous day, was found inside the oven." One of the visits by state officials in December found that the temperature in the living room and bedrooms in one of the homes was 55 degrees for several days. The reports also state that some of the group homes were understaffed, compromising the health and safety of the clients. Other pages of the reports detail instances in which one client had 12 to 15 teeth pulled by a dentist without first being told of the decision and another client was not being given doctor-ordered biweekly blood pressure checks. Consumer Driven Services had received state funding from the Western Region Developmental Disabilities Administration (DDA) until the local agency filed for bankruptcy on July 7. The DDA was the main funding source for the agency, contributing about \$1.2 million toward the agency's annual budget.

[Internet Access: <http://www.herald-mail.com>]

[Direct Access: http://www.herald-mail.com/news/2001/07/23/local/State_reports_cited_age.html]

Illinois

The Arc of Illinois — Today, July 20, 2001

HCFA Comes Back to Illinois

In 1998, the Health Care Financing Administration (HCFA; now called Center for Medicare and Medicaid Services (CMS)) audited the Illinois home and community-based waiver. At that time CMS stated: "The review team found that the State is not in compliance with the statutory and regulatory requirements set forth to protect the health and welfare of waiver individuals and to safeguard the integrity of Federal funds expended. Illinois Department of Public Aid has not fulfilled its responsibilities to oversee the integrity of the programmatic and financial aspects of the waiver program. It has not adequately overseen Illinois Department of Human Services functions and activities by failing to perform evaluations of the waiver's implementation including program and fiscal integrity and accountability for both Federal and State funds expended by Public Aid." As a result of these findings, a moratorium was placed on new waiver placements and adult foster care was withdrawn from the waiver program.

The 2001 CMS audit of the Illinois waiver program will not find the Illinois waiver in jeopardy and will be less dramatic in its findings. Nonetheless, there continue to be serious problems that require attention in the following areas: Implementation of Program Plans; Inappropriate Use of Psychotropic Medications; High Case Loads; Ineffective Problem Resolution; Lack of Authority; Failure to Communicate with Co-Agencies; Lack of Freedom of Choice; and Placement in Restrictive Day Programs.

[Internet Access: <http://www.thearcofil.org/newsletter>]

[For 1998 CMS audit information see: <http://www.thearcofil.org/newsletter/n121898.html>]

Virginia

Times-Dispatch, July 19, 2001

Mental care crisis looming? Psychiatric-beds shortage worsening

Hospitals and rescue squads were forced to use a regionwide emergency plan for the first time this week to find beds for acutely ill psychiatric patients in the Richmond area. The decision to use the emergency diversion plan Monday was the latest sign of the worsening shortage of hospital beds for psychiatric patients since the closing of Capitol Medical Center in Richmond this month. "I wouldn't say it's a crisis, but it's on the verge of being a crisis," said Jon R. Donnelly, executive director of Old Dominion Emergency Medical Services Alliance, which helps coordinate operations between hospitals and rescue squads. The emergency plan was put into effect early Monday and ended late that night, but the loss of Capitol's 62 psychiatric beds continues to be felt by local hospitals and mental health agencies. Hospital emergency departments are seeing more people with psychiatric problems and being forced to hold them longer until a bed becomes available.

[Internet Access: <http://www.timesdispatch.com>] [Direct Link to Archives: <http://www.archivesva.com>]

California

The Center for Outcome Analysis, July 1, 2001

Eight Years Later: The Lives of People Who Moved From Institutions to Communities in California/Year 2001 Report of the Quality of Life Evaluation of People with Developmental Disabilities (The "Quality Tracking Project")

This report seeks to answer two questions, "Are the people who moved ("Movers") better off than they were when living in Developmental Centers?" and "Are the people who moved into community homes better off than they were last year? (do they continue to grow, learn and flourish year after year in the community?)."

The report finds that Movers are generally better off in 11 of the 21 "dimensions." The report notes that the Movers are somewhat worse off in the "number of close friends," the "staff perceptions of the quality of health care," the "frequency of dental care," and the opportunity for supportive and competitive employment. Researchers also found, however, that the average Mover lost ground in adaptive behavior in the past year in the community. The average Mover also lost ground in the challenging behavior area; that is, their challenging behavior increased. The researchers noted, "This is the first time in 22 years of constant research by this team that such an outcome has been observed. We have never before seen people in community service systems lose skills and increase challenging behavior. However, the monitoring process put into place through Welfare & Institutions Code 4418.1 has resulted in early detection of these problems. A concerted effort to identify the reasons for these outcomes can surely result in quick and decisive action to arrest further decline. Without the kind of quantitative monitoring mandated by the Legislature for the present project, no one would even know that the average Mover has now begun to lose ground behaviorally." Researchers attribute the decline, in part, to an underfunded community system.

**Office of Inspector General, U.S. Department of Health and Human Services
May 3, 2001
Reporting Abuses of Persons with Disabilities**

Federal requirements for protecting persons with disabilities from abuse and neglect are directed at facility providers rather than State agencies. Some persons with disabilities reside in facilities that are subject to the Health Care Financing Administration's (HCFA) conditions of participation as well as State laws and regulations. However, we estimated that up to 90 percent of persons with disabilities reside in facilities, such as group homes, some residential schools, and supervised apartments, that do not receive HCFA funds or were not part of the Medicaid waiver program and rely solely on various levels of protections that are provided by State laws and regulations. In addition, Department of Health and Human Services (HHS) is at a disadvantage in identifying systemic problems since it receives incident information from a limited number of sources.

We recommend that HCFA, the Administration for Children and Families, the Substance and Mental Health Services Administration, and the Food and Drug Administration work cooperatively to provide information and technical assistance to States that would (1) improve the reporting of potential abuse or neglect of persons with disabilities; (2) strengthen investigative and resolution processes; (3) facilitate the analysis of incident data to identify trends indicative of systemic problems; and (4) identify the nature and cause of incidents to prevent future abuse. [Internet Access: <http://oig.hhs.gov/oas/reports/region1/10002502.htm>]

**Missouri
Missouri Office of State Auditor, March 15, 2001**

Missourians with developmental disabilities who rely on contractor-operated facilities are not well protected from acts of physical aggression by other clients or from medication errors. Inadequate monitoring by the states 11 regional centers over contractor-operated facilities, which provide day programs and residential environments to nearly 9,000 developmentally disabled, leave clients and staff at risk. The review included an analysis of incident and injury reports of eight contractors operating in five of the states regional centers. [Internet Access: <http://www.auditor.state.mo.us/press/2001-20.htm>]

**Wisconsin
The Milwaukee Journal, February 21, 2001
Inspector falsified reports on care sites, officials say; Misconduct charges sought amid state report alleging 'pattern of lying'**

A state inspector responsible for monitoring the care of frail elderly and disabled clients in more than 100 assisted living homes is accused of falsifying reports to show some homes were problem free when, in fact, he

had not visited them for years. "There . . . were ample indications that the employee's performance had not been adequate for a significant period of time," Patrick W. Cooper, director of the state Office of Program Review and Audit, wrote in a cover letter to the report. "The employee wrote only 11 statements of deficiency over an almost four-year period, when a typical licensing specialist might have written between 150 and 200. "The employee's work was also subject to many complaints by external parties, yet these complaints were not acted on in a manner that would lead to uncovering the extensive misrepresentation of work activities. . . . We believe he showed a pattern of lying about having completed licensing and complaint investigation work that he, in fact, had not performed." [Internet Access: <http://www.jsonline.com/news/metro/feb01/inspect21022001a.asp>]

Texas

WFAA-TV (Dallas News 8), February 8, 2001
News 8 investigates ResCare Part II

[Transcript excerpts] "Thirty years ago, a process began in this country to stop warehousing people with mental retardation in state institutions and move them out into community-based group homes. The theory was that by deinstitutionalizing people with mental retardation, we would give them better, more normal lives. ResCare is the largest provider of group homes in Texas and the nation. In Texas, many people may know ResCare as EduCare, because the two firms merged about two years ago. Together they operate more than 170 group homes around the state. No one else comes close in sheer volume of clients or revenue. It's become a multi-billion dollar business, which has some asking why the company only allocates \$5 per day per person to feed their mentally retarded clients . . ."

"According to ResCare, the amount [\$5 per day] is an 'acceptable and widely used rule of thumb for a daily food budget' and 'falls within the official guidelines available from (USDA).' But a 1995 study which specifically compares 700 group homes in Texas shows that even six years ago, the average daily allotment for food was \$5.86 per person. The study was provided by ResCare's own paid consultant . . . Today, criticism of ResCare's treatment of their mentally retarded clients extends beyond just food and the borders of Texas. The company has come under fire in Florida, Indiana and New Mexico, where there is a moratorium on placing any new residents in ResCare facilities because of serious health and safety issues . . . But what concerns advocates for the mentally retarded is that despite numerous warning signs over the years, state regulators have continued to let ResCare expand — to the point that even if regulators needed to close ResCare's facilities, there wouldn't be enough other group homes to take in their clients."

Washington

Washington State Internal Audit, December 2000

An internal, simulated audit of the DSHS Division of Developmental Disabilities (DDD) Community Alternatives Program (CAP) Medicaid Home and Community-based Services (HCBS) Waiver was conducted to identify potential problems when the program receives its next formal audit by the Federal Health Care Financing Administration (HCFA). The audit of the \$200 million state program for the developmentally disabled found that the program is so "woefully inadequate" that it poses a threat to the very health and safety of the 10,000 people it serves. Federal officials "would likely conclude that the lack of sufficient personnel and resources creates a situation in which no one is fully aware of what is happening to the average developmentally disabled client," the report reads. "Case management oversight and monitoring of individuals is so limited as to pose high risks for the individuals being served." [Internet Access: <http://www.wa.gov/dshs/geninfo/simaud.html>].

Connecticut

The Connecticut Post, December 22, 2000
Group homes need uniform safety rules

Advocates for the disabled and the State Department of Mental Retardation want to know whether two drownings at Connecticut group homes for people with mental retardation, being similar and occurring close together, indicate a widespread problem. The Department of Mental Retardation will investigate whether the drownings were isolated incidents or part of a pattern of neglect.

[Internet Access: <http://www.connpost.com/>]

[Direct Link: <http://www.connpost.com/S-ASP-Bin/ContentFrmBldr.asp?PUID=6747>]

Pennsylvania

The Post-Gazette, September 29, 2000

Retarded man drowns in group home; was moved from Western Center in May

The state Department of Public Welfare will launch an investigation into the death, said Jay Pagni, a spokesman. The parents' group that fought the closing of Western Center have tabulated that 23 mentally handicapped people have died from accidents in group homes since they were taken out of Western Center. In 1998, the state decided to close Western Center and move its remaining 380 residents to group homes. State Auditor General Bob Casey Jr. released a 162-page audit in May that criticized state welfare officials for being too lax, too slow, and too ineffective in ensuring the safety of mentally retarded individuals living in group homes. [Internet Access: <http://www.post-gazette.com/neighborhood/south/20000929barber2.asp>]

Maine

Maine Sun Journal, July 23, 2000

Institution gets new lease on life

It is what was best about Pineland, an institution that closed in 1996, that captured the imagination of Owen Wells who heads the Libra Foundation. "I found [Pineland] had spectacular potential," he says. "How better to meet the needs of the disabled people, both physically and mentally, here in Maine?"

Wells pictures a multi-use complex that would draw tenants from all walks of life, including white- and blue-collar businesses, accommodating all handicaps. It would mix business, industry, recreation and education. His picture is set out in blueprints, approved by town and state officials. In December, he signed a purchase agreement for the property. The deal closed last month with Libra paying \$200,000 for the campus and \$540,000 more for an additional 617 acres abutting the former school. Estimates for the completed project top \$40 million.

Rather than running from its controversial past, Wells chose instead to embrace it. "I thought there's nothing to be ashamed of in terms of what Pineland was for many years. It was a wonderful farm operation and it was a wonderful facility," he says. He's even commissioned a book about Pineland's 88 years as an institution. "We set out very early not to abandon the history," Wells says. "The history is good. We think it is a history that ought to be acknowledged."

Texas

Austin American-Statesman, May 31, 2000

Hard questions about their care

Between March 1999 and last April, Texas withheld Medicaid money from at least 104 group homes for health and safety violations. Unless there is a complaint, Texas conducts annual surprise inspections of its 11 state schools and 890 group homes with six or more residents. It surveys the providers of more than 200 smaller homes but doesn't inspect them. Most of the money was withheld from group homes because of minor infractions, but there also were about a dozen more serious cases of abuse and neglect. Texas will have to make a much bigger commitment than it's making to properly move to a community-based system. Compared to other states, Texas allocates little money for Medicaid, the joint state-federal program that pays for much of the care

in any setting. In 1998, Texas was 41st in total spending. It was 40th in community-care spending and 29th in institutional spending. Texas' relative stinginess may have contributed to some of the health and safety violations in the state schools and group homes. Many of the incidents were related to a lack of supervision. With an entry-level, direct care job at Austin State School paying just \$7.26 an hour — about 50 cents more than the starting salary at McDonald's — state schools and group homes have trouble attracting and keeping staff. [Internet Access: <http://archives.statesman.com>]

The American Prospect, Volume 11, No 12, May 8, 2000
Neglect for Sale

Two decades ago, advocates fought to shut down abusive institutions that warehoused the mentally retarded. Today, people with developmental disabilities face a new threat: big business. The American Prospect offers an investigative report by Eyal Press and Jennifer Washburn which looks at ResCare, the nation's largest for-profit provider of services to people with developmental disabilities.

[Internet Access: <http://www.prospect.org> - link: Archives (search by author -- Eyal Press)
[Direct Link: <http://www.prospect.org/print/V11/12/press-e.html>]

Pennsylvania

Pennsylvania Auditor General Audit, May 8, 2000

Audit finds serious deficiencies in Ridge administration's oversight of group homes; Casey offers nearly 50 recommendations to improve quality of care

A performance audit of the Commonwealth's oversight of group homes for the mentally retarded in western Pennsylvania has found serious deficiencies that threaten the health and safety of residents, including allegations of abuse and unexpected deaths that were not investigated promptly, direct care workers with criminal backgrounds, and inadequately trained caregivers. In addition to numerous audit findings, Pennsylvania Auditor General Robert P. Casey, Jr.'s audit report offers 47 recommendations to improve the Ridge administration's oversight of group homes and, ultimately, the quality of care provided to group home residents across Pennsylvania. Casey's audit, which examined the Pennsylvania Department of Public Welfare's (DPW) oversight of eight group homes in Allegheny, Beaver, Fayette, Washington, and Westmoreland counties from July 1, 1994, through June 30, 1999, focused on four areas: 1) unexpected deaths and incidents of abuse; 2) staffing issues that affect the health and welfare of group home residents; 3) the quality of service provided to residents; and 4) the physical condition of the group homes.

[Internet Access: <http://www.auditorgen.state.pa.us/Department/Press/grouphom.html>]

Pennsylvania

Post-Gazette, April 12, 2000

State closing home for mentally retarded amid continued appeals, protests

State officials said they would begin to shut down Western Center in Canonsburg today, an announcement that prompted last-minute court appeals, protests from parents and the near arrest of a mentally retarded resident after a confrontation with state police. As final preparations were made for the closing, the center operated more like a fortress than a home for the mentally retarded. State police set up a roadblock behind the administrative building yesterday so relatives could not visit residents until they were moved to other facilities.

New Mexico

Albuquerque Journal, April 9, 2000

Troubled Care: Assisted Living Provider Faces Lawsuit, Complaints, Moratorium on New Clients

On April 9, 2000, the *Albuquerque Journal* reported that ResCare New Mexico, which receives \$10 to \$12 million a year from the health department to serve its citizens with mental retardation and developmental disabilities, has been hit with a number of allegations of neglect and abuse over the past year. ResCare and its subsidiaries in New Mexico have the highest rate of abuse at about 18 cases of abuse per 100 clients; they are also one of the largest community-based providers. A lawsuit has been filed against ResCare alleging a pattern and practice of abuse and neglect; Arc of New Mexico, which serves as guardian for 153 people, will be moving all of its wards from ResCare homes; The Arc is threatening to file a lawsuit against ResCare; and there is a moratorium on new placements in ResCare programs. New Mexico closed its last state-operated developmental center in 1997, following a lawsuit by Protection and Advocacy.
[Internet Access: www.abqjournal.com]

Washington State

Seattle Times, March 24, 2000

Record verdict against state in abuse case

The state Department of Social and Health Services and two adult family-home operators were ordered by a jury to pay \$17.8 million - the largest judgment ever against the state - to three disabled men who say they were molested in the state-licensed facility. The size of the judgment from the Pierce County Superior Court jury shocked officials from the governor's office, DSHS and the Attorney General's Office, the agency that defended the state in the suit. The case has major implications for the future: At least a half-dozen other defendants abused or neglected in long-term care claim they could have been saved from suffering if the state had acted properly. These and other cases were highlighted in a Seattle Times investigation last year that concluded the state did little or nothing to stop abuse or neglect of people in state-licensed care, nor did it often prosecute their abusers.

Oregon

Oregon Statesman Journal, March 12 - March 15, 2000

Fairview's Legacy

- (1) Sunday, March 12, 2000: Day 1: Success and Failure
 - (a) Safety of disabled in doubt after deaths
 - (b) Inquiries find neglect a key factor
 - (c) Fairview history: Dignity wins out over time
 - (d) High turnover, heavy caseload plague system
 - (e) Homes that work: Group Home (Shangri-La) rebounds from bleak times
 - (f) Salem group home fell into dysfunction

- (2) Monday, March 13, 2000: Day 2: Comparing Services
 - (a) 4,000 disabled wait for state aid
 - (b) Waiting list can seem endless
 - (c) Fairview's end won't shorten list
 - (d) Past residents: Change can be difficult
 - (e) Other states face lawsuits
 - (f) Views on group homes varied:
 - Group home gets praise from mother
 - Father hopes to see end to group homes
 - Leaving Fairview a mistake: Brothers go without therapy

 - (g) Individual choice is the main advantage

- (3) Tuesday, March 14, 2000: Day 3: Market Shifts
- (a) Caregivers fight to remain solvent
 - (b) Group home boom: Turnover, funding still worrisome
 - (c) Workers face high demands
 - (d) Rising costs hit care provider
 - (e) Experiences of area facilities show challenges facing industry
 - (f) Low pay fuels staff turnover
 - (g) Group homes draw complaints
 - (h) Following Fairview's former employees: Many still caregivers; some rebuild careers
- (4) Wednesday, March 15, 2000: Day 4: Looking Ahead
- (a) Costs likely to delay developing campus
 - (b) Plot offers great variety of options
 - (c) Saving old sites possible
 - (d) Officials, residents plan for Fairview's future
 - (e) Fairview land use complicated issue
 - (f) Mothballing costs remain uncertain
 - (g) Buildings hard to save or sell
 - (h) Industry likely to replace farm

[Internet Access: www.statesmanjournal.com]

[Direct Link: http://online.statesmanjournal.com/special_section.cfm?i=1007]

Oregon

The Oregonian, January 7, 2000

State inquiry finds neglect of former Fairview resident

A longtime Fairview Training Center resident who died less than two months after moving into a group home in Salem was neglected by his new caregivers, and public officials who learned of the neglect failed to act, according to a state investigation released Thursday. The report from the Office of Client Rights concluded that neglect led to dehydration and malnourishment in the weeks before his death and that a number of public officials and Salem Hospital failed to report his condition or investigate as required by law. Gary Avery's death has heightened concern about how Fairview's former residents are faring in a community system plagued by high turnover of workers and relatively low wages. To make sure no similar problems exist, the state's Development Disability Services Division is reviewing the cases of 260 other former residents who have been moved into the community since May 1998. Fairview is scheduled to close in late-February.

[Internet Access: <http://www.oregonlive.com/search/oregonian>]

Washington, D.C.

Washington Post, December 1999 - January 2000

Invisible Deaths: The Fatal Neglect of D.C.'s Retarded

- (1) System Loses Lives and Trust, December 5, 1999
- (2) D.C. Vows Review of Deaths in Homes, December 6, 1999
- (3) City to Investigate Deaths, Williams Promises Accountability, December 7, 1999
- (4) D.C. Official Suspended in Probe of Homes, Records of Deaths Allegedly Shredded December 9, 1999

- (5) Files on Retarded Out of Reach, Advocates Frustrated by Lack of Cooperation from D.C. Superior Court, December 15, 1999
- (6) Group Home Administrator Named, December 20, 1999
- (7) Group Home Deaths, Washington Post Editorial, January 10, 2000

Note: There has been significant follow-up since the investigative series by *The Washington Post* (see e.g., "Progress Reported On Care of Retarded," September 26, 2000; "Group Homes' Dept to D.C.: \$6.8 Million," October 27, 2000; and "District Settles Claims for Retarded, Agreement Includes \$29 Million Fund," January 23, 2001).

Pennsylvania

A disabled boy, a family in crisis: Mounting pressures may have led a couple to abandon their child, December 1999

Extensive national news media coverage has been available about the crisis facing Dawn and Richard Kelso. The couple has been charged with "abandoning" Steven, their 10-year old son with severe developmental disabilities, at the hospital that had previously served Steven's extensive health care needs. In December, 1999 Mrs. Kelso retired as a member of the Pennsylvania DD Council; Mr. Kelso is the CEO of a Fortune 500 company.

[Internet Access: <http://www.phillynews.com> (news archives search link - keyword: kelsos)]

Washington, D.C.

Washington Post, March - May, 1999

Invisible Lives: D.C.'s Troubled System for the Retarded

- (1) Forest Haven is Gone, But the Agony Remains, March 14, 1999
- (2) Olympic Achievements Out of Reach, March 14, 1999
- (3) Elaborate Structure of Care, March 14, 1999
- (4) Residents Languish, Profiteers Flourish, March 15, 1999
- (5) Nonprofits Struggle in Current of Greed, March 15, 1999
- (6) Death Among the Mentally Retarded, March 15, 1999
- (7) U.S. Probes D.C. Group Homes, May 4, 1999

[Internet Access: <http://washingtonpost.com/invisible>]

Georgia

The Atlanta Constitution Journal, February 20, 1999

In February 1999, three former employees of the Northeast Georgia Community Service Board, which provides social services in a 10-county area, were charged with insurance fraud, theft by deception and conspiracy to commit theft by deception. The three were among nine employees fired on April 1, 1998, after an investigation into allegations of insurance fraud, abuse and neglect involving people with mental retardation. The former employees allegedly sold life insurance policies to the individuals with mental retardation and listed themselves as beneficiaries. Health care officials have said the situation represents one of the worst cases of systemic abuse of clients in Georgia in years. Investigators painted a picture of a community care network apparently operating with almost no oversight. An audit into nine of the 28 community service boards in Georgia was ordered. A preliminary draft reveals a system that lacks oversight and financial accountability and one in which officials manipulate treatment and billing practices to increase Medicaid payments (Source: *The Atlanta Journal Constitution*, February 20, 1999).

California

San Francisco Chronicle, February, 1997 - August, 1998

Fifty-six (56) articles were released detailing the abuse, neglect and death that plagued California's system of community-based care for people with mental retardation following the aggressive deinstitutionalization of over 2,000 people. The articles include reference to University peer-reviewed research that finds risk of mortality to be higher in California community-based programs than in the state institutions serving people with mental retardation.

The California mortality studies can be accessed on the Internet at <http://www.LifeExpectancy.com>, link: articles (comparative mortality studies).

[Internet Access: <http://www.psych-health.com> ("developmental disabilities" link, then years 1997 and 1998) or <http://www.sfgate.com/chronicle> (search link - key words Lempinen and disability).

Pennsylvania

The Philadelphia Inquirer, November 1997

Lawsuit without an End

- (1) Serving the Retarded: Some are more equal: Those who once endured a notorious institution get a cornucopia of care in Philadelphia. But others, in the arms of their families struggle. And wait. November 2, 1997.
- (2) Case studies tell a tale of disparity: Two men from Pennhurst exemplify the strides taken on their behalf. And then there's Denise Carruth. November 3, 1997.
- (3) Lawsuit aids some retarded at all costs: The rights of Pennhurst's alumni have been well guarded for years. But amid bounty, some feel forsaken. November 4, 1997.

[Internet Access: <http://www.phillynews.com> (news archives search link - keyword: pennhurst)]

APPL

PASSED 4/25/2009

ESHB 1244

1 may contract with nonprofit community organizations to aid in
2 mitigating the effects of increased public impact on urban
3 neighborhoods due to events in stadia that have a capacity of over
4 50,000 spectators.

5 (27) \$300,000 of the Washington auto theft prevention authority
6 account--state appropriation is provided solely for a contract with a
7 community group to build local community capacity and economic
8 development within the state by strengthening political relationships
9 between economically distressed communities and governmental
10 institutions. The community group shall identify opportunities for
11 collaboration and initiate activities and events that bring community
12 organizations, local governments, and state agencies together to
13 address the impacts of poverty, political disenfranchisement, and
14 economic inequality on communities of color. These funds must be
15 matched by other nonstate sources on an equal basis.

16 (28) \$1,800,000 of the home security fund--state appropriation is
17 provided for transitional housing assistance or partial payments for
18 rental assistance under the independent youth housing program.

19 (29) \$5,000,000 of the home security fund--state appropriation is
20 provided solely for the operation, repair, and staffing of shelters in
21 the homeless family shelter program.

22 NEW SECTION. **Sec. 129. FOR THE ECONOMIC AND REVENUE FORECAST**
23 **COUNCIL**

24	General Fund--State Appropriation (FY 2010)	...	\$727,000
25	General Fund--State Appropriation (FY 2011)	...	\$793,000
26	TOTAL APPROPRIATION	...	\$1,520,000

27 NEW SECTION. **Sec. 130. FOR THE OFFICE OF FINANCIAL MANAGEMENT**

28	General Fund--State Appropriation (FY 2010)	...	\$22,163,000
29	General Fund--State Appropriation (FY 2011)	...	\$20,792,000
30	General Fund--Federal Appropriation	...	\$23,597,000
31	General Fund--Private/Local Appropriation	...	\$1,270,000
32	State Auditing Services Revolving		
33	Account--State Appropriation	...	\$25,000
34	Economic Development Strategic Reserve Account--		
35	State Appropriation	...	\$280,000
36	TOTAL APPROPRIATION	...	\$68,127,000

1 The appropriations in this section are subject to the following
2 conditions and limitations:

3 (1) \$188,000 of the general fund--state appropriation for fiscal
4 year 2010 is provided solely for the implementation of Second
5 Substitute Senate Bill No. 5945 (Washington health partnership plan).

6 If the bill is not enacted by June 30, 2009, the amount provided in
7 this subsection shall lapse.

8 (2) The office of financial management shall conduct a study on
9 alternatives for consolidating or transferring activities and
10 responsibilities of the state lottery commission, state horse racing
11 commission, state liquor control board, and the state gambling
12 commission to achieve cost savings and regulatory efficiencies. In
13 conducting the study, the office of financial management shall consult
14 with the legislative fiscal committees. Further, the office of
15 financial management shall establish an advisory group to include, but
16 not be limited to, representatives of affected businesses, state
17 agencies or entities, local governments, and stakeholder groups. The
18 office of financial management shall submit a final report to the
19 governor and the legislative fiscal committees by November 15, 2009.

20 (3) \$500,000 of the general fund--state appropriation for fiscal
21 year 2010 is provided solely for a study of the feasibility of closing
22 state institutional facilities and a plan on eliminating beds in the
23 state institutional facility inventory. The office of financial
24 management shall contract with consultants with expertise related to
25 the subject matters included in this study. The office of financial
26 management and the consultants shall consult with the department of
27 social and health services, the department of corrections, stakeholder
28 groups that represent the people served in these institutions, labor
29 organizations that represent employees who work in these institutions
30 and other persons or entities with expertise in the areas being
31 studied.

32 (a) For the purposes of this study, "state institutional
33 facilities" means facilities operated by the department of corrections
34 to house persons convicted of a criminal offense, Green Hill school and
35 Maple Lane school operated by the department of social and health
36 services juvenile rehabilitation administration, and residential
37 habilitation centers operated by the department of social and health
38 services.

1 (b) In conducting this study, the consultants shall consider the
2 following factors as appropriate:

3 (i) The availability of alternate facilities including alternatives
4 and opportunities for consolidation with other facilities, impacts on
5 those alternate facilities, and any related capital costs;

6 (ii) The cost of operating the facility, including the cost of
7 providing services and the cost of maintaining or improving the
8 physical plant of the facility;

9 (iii) The geographic factors associated with the facility,
10 including the impact of the facility on the local economy and the
11 economic impact of its closure, and alternative uses for a facility
12 recommended for closure;

13 (iv) The costs associated with closing the facility, including the
14 continuing costs following the closure of the facility;

15 (v) Number and type of staff and the impact on the facility staff
16 including other employment opportunities if the facility is closed;

17 (vi) The savings that will accrue to the state from closure or
18 consolidation of a facility and the impact any closure would have on
19 funding the associated services; and

20 (vii) For the residential habilitation centers, the impact on
21 clients in the facility being recommended for closure and their
22 families, including ability to get alternate services and impact on
23 being moved to another facility.

24 (c) The office of financial management shall submit a final report
25 to the governor and the ways and means committees of the house of
26 representatives and senate by November 1, 2009. The report shall
27 provide a recommendation and a plan to eliminate 1,580 beds in the
28 department of corrections facilities, 235 beds from juvenile
29 rehabilitation facilities, and 250 funded beds in the residential
30 habilitation centers through closure or consolidation of facilities.
31 The report shall include an assessment of each facility studied, where
32 and how the services should be provided, and any costs or savings
33 associated with each recommendation. In considering the
34 recommendations of the report, the governor and the legislature shall
35 not consider closure of any state institutional facility unless the
36 report recommended the facility for closure.