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IN THE COURT OF APPEALS OF THE STATE OF WASHINGTON
DIVISION ONE

In the Matter of the

GUARDIANSHIP OF SANDRA LAMB

DISABILITY RIGHTS WASHINGTON'S AMICUS CURIAE BRIEF IN SUPPORT OF RESPONDENT'S RESPONSE AND CROSS-APPEAL

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Amicus Curiae

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I. INTRODUCTION

Disability Right Washington ("DRW") submits this Amicus Curiae brief in support of respondents, Department of Social and Health Services ("DSHS"), in the above-captioned action. DRW presents information demonstrating that guardians lack authority to substitute their beliefs for those of their ward and therefore should not be allowed to charge the ward for lobbing and community activism to maintain institutions like Fircrest.

II. INTERESTS AND IDENTITY OF AMICUS

Amicus, Disability Rights Washington ("DRW") submits this brief to inform the Court of the trend toward deinstitutionalization, the guardianship movement toward individual autonomy, and the nature of the protection and advocacy system and the services it provides. In doing so, DRW will show that state and federal law require such consideration of community integration to comport with the best interests of individuals with disabilities.

DRW has been designated by federal law and the governor of Washington to provide protection and advocacy services for people in Washington with physical, sensory and mental disabilities. Stroh Decl., ¶ 2. As the designated protection and advocacy organization, DRW has the authority to pursue a full range of legal assistance to people with disabilities including legal representation, regulatory and legislative

advocacy, and education and training. *Id.* at ¶ 2, 4, and 7. DRW has extensive knowledge about disability services, the scope of guardianships, the effects of institutionalization, and what makes a successful transition from institutions, such as Fircrest, to the community. *Id.*

Amicus is also part of a network of protection and advocacy systems located in all 50 States, the District of Columbia, Puerto Rico, the Northern Marianas Islands and the territories (the Virgin Islands, Guam, and American Samoa). Stroh Decl., ¶ 8. Protection and advocacy systems like DRW are particularly active in providing assistance to individuals whose disability may limit or preclude their ability to advocate for themselves. Because of its extensive involvement in the legal and social construct of community integration in Washington, DRW is well placed to assist the Court in surveying the impact upon the disability community if guardians were paid to lobby to keep institutions open.

III. STATEMENT OF THE CASE

DRW joins in Respondent's Statement of the Case.

IV. SUMMARY OF ARGUMENT

If James and Alice Hardman (the "Hardmans") prevail, a generation of cases, statutory law, and policy efforts to protect the autonomy of individuals with disabilities like Ms. Lamb and Ms. Robins will be eroded. The Hardmans acknowledge that a "one size fits all"

and interests." Opening Brief, p. 45.[1] DRW is an independent, nonprofit organization mandated by federal law to educate lawmakers on behalf of people with disabilities. 42 U.S.C.A. § 15043(2)(L).[2] Just as the Hardmans should seek out a licensed doctor if the person they are serving needs medical treatment, or an attorney if they need legal representation, they should work with established policy advocacy organizations instead of recreating that system themselves at the expense of their ward's estates.

Ultimately, the question of whether an institution like Fircrest remains open is one based on policy. Guardians are required to focus on the individual needs of individual wards, and policy issues are, by their nature, not individualized. Therefore, accessing systemic advocates is more appropriate than reinventing a systemic advocacy system via guardianship proceedings, which are individualized.

V. ARGUMENT

A. The Trend Toward Deinstitutionalization

The Hardmans argue that community living is dangerous and it is this danger that provides them with the authority to lobby lawmakers

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[1] Similar false allegations can be found on page twelve where they insinuate that the State and "disability rights organizations" like DRW are "teamed together and threaten [Ms. Lamb and Ms. Robins] best interests."

[2] There are several organizations like the Arc of Washington, the Developmental Disabilities Council, and the Independent Living Centers that provide policy makers with information regarding the needs and beliefs of people with disabilities: www.arcwa.org, www.ddc.wa.gov, and www.wasilc.org.

regarding the benefits of keeping Fircrest open. CR 180. However, it is the dangers associated with institutions that started the deinstitutionalized trend almost fifty years ago. R.W. Prouty & K.C. Lakin, eds., *Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1998* (1999). The national trend away from institutions and favor for community placement has been growing since then. *Id.* The efforts planned by DSHS to downsize institutions like Fircrest are consistent with the national trend. *See Parsons v. State, Dept. of Social and Health Services*, 129 Wash.App. 293, 118 P.3d 930 (Wash.App. Div. 1, 2005). The consistent trend towards deinstitutionalization illustrates how the Hardmans' political efforts are not aligned with the disability community, which overwhelmingly prefers community living.

1. Deinstitutionalization Leads to Quality of Life Improvement

A review of the relevant deinstitutionalization literature overwhelmingly found that deinstitutionalization has resulted in reduced maladaptive behaviors, increased adaptive behaviors, and overall improvement in the quality of life. *See Behavioral Outcomes of*

Deinstitutionalization for People with Intellectual Disabilities, supra.[3]. There, the reviewers looked at 38 studies and concluded that "community experiences increasingly provide people with environments and interventions that reduce challenging behavior" and an overall better quality of life.[4]

The position that community living somehow increases risk for individuals has been debunked by several studies[5]. Some pro-institutionalization activists have attempted to inappropriately use aggregate statistics to argue in favor of keeping institutions open, but expert findings in this field have established that aggregate data regarding the risks of deinstitutionalization often result in inaccuracies. *See* Byzek, "Fighting to Keep 'Em In", Ragged Edge Magazine (1998).[6] As the Hardmans concede, Opening Brief, p. 8, a "one size fits all" approach does not work when assessing the *individual's* risk when changing their living situation. Rather, the driving consideration when assessing an individual's unique needs should be that individual's providers who are licensed to make clinical judgments. However, here, the Hardmans instead seek to

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[3] *See also Eight Years Later: The Lives of People Who Moved From Institutions to Communities in California,* The Center for Outcome Analysis (1991) (8 year longitudinal study of movement from institutions to community).

[4] *See also Personal Control and Ecology of Community Living Settings: Beyond Living-Unit Size and Type*, 105 *Amer.J. on M.R.*, 431, 432 (2000).

[5] The Center for Outcomes Analysis has a bibliography of numerous state and national reports on quality of life for individuals moved from institutions to the community.

address the systemic issue of keeping Fircrest open without any reference to any independent analysis of the individual risks of community living. For example, the Hardmans cite to another lawsuit they filed against the state involving the downsizing of Fircrest; however, there is no reference to Ms. Lamb's individual discharge plan or whether she was even part of that settlement. Opening Brief, p.3, footnote 3.

2. Deinstitutionalization Upholds Constitutional and Statutory Rights Protections

Due to society's negative stereotypes, people with disabilities have been subjected to a long history of pervasive discrimination in all aspects of society, including but not limited to forced institutionalization and segregation from the community. Michael L. Perlin, *I Ain't Gonna Work on Maggie's Farm No More: Institutionalization, Segregation, Community Treatment, the ADA and the Promise of* Olmstead, 17 T.M. Cooley L. Rev. 53, 63 (2000). In enacting the Americans with Disabilities Act ("ADA"), Congress likewise found that "historically, society has tended to isolate and segregate individuals with disabilities, and...such forms of discrimination...continue to be a serious and pervasive social problem." U.S.C. § 12101(a)(2). In furtherance of the objective of eliminating discrimination against people with disabilities, Congress stated "the Nation's proper goals regarding individual's with disabilities are to assure

equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals" 42 U.S.C. § 12101(a)(8). "[I]ntegration is fundamental to the purposes of the Americans with Disabilities Act." 28 C.F.R. Part 35, App. A, § 35.130.

The courts have also upheld that the ADA defines unnecessary segregation and institutionalization as a form of illegal discrimination against individuals with disabilities. *See e.g. Helen L. v. Didario,* 46 F.3d 325 (3rd Cir. 1995). There, plaintiffs challenged the Pennsylvania residential welfare policies for people with disabilities, which only paid for nursing home programs forcing people to access services only in a nursing home. After reviewing the history of Section 504 of the Rehabilitation Act, 29 U.S.C. § 794, and the ADA, the court held that the state agency's policy violated 28 C.F.R. § 35.130(d), which requires a public entity to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."

The ADA's requirement that individuals with disabilities be served in integrated community settings rather than unnecessarily in institutions was addressed by the Supreme Court's decision in *Olmstead v. LC*, 527 U.S. 581, 119 S.Ct. 2176 (1999). The plaintiffs had a history of treatment in institutions and remained institutionalized even after their treating

professionals found them ready for community-based settings. The *Olmstead* court held that in enacting the ADA, Congress intended to remedy historical isolation and segregation of individuals with disabilities, the discrimination of forced institutionalization, and the failure to make accommodations to existing services and practices. *Id.* at 588-589.

Similar to *Helen L.*, the *Olmstead* Court also cited to ADA's regulation requiring a public entity to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." *Id.* at 592, citing to 28 C.F.R. § 35.130(d). However, the court went on to hold that the most integrated setting appropriate to the needs of qualified individuals to mean "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." *Id.* at 592. The *Olmstead* requirements have also been recognized in Washington State Courts. *See Townsend v. Quasim*, 328 F.3d 511 (9th Cir. 2003)(state Court of Appeals held that failure to provide services in a community setting was a form of discrimination).

Washington State law, like the ADA, prohibits discrimination based on disability. RCW 49.60.030. Washington also requires that persons with developmental disabilities be served in the least restrictive environment. The state legislature recognized "that the emphasis of state

developmental disability services is shifting from institutional-based care to community services in an effort to increase the personal and social independence and fulfillment of person with developmental disabilities..." RCW 71A.10.011. Additionally, DSHS is required to "provide every eligible person with habilitative services suited to the person's needs, regardless of age or degree of developmental disability," RCW 71A.12.020(1), and is required to "provide persons who receive services with the opportunity for integration with non-handicapped and less handicapped persons to the greatest extent possible." *Id* at (2).

Here, the Hardmans argue that institutions like Fircrest should remain open based on the best interests of the wards, Ms. Lamb and Ms. Robins. Opening Brief, pgs. 7-13. Beyond statements regarding the type of disability, the record lacks an individualized assessment regarding the needs and aptitudes of either Ms. Lamb or Ms. Robins. There is no evidence that either individual cannot have their needs met in a community setting and therefore no support for subjecting them to the harm of segregation in an institution. Therefore, it is unclear whether residing in Fircrest would comport with their best interests. Without any description of why each ward's needs could not be met in an alternative setting, these guardians have rejected what people with disabilities and

federal and state policy makers have resoundingly accepted: the benefits of individualized community settings.

B. The Scope of a Guardian's Duties Are Limited

1. A guardian's duties are limited to health, safety, and financial affairs and only to the extent necessary to preserve the autonomy of the ward.

Like the deinstitutionalization trend, the legal process to establish guardianship on behalf of a person with a disability has become individualized focusing on the autonomy of the ward. In 1990, Washington State modified the existing guardianship laws to reflect the policy that individuals with disabilities will no longer be regarded as indistinguishable; but rather, courts must tailor guardianship proceedings to address the unique needs and aptitudes of the ward and provide specific authority regarding how the guardians can either spend their money. RCW 11.88.095(a) and (f). These requirements highlight the legislature's stated intent to promote the autonomy of people with disabilities.

> It is the intent of the legislature to protect the liberty and autonomy of all people of this state, and to enable them to exercise their rights under the law to the maximum extent, consistent with the capacity of each person... *However, their liberty and autonomy should be restricted through the guardianship process only to the minimum extent necessary to adequately provide for their own health or safety, or to adequately manage their financial affairs.*

RCW 11.88.005 (emphasis added). This statement makes clear that the legislature intended to limit a guardian's duties to protecting the health, safety, and financial affairs of his or her ward, and only to the extent necessary for that particular individual. The legislature also intended to move toward limiting guardianships rather than the historically broad full guardianship with its assumptions and reduction of rights. RCW 11.88.010(2).

Citing this same limiting provision, the Certified Professional Guardianship (CPG) outlines the following as the guardian's duties:

> ...In general, a guardian is responsible for the individual's "care, custody, and control," while considering and respecting the individual's preferences....

Duties and Responsibilities of a Certified Professional Guardian (CPG). Guardianship laws and the committee in charge of governing professional guardians highlight that guardians' duties are limited to general care and custody of their wards and do not include interests like lobbying or community outreach.

2. Lobbying or community activism involves fundamental rights and shall be afforded due process before those rights can be conferred upon a guardian.

The legislative intent in the guardianship statute begins with protecting the liberty interests of people with disabilities "to the maximum

extent". This focus on the liberty of people with disabilities policy reflects both the *Olmstead* decision and due process protections. Under virtually identical language in both the 14th Amendment to the United States Constitution and Article 1, section 3 of the Washington State Constitution, no person may be deprived "of life, liberty, or property, without due process of law." It is well established that when a governmental entity seeks to terminate, reduce, or deny an individual his or her liberty interests, freedom or other civil rights, he or she must be provided with notice and a meaningful opportunity to contest the decision before those rights are discontinued. *Goldberg v. Kelly*, 397 U.S. 254, 267 (1970).

The fundamental liberty interests involved in lobbying or community activism require a meaningful process before those rights can be conferred upon a guardian. It should not be assumed that a professional guardian has the authority to either lobby or engage in community outreach on behalf of their ward. Both RCW 11.92.040 and RCW 11.92.043 list the duties of a guardian and neither includes politicking or community outreach. Further, an individual with a disability cannot have any legal rights removed absent those rights specifically set forth in the court order. RCW 11.88.010(2). For example, removing political rights like voting require a court order with a specific capacity determination that the individual is incapable of making an individual choice. RCW

11.88.010(5). Before a guardian can assume to act upon a ward's fundamental rights by lobbying in his or her best interests, the guardianship proceedings should be narrowly tailored so that the ward's rights are afforded the greatest deference.

Here, the Hardmans implicate three substantive fundamental rights: speech, property, and liberty. They seek state authorization to use their wards' property to substitute their ideas instead of the individualized needs of each ward for the purpose of maintaining the institution where they will continue to make their wards live. Not only have the Hardmans failed to show how these actions are responsive to specific needs of individual wards, but they have also failed to show how the actions are narrowly tailored to meet the state's purpose of protecting the wards.

3. Guardians Must Avoid Self-Dealing, Act in Their Individual Wards Best Interests, and Abide by the Legal Requirements for Community Integration.

While the law does not afford a guardian authority to lobby, the guardian does have several duties that are of relevance to the present case. A guardian must act in a ward's best interests. RCW 11.92.043(4).[7] A

[7] A study conducted by the New York Office of Administrative Hearings examined several selected guardianship cases and revealed that the guardians apparently did not always act in the best interests of their wards. Serious lapses were found in the quality of care that guardians provided in meeting the personal needs of the person with the disability. Moreover, guardians apparently did not always strive to promote and preserve

guardian must abide by the legal requirements for community integration pursuant requiring guardians to "...care for and maintain the incapacitated person in the setting *least restrictive* to the incapacitated person's freedom and *appropriate* to the incapacitated person's personal care needs...." RCW 11.92.043(4) (emphasis added).[8]

Here, the Hardmans argue that they, as guardians, have the authority to identify and then get paid to lobby on behalf of Ms. Lamb's and Ms. Robins' needs and best interests. Opening Brief, pgs. 7-13. However, it is unclear whether the Hardmans complied with the professional standards established by the CPG and obtained an independent assessment, or otherwise sought to determine the unique and individual needs of either Ms. Lamb or Ms. Robins. Instead, the Hardmans argue that lobbying for keeping an institution like Fircrest open comports with the best interests and needs of the wards by simply citing to their profound disabilities. Opening Brief, pgs. 2, 7-9, and 12. However, a medical diagnosis alone does not indicate the unique needs or aptitudes of a person with a disability; hence, a professional evaluation is needed. *See* CPG 401.4 and 401.10.

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the person with a disability's financial interests, as they were obligated to do as fiduciaries. http://www.courts.state.ny.us/ip/gfs/igfiduciary.html

[8] A professional guardian's duties found in the Certified Public Guardian's (CPG) Standard of Practice is also illustrative. Like the legislative intent in RCW 11.88.005, the independence and self-reliance of the incapacitated person shall be maximized to the greatest extent consistent with their protection and safety. CPG 401.

The lack of an independent assessment is especially troublesome in light of CPG 403 Ethics which require the highest degree of fidelity. "The guardian shall avoid self-dealing, conflict of interest, and the appearance of a conflict of interest. Self-dealing or conflicts of interest arise when the guardian has some personal, family, or agency interest from which a personal benefit would be derived..." CPG 403.1. Further, all expenses paid or incurred on behalf of the incapacitated person by the guardian shall be documented, *reasonable in amount*, and incurred for the incapacitated person's welfare. CPG 403.2. A guardian or limited guardian shall be allowed such compensation for his or her services as guardian or limited guardian as the court shall deem just and reasonable. RCW 11.92.180. In managing a ward's estate, the guardian shall exercise caution to avoid even the appearance of self-interest. CPG 406.9.

Here, if the Hardmans prevail, $150 each month will be taken out of estates of Ms. Lamb and Ms. Robins resulting in $3,600 annually. Since there is no evidence in the record describing individual needs of individual wards that necessitate the maintenance of institutions, there is nothing preventing the Hardmans from summarily proclaiming the maintenance of institutions is also in the best interest of some or all of their other wards. The Hardmans could collect these fees from a total of 28 wards (including Ms. Lamb and Ms. Robins), CP 136, which would push

their fees for lobbying efforts to a total of $50,400 per year. Not only is this amount arguably unreasonable, but the lobbying efforts themselves assert a political position that fails to consider the individual needs and best interests of both Ms. Lamb and Ms. Robins.

Moreover, the Hardmans have a potential conflict of interest in advocating for their wards to remain at Fircrest because guardian fees are often more available in an institutional setting as opposed to a community setting. This is because a ward that lives in an institution pays most of their social security benefits to the institution as "participation" towards their cost of care. Guardians may collect their fees from this "participation." In the community, however, the ward is not responsible for paying "participation" but most of his or her money is spent on rent and food and there is little if anything left over with which to pay the guardian. *See* WAC 388-515-1540(12); WAC 388-515-1509(4). The Hardmans' financial gain, coupled with the established trend against institutions like Fircrest, result in the appearance of self-serving by the Hardmans.

Further, the Hardmans' community outreach efforts also appear to be self-serving as they lack a connection to an individualized and personal need of either Ms. Lamb or Ms. Robins. For example, the Hardmans seek costs to increase guardianship courses incentives, attending Friends of

Fircrest meetings, media appearances, and drafting a newsletter. CP 135, 143, 193-197. Each of these activities lacks direct connection to the needs of the particular wards and appears to relate largely to the guardians' professional development. These professional guardians are using their position as guardian to increase their fees and promoting a political objective that comports with their best interest, not necessarily any individual ward's best interests. Ultimately, payment for these activities is both unreasonable in scope and amount.

C. DRW is uniquely situated to advocate for Ms. Lamb and Ms. Robins.

Following great outcry over deplorable conditions at an institution for people with developmental disabilities, Congress passed the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in 1973.[9] 42 U.S.C. § 15043, *et seq.* Among other things, the DD Act established the protection and advocacy systems which included the federal mandates to provide protection and advocacy services to individuals with developmental disabilities.[10] As the designated protection and advocacy organization for Washington State, DRW has the

[9] The conditions at New York's Willowbrook School promoted a national response to the at state-run institutions for people with developmental disabilities including the passage of the DD Act. *See Christmas in Purgatory,* Burton Blatt, (1974).

[10] Through future acts, Congress ultimately expanded the systems' scope to include other disabilities. PAIR Act, 29 U.S.C. § 794, *et seq.*, PAIMI Act, 42 U.S.C. § 10801, *et seq.*, and PATBI Act, 42 U.S.C.A. § 300, *et. seq.*

federal and state authority to provide the range of services – including educating policy and lawmakers – on behalf of individuals with disabilities like Ms. Lamb and Ms. Robins. *See* 42 U.S.C.A. § 15043.

The DD Act also provides DRW with the authority to advocate for the rights of individuals with developmental disabilities. 42 U.S.C.A. § 15043(1). DRW's authority includes ensuring appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of such individuals within the State who are or who may be eligible for treatment, services, or habilitation, or who are being considered for a change in living arrangements. 42 U.S.C.A. § 15043(2)(A)(i). This includes the authority to educate policymakers. 42 U.S.C.A. § 15043(2)(L).

DRW acts on behalf of and at the direction of individuals with disabilities. DRW's board must be comprised of a majority of either individuals with disabilities or family members, guardians, or advocates of individuals with disabilities. 42 U.S.C.A. § 15044(i) and (ii). DRW's board establishes the organization's policy and priorities ensuring DRW's actions represent constituents' interests including favoring community supports over institutionalization. DRW's public policy education efforts reflect the prevailing trends as described to it through its board of directors, advisory counsel, and constituents

These federal mandates highlight both DRW's authority to advocate on behalf of individuals with disabilities, like Ms. Lamb and Ms. Robins, and the congressional intent that there is a structure in place to independently act on behalf of the most vulnerable without any appearance of self-dealing or personal conflict of interest. The Hardmans, on the other hand, seek to reject the overwhelming support found in the disability community and federal and state governments for deinstitutionalization and instead tap into their wards' funds to pay themselves to present their opinion that, at a minimum, has the appearance of being self serving.

VI. CONCLUSION

For the reasons stated above, this Court should conclude that the Hardmans political or community outreach activities on behalf of either Ms. Lamb or Ms. Robins are potentially self-dealing, outside their duties as guardians, and lack an individualized basis for guardian fees.

Dated this 26th day of May, 2009.

Respectfully submitted,

Disability Rights Washington,
Applicant for Amicus Curiae

By _____
EMILY COOPER PURA, WSBA # 34406

No. 62711-2-I

IN THE COURT OF APPEALS OF THE STATE OF WASHINGTON
DIVISION ONE

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STATE OF WASHINGTON
2009 MAY 26 PM 4:05

In the Matter of the

GUARDIANSHIP OF SANDRA LAMB

DECLARATION OF EMILY COOPER PURA IN SUPPORT OF AMICUS CURIAE BRIEF

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Amicus Curiae

I, Emily Cooper Pura, declare as follows:

1. I am an attorney with Disability Rights Washington ("DRW").

2. Attached as Exhibit 1 is a true and correct copy of R.W. Prouty & K.C. Lakin, eds., *Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1998*, Research & Training Center on Community Living, University of Minnesota (1999).

3. Attached as Exhibit 2 is a true and correct copy of *Eight Years Later: The Lives of People Who Moved From Institutions to Communities in California,* The Center for Outcome Analysis (1991).

5. Attached as Exhibit 3 is a true and correct copy of the Center for Outcomes Analysis (COA) bibliography of federal, state, and local reports on quality of life for individuals moved from institutions to the community.

6. Attached as Exhibit 4 is a true and correct copy of Josie Byzek, "Fighting to Keep 'Em In", Ragged Edge Magazine (1998).

7. Attached as Exhibit 5 is a true and correct copy of Michael L. Perlin, *I Ain't Gonna Work on Maggie's Farm No More: Institutionalization, Segregation, Community Treatment, the ADA and the Promise of* Olmstead, 17 T.M. Cooley L. Rev. 53, 63 (2000).

8. Attached as Exhibit 6 is a true and correct copy of the Office of the Special Inspector General for Fiduciary Appointments and the Unified Court System's Internal Audit Unit, "*Fiduciary Appointments in New York: A Report to Chief Judge Judith S. Kaye and Chief Administrative Judge Jonathan Lippman*" (2000).

9. Attached as Exhibit 7 is a true and correct copy of Burton Blatt, *Christmas in Purgatory* (1974).

I declare under penalty of perjury of the laws of the State of Washington that the foregoing is true and correct.

Dated this 26th day of May, 2009 at Seattle, Washington.

EMILY COOPER PURA, WSBA # 34406

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STATE OF WASHINGTON
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No. 62711-2-I

IN THE COURT OF APPEALS OF THE STATE OF WASHINGTON
DIVISION ONE

In the Matter of the

GUARDIANSHIP OF SANDRA LAMB

CERTIFICATE OF SERVICE

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Amicus Curiae

Emily Cooper Pura declares as follows:

On May 26, 2009 I caused to be served by legal messenger true and correct copies of the following documents:

Disability Rights Washington's Motion To Appear As Amicus Curiae In Support Of Respondent's Response And Cross-Appeal

Declaration Of Emily Cooper Pura In Support Of Disability Rights Washington's Motion To Appear As Amicus Curiae

Declaration Of Mark Stroh In Support Of Disability Rights Washington's Motion To Appear As Amicus Curiae And Amicus Curiae Brief

Disability Rights Washington Amicus Curiae Brief In Support Of Respondent's Response And Cross-Appeal

Declaration Of Emily Cooper Pura In Support Of Amicus Curiae Brief

to the following parties:

Michael L. Johnson
703 Columbia St Ste 400
Seattle, WA 98104-1965

I also served by email and first-class mail, postage prepaid a copy of the same documents to the following:

John Bashford
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John Bashford
PO Box 40124,
Olympia, WA 98504-0124

I declare under penalty of perjury under the laws of the state of Washington that the foregoing is true and correct.

Dated this 26th day of May, 2009.

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Policy Research Brief

RESEARCH & TRAINING CENTER ON COMMUNITY LIVING
UNIVERSITY OF MINNESOTA

Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1999

This Policy Research Brief reports the results from a review of 38 published studies that measured behavioral outcomes associated with the movement of people with mental retardation from public institutions to community residential settings. The review was conducted by Shannon Kim, Department of Educational Psychology and Educational Leadership, University of Mississippi in University; and Sheryl A. Larson and K. Charlie Lakin of the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, Twin Cities.

Introduction

Deinstitutionalization as a policy and a practice has produced dramatic changes in the sizes and types of places where individuals with intellectual disabilities live. In the United States, this policy has produced dramatic reductions in the census at large state-operated institutions (from 154,638 people in 1977 to 52,488 in 1998) (Prouty & Lakin, 1999). Similar reductions have also occurred in other institutions serving 16 or more people with intellectual disabilities (declining from 52,718 people in 1977 to 35,247 in 1998). A corresponding trend has increased the number of people receiving residential supports in homes with six or fewer people with intellectual disabilities from 20,400 people in 1977 to 202,266 people in 1998. Four states (WV, RI, VT and DC) have moved all people with intellectual disabilities out of facilities serving 16 or more people. An additional seven states (AK, AZ, CO, HI, ME, MT, NM) serve more than 90% of all persons with intellectual disabilities receiving residential supports in settings with 15 or fewer residents (Prouty & Lakin, 1999). Clearly, the practice of deinstitutionalization has been accepted and adopted widely.

Despite the enormous changes that have occurred over the past 20 years, however, there were in June 1998 still 89,348 people with intellectual disabilities living in private or public residential institutions and an estimated 24,144 living in nursing homes in 1998 (Prouty & Lakin, 1999). This reality has not gone unnoticed by the national self-advocacy organization Self-Advocates Becoming Empowered (SABE), which has begun "Operation Close the Doors" (Nelis & Ward, 1996).

Despite the ongoing movement toward depopulation and closure of institutions, deinstitutionalization continues to be a controversial topic in states that continue to operate institutions. A considerable body of research has examined the relative risks and benefits associated with institutional and community living. Many studies have examined changes in adaptive or challenging behavior associated with movement from institutions to community settings. Summaries of this research noted that, overall, adaptive behavior was almost always found to improve with movement to community settings from institutions, and that parents who were often as a group initially opposed to deinstitutionalization were almost always satisfied with the results of the move to the community after it occurred (Larson & Lakin, 1989; Larson & Lakin, 1991). A recent meta-analysis of 11 studies of specific adaptive behavior skills found that self-care skills — and to a lesser degree communication skills, academic skills, social skills, community living skills, and physical development — improved significantly with

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deinstitutionalization (Lynch, Kellow & Willson, 1997). A recent literature review examined the outcomes of deinstitutionalization in the United Kingdom and Ireland and concluded that deinstitutionalization was generally, but not inevitably, associated with increases in adaptive behaviors and reductions in observed challenging behavior (Emerson & Hatton, 1996).

This study extends and updates an original report by Larson and Lakin (1989) reviewing all identifiable literature on changes in adaptive and challenging behavior associated with movement from institutional to community residences. It is understood in presenting the findings of this analysis that adaptive behavior and challenging behavior are only two of many important outcomes of residential services. However, considering the continuing debates regarding depopulation and closure of public and private institutions, and the frequent requests we receive for outcomes of studies conducted since our last review, we believe this update may be useful in informing future policy decisions.

Method

Selection of Studies

This review includes studies identified through the following methods: (a) a computer search of the *PSYCHINFO* database from 1980 to 1998; (b) a computer search of the *ERIC* database from 1980 to 1998; (c) a computer search of the *Dissertation Abstracts Online* database from 1980 to 1998; (d) a manual review of *American Journal on Mental Retardation*, *Education and Training in Mental Retardation*, *Journal of the Association for Persons with Severe Disabilities*, *Journal of Intellectual and Developmental Disabilities*, and *Mental Retardation* from 1980 to 1998; (e) use of the "ancestry approach," that is, the manual review of reference lists of relevant research to locate additional studies; (f) direct requests for assistance in identifying relevant studies made to researchers prominent in this area of research; and (g) inclusion of studies cataloged by the authors after publication of the original review.

Over 250 studies were screened for inclusion in this review. The following criteria were applied in selecting studies for inclusion: (a) a minimum of five subjects moved from institutional to community residences after 1974; (b) basic demographic information reported about the sample; (c) exclusive or primary use of adult subjects; (d) baseline data collected while the subjects were residing at the institution or within one month of moving to the community; (e) post-test results obtained after the subjects had resided in the community a minimum of six months; and (f) overall adaptive behavior, overall challenging behavior, and/or specific domains of adaptive or challenging behavior were measured with the same assessment instruments in the same manner at the times being compared. The authors conferred in applying the criteria to specific studies. These methods yielded a total of 38 studies for inclusion in this study.

Coding Procedures

The 38 studies were reviewed and coded by the authors according to research design, outcomes reported, and direction and magnitude of the findings. Two types of research design were identified: longitudinal designs, which examined changes within a single group over time ($\underline{n} = 29$ studies), contrast group designs, which compared changes in treatment and control groups over time ($\underline{n} = 14$ studies), and studies that used both types of design ($\underline{n} = 5$ studies).

Several different types of outcomes were reviewed and coded. Adaptive behavior outcomes were summarized into nine categories (e.g., overall, academic skills, community living skills, language/communication skills, motor/physical skills, leisure/recreation skills, self-care/domestic skills, social skills, and vocational skills). Challenging behavior outcomes were collapsed into the most frequently cited categories (overall, frequency, severity, external, internal, and asocial behaviors).

The procedure for coding the direction and magnitude of outcomes utilized the baseline (institutional) scores as the point of reference. A (+) was recorded to indicate the subjects' scores improved in the community, but not to a statistically significant degree, and a (+ +) was used to indicate this difference was statistically significant ($p \leq .05$). Likewise, a (–) was used to indicate scores declined in the community, with a (– –) used to indicate the difference was statistically significant ($p \leq .05$). In cases in which the authors did not test for statistical significance, an asterisk (*) was placed beside the direction indicator. A zero (0) was used to signify that no tendency was found, or that the results were presented in a way that prevented identification of tendencies. In summarizing the findings, blanks were used to indicate a category of outcome was not studied, or that no data were provided.

The decision rules were developed and consulted to resolve potentially conflicting findings. Conflicting findings were apparent when studies reported findings from more than one measure in a single domain. When such findings were in opposite directions, a "0" was recorded to indicate that the findings appeared to cancel each other out and/or that the results could not be interpreted. When the findings were in the same direction, but of different magnitudes (e.g., + +, +, and 0), they were reported to be not statistically significant. When studies used multiple baselines, the last baseline score obtained while the subjects resided in the institution was used as the point of reference. When studies reported results from more than one post-test this review noted the outcome for the longest interval between baseline and follow-up.

■ Results

Contrast Group Studies

Fourteen studies compared people who moved from institutions to small residential settings with a "contrast" group of people who stayed in institutions. All but one of the studies found either a significant improvement associated with community placement or found improvements that did not reach statistical significance (see Table 1). In terms of overall challenging behavior, only one study reported a difference between stayers and leavers that was statistically significant. In that study, movers stayed the same while the stayers had overall challenging behavior ratings that declined significantly.

The findings regarding outcomes within specific domains of adaptive behavior among the contrast group studies (see Table 2 on next page) showed movers with either statistically significant improvements relative to the stayers, or with

Table 1: Overall Adaptive and Challenging Behavior Outcome: Contrast Group Studies

Study	Location	N[a] (exp, cont)	Age[b]	Level of Mental Retardation[c]	Time (months)	Adaptive Behavior[d]	Challenging Behavior[d]	Instrument[e]
United States								
Bradley, Conroy, Covert, & Feinstein (1986)	NH	160 (80, 80)	AC	B, Mi, Mo, S, P	72	+ +	–	CDER
Calapai (1988)	NY	106 (53, 53)	NS	Mo, S, P	24	+		DDIS
Conroy, Efthimiou, & Lemanowicz (1982)	PA	140 (70, 70)	A	Mi, Mo, S, P	24	+ +	+ +[f]	BDS
Conroy, Lemanowicz, Feinstein, & Bernotsky (1991)	CT	248 (124, 124)	A	Mi, Mo, S, P	60	+ +	+	CIER
D'Amico, Hannah, Milhouse, & Froleich (1978)	WV	13 (6, 7)	AC	Mi, Mo, S, P	12	+ +		CBC
Davis (1990)	PA	66 (33, 33)	A	NS	48	+	+	BDS
Rosen (1985)	AR	112 (56, 56)	A	B, Mi, Mo, S, P	24	+ +		SSSQ
Schroeder & Henes (1978)	NC	38 (19, 19)	A	MA range 4.0 to 6.8 yrs	12	+ +		PAC
Williams, Paskow, Thompson, & Levine (1985)	DC	26 (13, 13)	AC	B, Mi, Mo, S, P	15	+	–	ABS
International								
Molony & Taplin (1990)	Australia	57 (26, 31)	A	B, Mi, Mo, S, P	12	+ +	0	VABS

[a] N: numbers in parentheses indicate the number of persons in the experimental and control groups.
[b] Age: A, Adults; AC, Adults and Children; NS, Not Specified.
[c] Level of Mental Retardation: B, Borderline; Mi, Mild; Mo, Moderate; S, Severe; P, Profound; NS, Not Specified.
[d] Results: + + statistically significant improvement relative to the control group at $p \leq .05$.; + improvement relative to the control group, but not statistically significant; – – statistically significant decline relative to the control group at $p \leq .05$.; – decline relative to the control group, but not statistically significant; **0**, no change or conflicting results relative to the control group.
[e] Instruments: ABS, *Adaptive Behavior Scale*; BDS, *Behavior Development Scale*; CBC, *Camelot Behavior Checklist*; CDER, *Client Development Evaluation Report*; CIER, *Connecticut Individual Evaluation Report*; DDIS, *Developmental Disabilities Information Survey*; PAC, *Progress Assessment Chart*; SSSQ, *Street Skills Survival Questionnaire*; VABS, *Vineland Adaptive Behavior Scales.*
[f] The experimental group stayed the same while the control group declined.

Table 2: Adaptive and Challenging Behavior Domain Outcomes[a]: Contrast Group Studies

Study[b]	Academic Skills	Community Living Skills	Language/ Communication Skills	Motor/ Physical Skills	Leisure/ Recreation Skills	Self-Care/ Domestic Skills	Social Skills	Vocational Skills	Challenging Behavior Frequency	Challenging Behavior Severity	External Behavior	Internal Behavior	Asocial Behavior
United States													
Bradley, Conroy, Covert, & Feinstein (1986)								0					
Calapai (1988)	+	+	+	+		+							
Close (1977)[c]						+ +							
D'Amico, Hannah, Milhouse, & Froleich (1978)	0	+ +	+ +	+ +		+ +	+ +	0					
Eastwood & Fisher (1988)[d]	+ +	+ +	+			+ +	+ +	+ +					
Fuess (1987)[e]	+	0	+	+		+ +	0	+			+ +	+	+
Horner, Stoner, & Ferguson (1988)[f]		+				+ +	+ +				+ +	+	
Rosen (1985)	+ +	+ +				+ +		+ +					
Schroeder & Henes (1978)			+			+	+						
International													
Molony & Taplin (1990)			+ +			+ +	+ +				+	+	0

Guide: **+ +**, statistically significant improvement relative to the control group; **+**, improvement relative to the control group, but not statistically significant; **– –**, statistically significant decline relative to the control group; **–**, decline relative to the control group, but not statistically significant; **0**, no change or conflicting results relative to the control group. Statistical significance reflects a p-value ≤ .05

[a] In cases where repeated measures are reported, results from the last time period are used.

[b] Complete information on study characteristics can be found in Table 2 unless otherwise indicated.

[c] This study was conducted in Oregon with 12 adult subjects (6 per group) who had severe and profound levels of mental retardation. The Developmental Record (DR) was used to assess subjects after 12 months in the community.

[d] This study was conducted in the Northeastern United States with 98 adult subjects (49 per group) who had borderline, mild, moderate, severe, and profound levels of mental retardation. The MDPS was used to assess subjects after 60 months in the community.

[e] This study was conducted in Ohio with 122 (104, 18) adult subjects who had borderline, mild, moderate, severe, and profound levels of mental retardation. The ABS was used to assess subjects after 48 months in the community.

[f] This study was conducted in Oregon with 46 adult subjects (23 per group) who had mild, moderate, severe, and profound levels of mental retardation. The BDS was used to assess subjects after 60 months in the community.

improvements that did not reach statistical significance. As the Lynch, Kellow & Willson (1997) meta-analysis reported, the self-care or domestic skills domain of adaptive behavior showed the most consistent statistically significant improvements. Other adaptive behavior domains that showed statistically significant improvements in at least two separate studies included academic skills, community living skills, language or communication skills, social skills, and vocational skills. Unlike the overall challenging behavior findings which showed little consistency in differences between stayers and movers, externalized challenging behavior (e.g., aggression toward other people and property destruction) improved significantly for movers in two studies relative to stayers and improved, but not significantly so, in the third study.

Longitudinal Studies

General adaptive behavior. A total of 19 studies examined changes in overall adaptive behavior among movers in samples in the United States (see Table 3). Of those studies, 13 reported statistically significant improvements in overall adaptive behavior associated with moving to a small community setting, one reported improvements that were not statistically significant, one reported improvements that were not tested for significance, one reported a decline that was not statistically significant, and two reported significant declines. One international study reported statistically significant improvements in overall adaptive behavior at the longest point measured, one reported improvements that were not

Table 3: Overall Adaptive and Challenging Behavior Outcome: Longitudinal Studies

Study	Location	N	Age[a]	Level of Mental Retardation[b]	Time (months)	Adaptive Behavior Results[c]	Challenging Behavior Results[c]	Instrument[d]
United States								
Apgar, Cook, & Lerman (1998)	NJ	44	A	B, Mi, Mo, S, P	60	+ +	+	JIF
Bolin (1994)	OK	44	AC	Mi, Mo, S, P	12	+ +		ADS
Bradley, Conroy, Covert, & Feinstein (1986)	NH	93	AC	B, Mi, Mo, S, P	84	+ +	–	CDER
Business Services Group (1999)	CA	44	AC	B, Mi, Mo, S, P	12	–	+	CDER
Calapai (1988)	NY	53	NS	Mo, S, P	6	– –[e]		DDIS
Center for Oucome Analysis (1999)	IN	92	AC	Mi, Mo, S, P	6	+ +	–	ABS
Colorado Division of Dev. Disabilities (1982)	CO	115	AC	Mi, Mo, S, P	12	+		BDS
Conroy (1995)	OK	382	AC	B, Mi, Mo, S, P	60	+ +		BDS
Conroy (1998)	KS	88	AC	P	12	+ +	+	ABS
Conroy & Bradley (1985)	PA	383	AC	B, Mi, Mo, S, P	72	+ +	+	BDS
Conroy, Feinstein, & Lemanowicz (1988)	CT	207	A	B, Mi, Mo, S, P	24	+ +	– –	CIER
Conroy, Lemanowicz, Feinstein, & Bernotsky (1991)	CT	569	A	Mi, Mo, S, P	60	+ +	+	CIER
Conroy, Seiders & Yuskauskas (1998)	CA	91	A	Mi, Mo, S, P	36	+ +	+ +	CDER
Feinstein, Lemanowicz, Spreat, & Conroy (1986)	LA	158	AC	B, Mi, Mo, S, P	9	+ +	+ +	BDS
Fortune, Heinlein, & Fortune (1995)	WY	157	AC[f]	B, Mi, Mo, S, P[f]	72	– –	+ +	ICAP
Hayden, DePaepe, Soulen, & Polister (1995)	MN	190	A	B, Mi, Mo, S, P	12		0	ICAP
Kleinberg & Galligan (1983)	NY	20	A	Mi, Mo, S, P	12		–	ABS
Maisto & Hughes (1995)	NC	42	A	Mo, S, P	12	+ +		SIB
Rose, White, Conroy, & Smith (1993)	PA	7	A	Mi, Mo	12	+ +	+	ICAP
Thompson & Carey (1980	MN	7	A	S, P	24	+*		MDPS
Williams, Paskow, Thompson, & Levine (1985)	DC	80	AC	B, Mi, Mo, S, P	15	+	– –	ABS
International								
Conneally, Boyle, & Smyth (1992)	Ireland	11	A	S, P	24	+ +	+ +	PAC/ABS
Cullen, Whorisky, Mackenzie, Mitchell, Ralston, Shreeve, & Stanley (1995)	Scotland	39	A	B, Mi, Mo, S, P	24	+	+ +	ABS
Webb, Wells, & Hornblow (1986)	New Zealand	19	A	MA 1-9	12	– –	–	ABS

[a] Age: A, Adult; AC, Adults and Children, NS, not specified.

[b] Level of Mental Retardation: B, Borderline; Mi, Mild; Mo, Moderate; S, Severe; P, Profound; MA, Mental Age.

[c] Results: **+ +**, statistically significant improvement after move to the community; **+**, improvement after move to the community, but not statistically significant; **– –**, statistically significant decline after move to the community; **–**, decline after move to the community, but not statistically significant; **0**, no change or conflicting results after move to the community; *, mean scores not tested for statistical significance. Statistical significance reflects a p-value ≤ .05.

[d] Instruments: ABS, *Adaptive Behavior Scale*; ADS, *Adaptive Development Scale*; BDS, *Behavior Development Scale*; CDER, *Client Development Evaluation Report*; CIER, *Connecticut Individual Evaluation Report*; DDIS, *Developmental Disabilities Information Survey*; ICAP, *Inventory for Client and Agency Planning*; JIF, *Johnstone Information Form*; MDPS, *Minnesota Developmental Progress Scales*; PLQP, *Personal Life Quality Protocol*; PAC, *Progress Assessment Chart*; SIB, *Scales of Independent Behavior.*

[e] The subjects demonstrated statistically significant gains between 6 and 12 months and between 12 and 24 months. However, tests were not conducted to compare later years' results with baseline findings.

[f] Demographics were reported for the entire population of Wyoming service recipients. The authors report the sample to be representative of the population.

[g] Sample size declined over the life of the experiment. Only testing periods for which the number of subjects was reported are listed here.

statistically significant, and one in New Zealand reported statistically significant declines associated with movement.

General challenging behavior. Longitudinal studies of changes in challenging behavior showed the same variability reported for the contrast group studies. Eight U.S. studies found improvements in challenging behavior after the move, including three studies in which these changes were statistically significant (after 9, 36 and 72 months). Five U.S. studies reported increased levels of challenging behavior after the move, including two studies that reported statistically significant increases (after 15 and 24 months). Two of the three international studies of challenging behavior reported statistically significant improvements (after 24 months), with the third reporting declines that were not statistically significant. All of the studies published in 1990 or later reporting significant findings regarding changes in challenging behavior reported significant improvements.

Specific domains. Sixteen longitudinal studies examined changes in specific domains of adaptive and challenging behavior (See Table 4). While the contrast group studies found the most consistent pattern of improvement in self-care or domestic skills, among the longitudinal studies social skills showed the most consistent improvement. Eight of the nine longitudinal studies that measured social skills found statistically significant improvements after movement to the community, and the ninth found improvements that did not reach statistical significance. Similarly, consistent improvements were reported for community living skills and motor or physical skills.

Again, patterns within specific domains of challenging behavior were not predictably associated with movement to the community. Two studies reported significant improvements in internal maladaptive behavior (e.g., self-injurious behavior), but another study found statistically significant deterioration. For externalized maladaptive behavior, four studies found improvements that were not statistically significant while one found deterioration that was statistically significant. The only study reporting interpretable findings for asocial maladaptive behavior reported statistically significant improvement associated with a move to the community.

■ Discussion

Ten years ago when we published our first synthesis of the literature on the outcomes of deinstitutionalization, we concluded that "available research denies support for the assertion that people obtain greater or even equal benefit in adaptive behavior from living in institutions. In fact, this research suggests that those benefits very consistently accrue more to the people who leave institutions to live in small community homes" (Larson & Lakin, 1989). Studies conducted in the subsequent decade continue to support this conclusion. In a few studies, adaptive behavior did not improve in conjunction with community living, but in more than two-thirds of the studies reviewed, statistically significant improvements were found.

Interestingly, in the area of challenging behavior, all of the findings of decline associated with deinstitutionalization occurred in studies published during the 1980s. The studies of challenging behavior in the 1990s consistently found improvements (some statistically significant, some not) in both overall challenging behavior, and in the specific subdomains of challenging behavior measured. One possible explanation for these more positive and more consistent outcomes could be improved behavioral supports available to persons in community settings. Increasingly, examples of systems and strategies of community behavioral support can be found in the professional literature and descriptions of innovations in community services. States as large as California and as small as Vermont are developing systems of behavioral support and crisis response for people with challenging behavior outside of the institutional context. Evaluations of community behavior support and crisis response systems show that they can be both effective in addressing challenging behavior and preventing institutionalization, and at the same time cost-effective (Coland & Weiseler, 1995; Rudolph, Lakin, Oslund & Larson, 1998). Perhaps the development and refinement of community supports for people with challenging behavior is now contributing to improved outcomes. Perhaps the greater experience in serving people with challenging behavior in community settings is increasing the effectiveness of those services. Perhaps the substantial shift in the 1990s toward more personalized housing and person-centered services has reduced the stimuli of challenging behavior. Perhaps these and other factors have operated in concert to make movement to community settings more predictably associated with reductions in challenging behavior.

While it is beyond the scope of this manuscript to comprehensively review the literature on other outcomes associated with deinstitutionalization, these and other studies we reviewed examined a wide range of quality-of-life outcomes. For example, Apgar, Cook & Lerman (1998) found that people who moved from institutions not only increased adaptive behavior significantly and reduced challenging behavior, they also improved material well-being and community integration over that of a contrast group of people who remained in institutions. Similarly Conroy, Lemanowicz, Feinstein & Bernotsky (1991) found that movers had adaptive behavior that improved significantly and challenging behavior that declined; they also found that social presence increased significantly when people moved from institutions to community settings, and that movers reported significantly higher overall quality of life, satisfaction, productivity, independence, and integration than a comparison group who stayed in an institution. Conroy (1995) found that 382 Oklahomans who moved from institutions to community homes not only improved

Table 4: Adaptive and Challenging Behavior Domain Outcomes[a]: Longitudinal Studies

Study[b]	Academic Skills	Community Living Skills	Language/ Communication Skills	Motor/ Physical Skills	Leisure/ Recreation Skills	Self-Care/ Domestic Skills	Social Skills	Vocational Skills	Challenging Behavior Frequency	Challenging Behavior Severity	External Behavior	Internal Behavior	Asocial Behavior
United States													
Apgar, Cook, & Lerman (1998)		+	–	+		+ +	+ +				+		
Bolin (1994)									+[i]	+[i]			
Bradley, Conroy, Covert, & Feinstein (1986)								+ +					
Conroy (1995)										+ +[i]			
Conroy (1998)								+ +[j]					
Conroy, Feinstein, & Lemanowicz (1988)								+ +					
Fortune, Heinlein, & Fortune (1995)											+	+ +	+ +
Horner, Stoner, & Ferguson (1988)[c]		+ +				+ +	+ +				+	0	
Kleinberg & Galligan (1983)			0		0[d]	0	+ +[d]	– –[d]					
O'Neill, Brown, Gordon, & Schonhorn (1985)[e]			0			0							
Rose, White, Conroy, & Smith (1993)		+ +	+ +	+ +		+ +	+ +				+	+ +	0
Thompson & Carey (1980)			+[f]		+[f]	+[f]	+[f]						
Williams, Paskow, Thompson, & Levine (1985)		+ +		+		– –	+ +				– –	– –	
State of Wisconsin (1986)[f]	+	+ +	+ +			+	+ +	+ +					
International													
Conneally, Boyle, & Smyth (1992)			+ +[g]			+ +[g]	+ +[g]	+ +[g]					
Cummins, Polzin, & Theobald (1990)[g]			0	+ +		+ +	+ +						
McKay & MacKay (1989)[h]						– –		– –					

Guide: **+ +**, statistically significant improvement after move to the community; **+**, improvement after move to the community, but not statistically significant; **– –**, statistically significant decline after move to the community; **–**, decline after move to the community, but not statistically significant; **0**, no change or conflicting results after move to the community. Statistical significance reflects a p–value ≤ .05.

[a] In cases where repeated measures are reported, results from the last time period are used.

[b] Complete information on study characteristics can be found in Table 1 unless otherwise indicated.

[c] This study was conducted in Oregon with 23 adult subjects who had mild, moderate, severe, and profound levels of mental retardation. The BDS was used to assess subjects after 60–84 months in the community.

[d] The MDPS was used as the outcome measure.

[e] This study was conducted in New York with 27 adult subjects who had mild, moderate, severe, and profound levels of mental retardation. The *Skill Indicator* (SI) was used to assess subjects after 9 months in the community.

[f] The PAC was used as the outcome measure.

[g] This study was conducted in Australia with 57 adult subjects who had severe and profound levels of mental retardation. The PAC was used to assess subjects after 12, 17, and 49 months in the community. Results obtained after 49 months are reported here.

[h] This study was conducted in Northern Ireland with 11 adult subjects who had mild mental retardation. The ABS was used after 18–84 months in the community.

[i] The *Challenging Behavior Scale* (CBS) was used as the outcome measure.

[j] Used the *Orientation Toward Productive Activities* scale.

their adaptive behavior significantly, they also enjoyed more opportunities to make choices after they moved.

Another "outcome" of importance is the relative cost of serving people in community versus institutional settings. The average expenditure for state institutions (about $104,000 per person per year) is substantially greater than the average expenditure for community service recipients (about $30,000 per year for people supported by services funded by the Medicaid Home and Community Based Services Waiver program; Prouty & Lakin, 1999). Recognizing the differences between "typical" community and institution residents, one recent study used an analysis of covariance in a matched sample of individuals moving from institutions to community settings and those remaining behind (Stancliffe & Lakin, 1998). This study found that controlling for individual differences, the individuals who left institutions used significantly more community places, engaged in significantly more social activities, experienced significantly more personal integration, had significantly more family contacts, and made significantly more choices at an adjusted expenditure that was 66% of that of their counterparts who remained in institutions.

The studies reviewed here demonstrate strongly and consistently that people who move from institutions to community settings have experiences that help them to improve their adaptive behavior skills. The studies suggest that community experiences increasingly provide people with environments and interventions that reduce challenging behavior. And, a growing body of research suggests that people enjoy a better quality of life along dimensions that have been quantified differently by different researchers.

This review has been able to draw on a data set of remarkable size (over 2,600 subjects) and scope (pre- and post-tests over a period of six months to seven years). The findings are not easily dismissed. There are, however, limitations that must be noted:

- While this review examined more than 250 studies on this topic, there are undoubtedly other studies that were not identified by the methods we employed. Although we used many approaches to identify relevant studies, much of this research is contracted evaluation research and is not submitted for publication. Its identification, therefore, is not always successful.
- Maturation effects cannot be ruled out. As people get older they grow and develop skills. In a longitudinal study, people are maturing during the study. The selection criteria attempted to control for this by ruling out studies conducted primarily on children who are most susceptible to "maturation effects." The congruence between the findings of the "contrast" group and longitudinal studies suggest that the outcomes we noted were not due solely to maturation effects.
- Many studies adapted existing instruments to meet their own purposes. While most studies reviewed reported the reliability and validity of their measures or used measures with reliability reported elsewhere, not all did.
- While all of the studies met basic criteria listed in the methods section, studies varied in their scientific rigor or at least in the degree to which the rigor of the methodology was described.
- The subject selection for the studies may have a positive bias in that some persons who moved to the community and experienced declines in adaptive behavior or increases in challenging behavior were re-institutionalized. Score changes for persons re-institutionalized before follow-up were not generally included in the data sets.
- Although this report differentiates between findings that were statistically significant and those that were not, it does not report indices of effect size, or practical significance for those studies that had statistically significant findings. Effect sizes were rarely reported in the studies reviewed. No study reviewed reported an index of beta, or statistical power. On a positive note in this regard, the one meta-analysis that has addressed research on this topic reported findings that were consistent with those reported in this manuscript (Lynch, Kellow & Willson, 1997).

Despite these limitations, this is a robust array of research whose findings are remarkable for their consistency.

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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 Moving from Developmental Centers into the Community *(The "Quality Tracking Project")*

Final Report

(Year 2) [1]

Submitted to:

The Honorable Gray Davis
The Honorable Steve Peace, Senate Budget and Fiscal Review Committee
The Honorable Dede Alpert, Senate Appropriations Committee
The Honorable Carole Migden, Assembly Appropriations Committee
The Honorable Wesley Chesbro, Senate Select Committee on DD & MH
The Honorable Dion Aroner, Assembly Human Services Committee
Mr. Dale Sorbello, Department of Developmental Services

Submitted by

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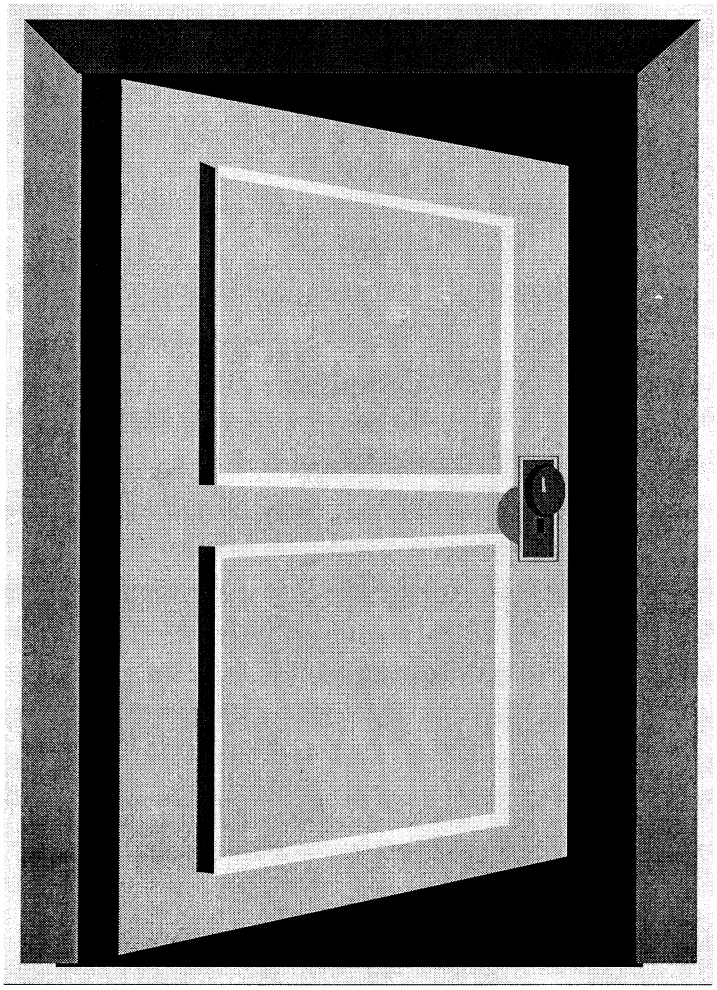
July 1, 2001

[1] **Prepared Pursuant to Contract Number HD989038 from 1999 to 2002 in the Amount of $1,410,515**

Exhibit 2

Acknowledgment

The authors wish to acknowledge and thank the more than 2,000 people who allowed us into their homes and workplaces to find out how they were doing. We also thank the 21 Regional Centers for their cooperation, the staff of the provider agencies who made time for our visits, and all the relatives who took time to complete our mail survey. In gratitude, we dedicate our work and this report to people with disabilities and their families.



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Executive Summary

The Quality Tracking Project of the California Department of Developmental Services is intended to track and monitor the well-being of more than 2,000 Californians with developmental disabilities who left institutions (Developmental Centers) since 1993. The origin of the project can be found in Welfare and Institutions Code 4418.1, which is reproduced below.

Welfare & Institutions Code 4418.1

(a) The Legislature recognizes that it has a special obligation to ensure the well-being of persons with developmental disabilities who are moved from state hospitals to the community.

(b) To ensure that persons with developmental disabilities who are moved from state hospitals to the community are receiving necessary services and supports, the department shall contract with an independent agency or organization for the tracking and monitoring of those persons, including all persons moved as a result of the Coffelt v. State Department of Developmental Services settlement agreement and any persons moved after the terms of that agreement have been met.

(c) The contractor shall be experienced in all of the following:

(1) Designing valid tracking instruments.

(2) Tracking the quality of community programs, including outcome-based measures such as health and safety, quality of life, integration, choice, and consumer satisfaction.

(3) Tracking the quality and appropriateness of community placements for persons moving from large institutions into community settings.

(4) Developing data systems.

(5) Data analysis and report preparation.

(d) The contractor shall measure consumer and family satisfaction with services provided, including case management and quality of life, including, but not limited to, health and safety, independence, productivity, integration, opportunities for choice, and delivery of needed services.

(e) The information maintained for each person shall include the person's name, address, nature of disability, medical condition, scope of community-based services and supports, and the annual data collected by the contractor.

(f) The contractor shall meet with each person, and the person's family, legal guardian, or conservator, when appropriate, no less than once a year to discuss quality of life and observe the person's services and supports. In cases where the consumer is not capable of communicating his or her responses and where there is no family member, guardian, or conservator involved, the contractor shall meet with no less than two persons familiar with the consumer. Additionally, the contractor shall interview staff and friends who know the consumer best and review records, as appropriate.

(g) If the contractor identifies any suspected violation of the legal, civil, or service rights of an individual, or if the contractor determines that the health and welfare of the individual is at risk, that information shall be provided immediately to the regional center providing case management services, the client rights advocate, and to the department.

(h) The department shall monitor the corrective actions taken by the regional center and maintain a report in the person's file. The consumer and, when appropriate, his or her parents, legal guardian, or conservator, shall be provided with access to the person's file and be provided with copies of all reports filed with the regional center or department relative to them.

(i) The department shall establish a task force, including representatives from stakeholder organizations, to annually review the findings of the contractor and make recommendations regarding additional or differing criteria for information to be gathered by the contractor in future interviews.

(j) As of July 1, 1998, and annually thereafter, the contractor shall provide a report to the Governor, the Legislature, and the department outlining the activities and findings of this process. The reports shall be public and shall contain no personally identifying information about the persons being monitored.

The present Annual Report is the third one delivered in response to the law above. It is the second report prepared for the Governor, the Legislature, and the Department of Developmental Services, by the Center for Outcome Analysis.

Our primary goal in this Report is to answer the question "Are the people who moved better off than they were when living in Developmental Centers?" And, for the first time, we have explored a related question, "Are the people who moved into community homes better off than they were last year?" In other words, do they continue to grow, learn, and flourish year after year in the community? Our third purpose is to describe in quantitative, scientific terms what are the characteristics of the people and what are the qualities of life they experience in their new community homes? When appropriate, we also include comparisons to similar studies we have conducted in other states.

As for the first question, we find that the "Movers" (the people who moved from institution to community) have benefited considerably from community living. We attempted to conduct a visit with every single Mover, and we were successful with 2,170 of them (94% of all known Movers). The average visit lasted 79 minutes. We collected data and scales that have been very widely used, extensively tested, and are known to be reliable and valid. The data collected included measures of independence, behavioral challenges, choicemaking, friendships, integration, person-centered planning, health, service intensity, earnings, and both consumer and family satisfaction.

In this Report, we delineate exactly what has changed in the lives of 191 of the Movers compared to what their lives were like when they were living in Developmental Centers. We can do this because, back in 1994, we collected the same data for a random sample of 839 people living in Developmental Centers. Now, 7 years later, 191 of those 839 happen to be out in the community, and we now know how they are doing in dozens of ways.

The data show, with considerable clarity, that the Movers are better off than they were when living in a DC in 1994 in 11 of 21 major dimensions that we measured. Some of these

are "integrative activities," "individualized treatment," "progress toward individual goals," "opportunities for choicemaking," "reduced challenging behavior," and "perceived quality of life in 10 areas." Families too are unexpectedly and overwhelmingly happy with community living, even those who formerly opposed the change. However, they are somewhat worse off in the "number of close friends," the "staff perceptions of the quality of health care," and the "frequency of dental care." Moreover, very few people have become involved in competitive or supported employment. We suggest that the community system still needs attention in the areas of health and dental care, and employment and income generation, and also that systematic thought needs to be devoted to the issue of natural relationships with other than paid employees.

Our analyses over the years revealed that the earlier Movers experienced major behavioral gains – adaptive behavior increased, and challenging behavior decreased. The later Movers tended to show smaller gains. This led to a new analysis, for all the Movers, in which we examined changes in life from the year 2000 to the year 2001 for 1,912 Movers. We found that the average Mover actually lost ground in adaptive behavior in the past year in the community. We also found that the average Mover lost ground in the challenging behavior area too; that is, their challenging behavior increased. These findings, although small, were both highly significant, and both scales are sufficiently reliable to be virtually certain that something genuine is being measured.

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.

At the same time that the Movers were experiencing the first behavioral decline, they were rapidly increasing their choicemaking opportunities. This apparently paradoxical finding is fully discussed in the second section of Pre-Post Results. We must proceed with considerable caution in trying to interpret the new findings. The new findings are mixed. Before we make a judgment about how "bad" or "good" these findings are, we must carefully study how people's lives have changed. If they are expressing fewer adaptive skills, and more challenging behaviors, while they have gained rapidly in controlling their own daily lives and decisions, then what exactly is the nature of the balance that seems to have shifted? How did this balance shift over the past year or two, and why? These are the questions that must be explored before any parties, on either side of the ever-present community versus institution debate, claim to know what these findings imply. We do not yet know what they imply.

Since 1995, the staff of the California Quality Tracking Project have been reporting to DDS that the community system is "underfunded." We repeat this refrain. The evidence has always been very clear. Other states have undergone very successful deinstitutionalization movements, and they too did it in ways that saved some money, and that money then went to support people and families who were in need. But, California was different from the other states.

California "saved" much more money than the other states as reported to DDS and the court in the Coffelt case in 1996 in Report 8 of the prior series.[2] For example, New Hampshire expended 86% of its institutional cost per person on community supports, Pennsylvania 85%, and Connecticut 80%. In contrast, California spent 55%. Other national studies have noted

[2] Conroy, J. (1996, February). ***Patterns of Community Placement II: The First 27 Months of the Coffelt Settlement***, Report Number 8 Of the 5-Year Coffelt Quality Tracking Project, California Department of Developmental Services

that California's fiscal effort with regard to funding community programs is low in comparison to other states.[3] It is difficult to draw precise fiscal comparisons with other states as each state develops and allocates resources from multiple funding streams. However, California's rating on several standard measures of fiscal commitment appears low. We will note again that there is danger in trying to save too much money on institutional to community transition initiatives.

Although we have evidence of a service system that may be troubled, in that two behavioral outcomes have slipped in the past year, it needs to be reiterated that the Movers are still much better off than they were at the Developmental Centers. Almost no one wants to go back. Only a few families would like their relatives to go back. The people themselves, and those closest to them, believe their lives are significantly better in 9 out of 10 ways we asked them about. The people who moved are far more integrated, and have much more of a role in making choices about their daily lives. There has been no major decrement in health and/or safety. The people and their families believe they are as healthy as ever, and as safe as ever.

The movement of more than 2,000 Californians from institutions to community homes was excellent social policy. However, the data deliver a clear warning that should not be ignored. The recent downturn in two behavioral outcomes needs to be understood, and analyzed in the context of other behavioral outcomes that were enhanced. The meaning and causes of the new findings must be explored in depth.

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[3] Braddock, D., Hemp, R., Bachelder, L., & Fujiura, G. (1995). The state of the states in developmental disabilities: Fourth edition. Washington, DC: American Association on Mental Retardation.

Methods

The purpose of a Methods section in a scientific report is to enable other researchers to replicate our findings. We describe exactly how we collected our data, the measurement tools we used, and the people we visited. Our own findings are enhanced by independent validation and so we are careful to furnish detailed information. This section therefore describes the technical aspect of our project from start to finish; the instruments we use to measure qualities of life; the procedures for Visitor assignments; data collection and analysis procedures; the family survey instrument.

Participants: The People in this Study

Our task, as set by the California Legislature and as detailed in our contract with Developmental Disability Services is to:

> ...conduct statewide evaluations annually of the quality of life of all persons with developmental disabilities who have moved from state developmental centers into community settings throughout the state commencing in April, 1993. The instrument to be used for the evaluation will be provided to Contractor by DDS, or approved by DDS. This instrument will measure consumer and family satisfaction with services provided, including case management and quality of life, including, but not limited to, community placement, health and safety, independence, productivity, integration, opportunities for choice, and delivery of needed services.

The population we visit is defined by the list furnished to us by DDS. In 2000 we began with a list of 2,458 people. These people were reported to be Community Target Group Members and all those who had moved from a developmental center between April 1, 1993 and June 30, 2000. In collaboration with our DDS Project Officers, we used the legislative mandate for our research to narrow the list to only those "persons with developmental disabilities who are moved from state hospitals to the community" (4418.1-(a)). We were unable to meet with 184 of those people for reasons ranging from death or incarceration to moved out of state, reducing the list to 2,274 people. We completed visits with 2,271 people. For the purposes of the analyses in this report, we removed 57 people who are listed as members of the Community

Target group and 47 people who have returned to developmental Centers. Our report therefore refers to 2,170 Movers.

Results of the Field Work: A Population, Not A Sample

In the executive summary, we explained that for the purposes of this project we did not use sampling. We included every individual in the Mover population, that is, all 2,170 Developmental Center residents who were known to DDS, who moved to the community from April 1, 1993 through June 30, 2000, and who continued to reside in the community at the time of our data collection.

The distinction between a sample and a population is scientifically important. A population is everyone in a certain group. A sample is a selected subgroup from that population. When we use a sample, we measure things and then attempt to "infer" that what we observe in the sample is also true for the population. The term "inferential" in the phrase "inferential statistics" means exactly that: inferential statistics help us infer something we measure in a sample to the whole population of which the sample is a part.

In the present study, we have included the entire population. ***Therefore inferential statistics are not strictly necessary***. The measurement results we obtain for this population simply "are what they are." We still have the ever-present problems of measurement imprecision, plus the fact that we could not complete visits with a few people, but all in all, the work reported here must be considered and treated as the population, not as a sample. (Nevertheless, some analysts and readers may find statistics useful as indicators of the magnitude of effects, so we will include them in this Report wherever helpful.)

This fact is also important in a very practical sense. It enables us, and the state of California, to say that we attempted to visit every single person who was affected by the Coffelt settlement and its aftermath. ***No one "fell through the cracks."*** For the second year in a row, we located every individual and documented their current living arrangement. We completed

visits with 2,271 people. These visits took between 20 and 340 minutes. They averaged 79 minutes.

During these visits, we measured many aspects of the people's well-being and quality of life. We can now compare our findings to the results from last year and from now on we can detect any changes that might affect this population. This is the highest form of system accountability: to be accountable for the qualities of the individual lives of the people who are receiving services from the system.

We completed visits with 2,271 people. This was a "response rate" of **93.8%.** The most common reason for not completing a Visit was that multiple appointments were made and then broken. Our Visitors were instructed to stop after three appointments were broken by the person and/or the person's support personnel.

This response rate compared very favorably with the prior work of Berkeley Planning Associates or BPA [4], who reported two separate completion rates (80% on page i and 80.7% on page 1.10). Whichever figure was correct for the BPA study, our completion rate exceeded theirs by more than 12%. Our own Visitors exceeded their own previous completion rate of 92%

The major variable that we are studying in the lives of these 2,170 people is their place of residence. Therefore, we present the following Table 1 to illustrate the type and frequency of residential alternatives for the "Active Movers" visited this year.

[4] Berkeley Planning Associates (1998). ***Quality Of Life For Persons With Developmental Disabilities Moving From Developmental Centers Into The Community.*** Sacramento: Department of Developmental Services.

Table 1
Detailed Living Situations of the 2,170 "Active Movers"

Type of Setting	Number	Percent
State Mental Hospital	1	0.0
ICF/DD > 15 Beds	15	0.7
Skilled Nursing Facility	21	1.0
Private Facility	5	0.2
Board and Care	8	0.4
Hospital, Acute Care	3	0.1
Nursing Home	5	0.2
Jail or Detention Center	2	0.1
ICF/DD 4 to 15 Beds	9	0.4
ICF/DD-N 4 to 6 Beds	361	16.9
ICF/DD-N 7 to 15 Beds, Nursing	16	0.7
ICF/DD-H 4 to 6 Beds Habilitative	509	23.8
ICF/DD-H 7-15 Beds Habilitative	10	0.5
CCF Level 2 Owner	6	0.3
CCF Level 2 Staff	7	0.3
CCF Level 3 Owner	43	2.0
CCF Level 3 Staff	85	4.0
CCF Level 4 A/Staff	23	1.1
CCF Level 4B/Staff	8	0.4
CCF Level 4C/Staff	45	2.1
CCF Level 4D/Staff	13	0.6
CCF Level 4E/Staff	16	0.7
CCF Level 4F/Staff	79	3.7
CCF Level 4G/Staff	159	7.4
CCF Level 4H/Staff	79	3.7
CCF Level 4I/Staff	341	15.9
Adult Foster Care	2	0.1
Foster Care Dept. of Social Services	2	0.1
Adult Family Home SB1730	10	0.5
Supported Living > 21 hours/week	115	5.4
Supported Living 11-20 hours/week	6	0.3
Supported Living 0-10 hours/week	4	0.2
Independent Living	30	1.4
In Parent's Home	43	2.0
Other Relative's Home	14	0.7
In Friend's Home	7	0.3
Other Community Setting	38	1.8
No description given	30	1.4
Total	2170	100.0

The names for types of settings in the table are taken from various California and Medicaid codes and titles that are used to describe residential living arrangements for people with disabilities. Some differ in the number of residents they accommodate e.g., ICF/DD-h 4-6 beds versus ICF/DD-h 7-15 beds. Others vary according to people's levels of disability and the related kinds of support and staff ratios that they require. For example, CCF Level 4-A/staff versus CCF Level 4-E/staff, and supported living services are classified according to the hours of support that people receive per week, e.g., Supported Living >21 hours versus Supported Living 0-10 hours.

It is important to note that the first eight lines of Table 1 record 60 people living in nursing homes, or other large, congregate care type facilities. These people were included because they were originally members of the group who moved from Developmental Centers to the community, "Movers", and so we feel it is necessary to track their subsequent moves. In addition, there is a detailed section on "Returnees", beginning on page 117, that describes the characteristics of 47 people who returned to developmental centers after community placement.

The distinctions noted in Table 1 are important for some analyses and are therefore included in this report. However, for most discussions of the characteristics and outcomes of the Movers, we have collapsed the 37 categories into the eight categories listed in Table 2.

Table 2
Broad Categories of Living Situations

Living Situation Category	Number	Percent
Congregate	60	2.8%
ICF (Small)	905	41.7%
CCF	904	41.7%
Foster Care	4	0.2%
Supported Living	125	5.8%
Independent Living	30	1.4%
Relatives' Homes	57	2.6%
Other	85	3.9%
Total	2,170	100.0%

The 60 people listed in the congregate living situation category were not technically living "in the community" at the time of our Visit. It is a generally accepted practice that any facility housing 16 or more individuals is not referred to as a "community" facility. This custom is legitimatized by several respected sources:

- Definitions established by regulations of the Health Care Financing Administration's ICF/MR (Small) Program, which was defined as "4 to 15 beds." Anything larger than that must obey the standards set for institutions.
- The National Residential Information Systems Project of the University of Minnesota (R.W. Prouty & K.C. Lakin (Eds.), *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1998.* Minneapolis: University of Minnesota, Research & Training Center on Community Living, Institute on Community Integration. Their reports break all living situations into 15 and smaller versus 16 and larger.
- The fiscal tracking Project of National Significance of the University of Illinois at Chicago (Braddock, D., Hemp, R., Parish, S., & Westrich, J. (1998). *The state of the states in developmental disabilities: Fifth Edition.* Washington, DC: American Association on Mental Retardation.

Despite a national consensus that larger settings are not "community," we included all 2,170 Movers in our analyses. The basis for keeping the 60 congregate care people in these

analyses was that they were, in fact, part of the Coffelt and subsequent deinstitutionalization initiatives. Wherever they wound up, they had to be tracked and included. Moreover, many such large settings could, in theory, be "appropriate" for some people. For example, the three people we visited in acute care hospitals were surely in them for good reason. And some or all of the 26 people in skilled or other nursing homes may have required that level of care. Hence we determined to include people in the congregate care settings. We think this produces the fairest picture of what happened to all the people who moved out of, and stayed out of, California's Developmental Centers.

Table 3 shows a breakdown of current living types and the average number of people with disabilities living at each type.

Table 3
Average Sizes of Community Homes

Type of Home	Average Number of People with Disabilities
ICF/DD 4-15 Beds	6.9
ICF/DD-N 4-6 Beds, Nursing	5.9
ICF/DD-N 7-15 Beds, Nursing	9.6
ICF/DD-H 4-6 Beds, Habilitative	5.7
ICF/DD-H 7-15 Beds, Habilitative	10.3
CCF L2 Owner	4.0*
CCF L2 Staff	5.4
CCF L3 Owner	7.0*
CCF L3 Staff	7.8
CCF L4-A/Staff	7.3
CCF L4-B/Staff	5.0*
CCF L4-C/Staff	5.1
CCF L4-D/Staff	4.1
CCF L4-E/Staff	4.9
CCF L4-F/Staff	5.3
CCF L4-G/Staff	5.3
CCF L4-H/Staff	4.7
CCF L4-I/Staff	4.7
Adult Foster Care	3.5
Foster Care, Dept. Of Social Services	2.0
Adult Family Home SB1730	2.7
Supported Living >21 hours/week	2.2
Supported Living 11-20 hours/week	1.2
Supported Living 0-10 hours/week	1.3
Independent Living	2.5
Parent's Home	1.0
Other Relative's Home	0.9
Friend's Home	2.6
Other Community Setting	14.2

*The median rather than the mean was used for these types of homes because one or two people in these categories reported living with large numbers of people.

Table 3 shows that aside from the ICF homes, Other Community Settings has the largest average number of people with disabilities with an average of 14.2 residents. The next highest in average number of residents is CCF L-3 Staff at 7.8, followed by CCF L-4-A Staff at 7.3.

Instruments

COA's package of measures of qualities of life is generally called the **Personal Life Quality** protocol (PLQ). Many of the elements of this package evolved from the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). Pennhurst Class members have been visited annually since 1978. An extensive battery of quality-related data has been collected on each visit. Over the years, other groups have been added to the database, such as all people living in Community Living Arrangements in Philadelphia who were not members of the Pennhurst Class.

Prior to the present work in California, the PLQ package had also been applied in deinstitutionalization studies and quality assurance systems in Arkansas, Colorado, Connecticut, Florida, Georgia, Louisiana, Maryland, Minnesota, New Hampshire, New Jersey, North Carolina, and Texas, as well as in Canada, France, and Australia. COA's PLQ approach has been selected as the primary method for evaluating the impacts of self-determination in the 29 participating states funded by the Robert Wood Johnson Foundation and was most recently selected as the instrument to track court mandated deinstitutionalization in Tennessee.

This comprehensive battery of instruments was based on the notion that "quality of life" is inherently multidimensional (Conroy, 1986). It is essential to measure many kinds of individual outcomes to gain an understanding of what aspects of quality of life have changed over time (Conroy & Feinstein, 1990a).

Modifications made to the battery of instruments over the years have been based on the concept of "valued outcomes" (Conroy & Feinstein, 1990b; Shea, 1992). Professionals may value some outcomes most highly, such as behavioral development; parents and other relatives may value permanence, safety, and comfort more highly; and people with mental retardation may value having freedom, money, and friends most highly. The goal in our research on

deinstitutionalization, and later in self-determination, has been to learn how to measure aspects of all of these "valued outcomes" reliably.

The primary instrument package for this project is called the Personal Life Quality protocol or PLQ. It is included herein as **Appendix B**. It includes measures of independence, productivity, choice making, integration, friendships, behavioral progress, health, health care utilization, health care quality ratings, case management, activities and supports, individual planning, environmental qualities, and satisfaction. The PLQ used in this year's work was reviewed by a Task Force in 1999.

The reliability of the PLQ was explored in detail in Report Number 7 in the previous series, with very positive results (Conroy, 1995). The components have been subjected to other reliability tests over the years, (Devlin, 1989; Fullerton, Douglass, & Dodder, 1996; Isett & Spreat, 1979). The components of the PLQ have been shown to be highly objective, scientific, and reliable. The dimensions measured in the PLQ were derived from many years of interviews with services users, parents, other family members, service providers, and other stakeholders, about what is really important in peoples' lives.

The instrument package contains dozens of measures of quality of life and outcomes. Some of them are:

- power to make one's own life choices (with support if needed)
- self-care skills and skill development (adaptive behavior)
- vocational skills and skill development
- challenging behaviors and reduction of such behaviors
- stability of living and working environments
- attitudes and experience of primary caregivers
- health
- health care utilization patterns
- health care satisfaction
- use (versus overuse) of medications
- earnings
- hours per week of productive activity

- individual planning process timeliness
- individual planning process usefulness
- individual planning process degree of "person-centeredness"
- case manager involvement and quality of support
- integration
- relationships with neighbors
- friendships
- family contacts and family relationships
- opportunities for intimate relationships
- having a financial interest in the home
- satisfaction with home
- satisfaction with work
- satisfaction with leisure time
- satisfaction with services rendered (including case management)
- individual wishes and aspirations
- size of the home environment
- characteristics of the home environment (e.g. staffing)
- physical quality of the home environment
- individualized treatment in the home environment
- normalization in the home environment
- costs of the service/support elements
- family/next friend opinions and satisfaction

The Task Force that was convened for this project recommended that the tool utilize symbols, pictures, and/or simple language in our interviews with the focus people. Our Personal Interview was, in fact, constructed in simple language and tested more than 30,000 times across the country. We decided to use that simple-language instrument for the current project.

The Task Force also recommended that we ask questions concerning the staff of the homes, such as turnover, wages, and benefits. We did include questions about staff longevity, and also questions about how long staff have supported the specific person being visited. We also included optional wage questions.

The second instrument for this project is the Family Survey (**Appendix C**). This form was derived from 20 years of work surveying the families of people living in institutions and in communities. The first such survey was conducted with families of people living at Temple University's Woodhaven Center in 1975. The Pennhurst Longitudinal Study produced the next generation of family surveys, followed by versions adapted for Arizona, Arkansas, Connecticut, Colorado, Georgia, Massachusetts, New Hampshire, New Jersey, North Carolina, Oklahoma, and Texas. The 1996-97 California Coffelt Family Survey form, developed in 1993, was included in Report 12 as an Appendix. It was first sent to families of Coffelt Class Members in 1994, and every year thereafter. The results of the Family Surveys were summarized in Reports 6, 8, and 11, 12, and 14. For the current 3 year project, we will present the results of family surveys annually.

Procedures for Field Work and Data Collection

The time and coordination necessary to schedule and complete individual visits with 2,170 people living in the community is enormous. The three Regional Coordinators for this project have perfected a system that is efficient and responsive to the needs of all stakeholders as well as to the time constraints of the project.

In the first year of the project, COA recruited and trained local professionals, paraprofessionals, and graduate students to Visit each person in the Quality Tracking Project and to collect the PLQ data. These data collectors, referred to as "Visitors", function as Independent Contractors. The majority of the Visitors returned for this year's round of visits. This continuity facilitates timely data collection as the Visitors utilize personal connections with the person to be visited, and often with family members or residential staff, to schedule visits.

Visitors are paid a fixed rate for each completed interview plus expenses for overnight trips or significant distances. The Visitor instructions from the PLQ are reproduced below:

This package is composed of many measures, scales, instruments, and interview items. Practically all of the information collected in this package is related to quality of life. In order to complete the package, you must have access to:

1. The person (to attempt a 5 to 15 minute direct interview)
2. The person's home (for a 5 to 10 minute tour and observation)
3. Whoever knows the individual best on a day to day basis (average 45 minutes)
4. The person's records, including medical records
5. In some cases, a health care professional (about 5-10 minutes)

With access to these five sources of information, you should in most cases be able to complete this package within the range of 60 to 90 minutes.

Visitor training was conducted in the first year by Dr. Conroy, the Principal Investigator. The training consisted of an introduction to the project, a role-playing exercise, and a review of the instrument sections and purposes. On site field supervision was provided by Regional Coordinators. New Visitors hired in year two were trained and directly supervised by their Regional Coordinators. Dr. Conroy hosted a two-day project meeting with all Regional Coordinators and Visitors in February, 2001 in Oxnard, California. The agenda for the meeting was a presentation of the results from Year One, a review of all instruments, and a question and answer session regarding instruments and methods. This meeting provided a forum for Visitors to learn from each other and to make suggestions to improve the instruments used by COA.

The data collection process begins with an updated list of Active Movers from DDS. The list is divided according to COA's three regions, North, Central and South, and distributed to the Regional Coordinators. The Regional Coordinators assign names to Visitors who are them responsible for scheduling and completing appointments. Visitors are trained to be sensitive to the schedules of the people to be visited and to the programmatic needs of staff. All visits are scheduled for the person's convenience, not our Visitor's convenience. Visitors can make appointments for evenings and weekends if that is what is preferable. The average length of a visit for this year was 79 minutes, down from an average of 83 minutes from last year. We collected reliable quantitative data on dozens of qualities of life in a very short time, with very little intrusion into peoples' lives.

Pre-Post Results for 191 Movers

Pre-Post Results 1: "Before and After" Qualities of Life

The central question of any evaluation of a social intervention is "Are the people who received the intervention better off?" In the case of California's recent deinstitutionalization initiative under the terms of the Coffelt settlement, this question is very appropriate. California's stakeholders deserve to know whether the people who moved from Developmental Centers (DCs) to community homes from 1993 to the present are better off, worse off, or about the same --- and, it is important to know in what ways and how much.

The "Pre-Post" Design

In prior reports, we approached these questions in several ways, with several designs.[5] First, we used matched comparison, to test whether "similar" Movers and Stayers experienced different qualities of life (Reports 2 and 3 of the first series of 20 Reports). Second, we used analysis of covariance to mathematically control for differences between Movers and Stayers, and then to test for differences in quality between the groups (Report 10). Third, we used "before and after" or "pre-post" measures of qualities of life for a group of people when they were still in DCs back in 1994, and again when they were out in their new community homes (Reports 7, 12, and 17 of the first series).[6]

What made this "pre-post" design possible was a decision we made back in 1994. Although not originally mandated by the Court or by DDS, we contended that we needed to collect "baseline data" for as many people as possible before they left DCs. We requested permission from Court representatives and DDS officials to rework our study designs so that

[5] The ideal research design, as noted by Campbell (1969), would have been random assignment to "treatment" and "control" groups. Naturally, this was not feasible, because program implementers felt they should select people for placement according to their characteristics and perceived potential for community living, their wishes, and the wishes of their families.

we could immediately visit as many DC residents as possible, and it was granted. Hence, back in 1994, we conducted data collection visits with as many DC residents as resources would permit. We visited 839 individuals in DCs, selected purely at random from the more than 5,000 DC residents.[7]

This decision provided DDS and COA with a crucial advantage. For any of those 839 people who later moved out of DCs, we would then be able in any future year to measure any changes in the qualities of their lives, compared to when they lived at a DC.

If we had not collected this "baseline data" on quality of life for people in the DCs at the beginning of this social change, we would never have been able to answer the most fundamental and important questions: ***"Have the qualities of these peoples' lives changed, and if so, in what ways, in what direction, and how much?"***

This year, we completed visits with 2,170 Movers (people who once lived in a DC, but now are living in the community). Included in that number, by pure random sampling, are 191 of the people who had been visited at their previous DC homes back in 1994. These 191 people are the topic of this chapter. We can now examine what, if any, qualities of their lives have changed since community placement.

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[6] In a "fourth design," we surveyed the closest relatives, guardians, and conservators each year to obtain their opinions about comparative quality back at the DC and in the community.

[7] Sample drawn by DDS statistical program as simple random 15%.

Limitations of the Pre-Post Design

The number of people in the analysis, 191, is definitely large enough for studies of this kind. For example, a peer-reviewed article on Movers from Pennhurst (Conroy, Efthimiou, & Lemanowicz, 1982), was based on a smaller number of people who moved from institution to community (70). Many other published articles have relied on considerably smaller sample sizes. [8] For reference, the "sampling margin of error" for 191 out of 2170 people is, in the very simplest case, calculated as plus or minus 7%. This meets most professional standards for sample size and precision.

However, the 191 Movers who were in our original baseline of 839 people may have had different characteristics than those 648 people who remained in DCs. If so, this would limit our ability to generalize from the 191 to all the remaining people in DCs. In plain language, what has been observed to be true for the Movers so far may or may not be what is true for any future Movers. This will depend in part on whether the current Movers are "similar to" the future Movers. In Table 4 below, we can see that there is at least one significant difference between the 191 Movers in our sample and the 648 "potential future Movers" (in other words, the 648 Stayers).

[8] For example, see Aanes, D., & Moen, M. (1976). Adaptive behavior changes of group home residents. *Mental Retardation, 14,* 36-40.

Table 4
Tests of Initial 1994 Differences Between Movers and Stayers

	The 648 Stayers	The 191 Movers	Mean Difference	t	df	Significance (1-tailed)
Average Adaptive Behavior in 1994	36.5	45.9	-9.41	-5.07	301.9	0.0000
Average Challenging Behavior in 1994	70.4	68.0	2.48	1.46	353.8	0.1454
Average Age in 1994	38.0	36.6	1.46	1.32	400.4	0.1887

The table shows that the average Stayer started out in 1994 with a lower adaptive behavior total score than the average Mover, by 9.41 points. And on the extreme right of the adaptive behavior row, the figure "0.0000" means that this difference is large and almost certainly not something that happened by chance.[9] Thus the Movers in our sample were initially somewhat higher in self-care abilities and independent functioning than the Stayers, by about 9 points on a 100 point scale. Although highly significant, this difference was not overwhelmingly large. Yet even small differences in adaptive behavior, which is a very global and reliable measure, can influence many other aspects of life.

The second row of the table shows only a small difference in challenging behavior between the Movers and the Stayers, about 2 ½ points (this time with the Movers having more challenging behavior than the Stayers -- lower scores on this scale mean more challenging behaviors). That difference did not reach significance -- the figure at the extreme right of the row is not below the usual criteria of .0500 or .0100. The finding for age is similar. The difference of about 1½ years was not statistically significant.

Thus the tendency was for these 191 randomly identified Movers to be slightly higher functioning in adaptive behavior, to display somewhat more challenging behaviors, and to be slightly younger, than the average Stayer. But only the adaptive behavior finding was

[9] Statisticians generally require that significance numbers fall below some arbitrary standard, usually 0.0500 or 0.0100.

significant. We think the proper conclusion is that our findings about these Movers should be interpreted as generalizable with caution. That is, what we find about the experiences of these 191 Movers over the past 7 years would likely have been similar for the other 648, if they had moved. However, this is not certain, and in some areas of quality, outcomes might have been different. In the text above, we have simply emphasized that we must be very careful about generalizing findings from one group to all kinds of other groups.

In addition to the above caution about generalization, the pre-post design suffers from another threat to validity. The pre-post design by itself does not answer the question "How do we know the Stayers haven't experienced the same kinds of changes in qualities of life as the Movers?" With the pre-post design by itself, the answer is that we don't. There is no "control group." A valuable addition to this study would be to conduct visits with the people who continue to live in Developmental Centers, the "Stayers", particularly the 648 people that we visited in 1994. This additional data would allow us to track their progress since 1994 and to compare it to the "Movers".

It is true that our past matched comparison and covariance designs did shed light on that issue, with the inference that the Stayers did not show similar changes.[10] Nonetheless, it needs to be said that the analyses in this Chapter by themselves are vulnerable to several threats to validity, even though these threats have already been diminished by other designs in the present body of work.

10 Incidentally, the best available design to settle this question would be a matched comparison study of change over time, which would require current visits with 191 Stayers who are "twins" (people still in DCs who have characteristics very similar to the 191 Movers). The cost of such a study would be under $40,000.

What Kind of Community Homes Are the 191 Movers Now Living In?

The 191 people moved into the types of community settings shown in Table 5.

Table 5
Current Homes of 191 Pre-Post Movers

Type of Community Setting	Number of People	Percent
9 ICF/DD >15 Beds	1	0.5%
10 Skilled Nursing Facility	2	1.0%
14 Nursing Home	1	0.5%
22 ICF/DD-N 4-6 Beds, Nursing	39	20.4%
23 ICF/DD-N 7-15 Beds, Nursing	1	0.5%
24 ICF/DD-H 4-6 Beds, Habilitative	47	24.6%
25 ICF/DD-H 7-15 Beds, Habilitative	4	2.1%
29 CCF L3 Owner	2	1.0%
30 CCF L3 Staff	10	5.2%
31 CCF L4-A/Staff	4	2.1%
32 CCF L4-B/Staff	1	0.5%
33 CCF L4-C/Staff	4	2.1%
36 CCF L4-F/Staff	6	3.1%
37 CCF L4-G/Staff	19	9.9%
38 CCF L4-H/Staff	4	2.1%
39 CCF L4-I/Staff	24	12.6%
43 Adult Family Homes SB1730	2	1.0%
44 Supported Living >21 Hrs Per Week	7	3.7%
47 Independent Living	2	1.0%
48 In Parent's Home	3	1.6%
50 In Friend's Home	1	0.5%
52 Other Community Setting	7	3.7%
Total	191	100.0%

The table shows that four of these Movers are currently living in a congregate care setting, i.e., the first three rows. Nearly 100 are in some variety of federally assisted Medicaid ICF/MR setting. The rest are in a diverse set of community settings, with the preponderance in group homes that receive federal financial assistance through the Medicaid Waiver. This general pattern reflects the fact that nearly all of the Coffelt Movers went to settings that were assisted by the federal Medicaid program --- about half via ICF/MR and about half via Waiver.

Outcomes Summary

For the quantitative part of our work, we visited hundreds of people with disabilities, interviewed hundreds of staff members, reviewed records, and toured homes and day programs. The data permitted us to analyze more than 700 items of information for each person. Most of these items were combined into scales for ease of interpretation.

For example, there were 16 items on "getting out" and going on outings. The 16 items were combined into a single scale of how many times each person went out into integrated settings each month. This produced a simple measure of "how often people got out each month." If this measure increased between 1994 and 2001, then we would conclude that the level of "integrative activities" increased. That would be a positive outcome, insofar as reduced segregation is viewed as a good thing. For the Quality Tracking Project, we collected a series of measures related to quality of life and therefore to outcomes.

Table 6 presents a summary of results for a variety of important quality and outcome indicators for the 191 Movers.

Table 6
Summary of Outcomes
For 191 Movers

Quality Dimension	Pre	Post	Change	Outcome
Progress Reported Toward IP Goals	45.2	78.9	33.7	Positive
Number of Services in Individual Plan	6.1	8.9	2.8	Positive
Hours of Day Program Services	23.4	27.1	3.6	Positive
Earnings	5.2	4.1	-1.1	Not Signif. *
Number of Close Friends Reported	3.3	2.2	-1.1	Negative
Integration	14.0	27.6	13.7	Positive
Qualities of Life Ratings (Now 1994-Now 2001)	71.3	83.8	12.5	Positive
Staff Job Satisfaction	8.9	9.4	0.6	Positive
Staff Like Working With This Person	8.2	9.3	1.1	Positive
Staff Get Sufficient Support	4.1	4.6	0.5	Positive
Number of Daily Medications	4.9	5.0	0.1	Not Signif.*
Number of Psychotropic Medications	0.4	0.4	0.0	Not Signif.*
Health by Days Ill Past 28	0.5	0.9	0.4	Not Signif.*
Perceived Quality of Health Care (Staff responses)	4.7	4.4	-0.3	Negative
Doctor Visits Per Year	34.4	13.5	-21.0	Unclear
Dental Visits Per Year	2.2	1.5	-0.7	Negative
Relative Visits Person Here At This Home	8.4	7.3	-1.1	Not Signif.*
Individualized Practices Scale	61.7	67.4	5.8	Positive
Adaptive Behavior	45.7	45.0	-0.7	Not Signif. *
Challenging Behavior	68.0	78.0	9.9	Positive
Choicemaking	32.7	47.3	14.7	Positive

* "Not Signif." means the change did not attain statistical significance at the .05 level by Paired t-test and is therefore not labeled as either positive or negative.

For each quality dimension in Table 6, we have presented the average score for Movers on that dimension prior to the move (in the column headed "Pre"). The column headed "Post" shows the average score in 2001, after moving into the community. Next, the column headed "Change" shows the average number of points of change that occurred in each dimension.

Since many of these dimensions are measured on different scales, the amounts of change cannot always be compared directly. Therefore each dimension will be discussed individually below.

The final column headed "Outcome" shows whether the change in each dimension was positive or negative; that is, whether each represented an improvement or a decline in quality of life. Any findings that did not reach statistical significance are labeled "Not Signif.," meaning that we are unable to conclude that any real change occurred. The label "Unclear" means that the direction of the change cannot be obviously identified as positive or negative, e.g., are 13.5 doctor visits per year "worse" than 34.4, or are 34.4 visits excessive? A coherent argument can be constructed that 13.5 visits, on the average, shows sufficient access to health care and is not "worse" than 34.4. The opposite argument can also be made. Hence our conclusion is "Unclear", and the reader may draw his or her own inference on such an outcome.

Table 6 lists outcomes for 21 quality dimensions that were compared from the pre (DC 1994) to post (community 2001) visits. There are 11 significantly positive outcomes, 3 significantly negative outcomes, 6 outcomes that are neither significantly positive nor negative and 1 outcome for which the comparison is unclear. In other words, for these 191 Movers, quality of life improved in half the ways measured, got worse for one seventh of the ways measured, and did not change for about a third.

In summary, the Table data support the inference that people's lives have improved in more than three times as many dimensions as they have declined. This leads to the conclusion that, at least for these 21 indicators of quality, moving out of institutions allowed these 191 people, on the average, to experience improvements in many qualities of their lives.

Following are individual explanations and implications for each of the 21 indicators of quality.

Progress Reported Toward Individual Plan Goals

For each of the top five goals in each person's Individual Plan, we ask "Has there been any progress toward this item in the past year?" Responses are given on a five point scale: Major Loss, Some Loss, No Change, Some Gain, Major Gain. These five point scales are combined across the five goals, and we construct an overall scale of progress toward goals. This overall scale is computed so that it can potentially range from 0 to 100.

As the table shows, the respondents at the DCs produced an overall scale score of 45.2 back in 1994, which can be interpreted as an average perception of a little below "No Change". In the community in 2001, the average rating was 78.9, which can be interpreted as an average perception of a little above "Some Progress". The difference is large. Since staff of the residences almost always answered these items, it can safely be concluded that community staff believe they are seeing a lot more progress than did institutional staff back in the DCs.

The proper conclusion is that these 191 Movers are "better off" than they were back in the DCs in terms of making progress toward the goals in their Individual Plans.

Number of Services in Individual Plan

The Personal Life Quality protocol (PLQ) contains a checklist of 15 traditional therapies, training programs, services, and supports that might be delivered via the residential program. The number of services for these Movers increased from 6.1 at the DCs in 1994 to 8.9 in the community in 2001. The increase of 2.8 services was statistically significant.

The proper conclusion is that these 191 Movers are receiving a wider range of services and support than they were back in 1994 at the DCs. Since we did not measure amount of services, however, we cannot comment on how much of each such service is being provided.

Hours of Day Program Services

We collected the number of hours per week of each of 17 types of day activities, from self-employment to community experience to school. The average number of hours of day program services of all types increased from an average of 23.4 hours per week back at the DCs to 27.1 hours per week in 2001 in the community. This increase of 3.5 hours is significant.

We conclude that community placement appeared to be related to a greater number of hours per week that people spend in some kind of "productive activity". Further research into changes in the distribution of types of day activities could be performed within the present data set, but is beyond the scope of this chapter.

Earnings

Comparison of average weekly earnings back at the DC to earnings in the community reveal a slight decrease, which is not statistically significant. The average amount in the DCs was $5.20 per week, and the average amount in the community is $4.10. Both of these figures are so low that they should engender a statewide discussion of the potential role of work and income generation for all Californians with developmental disabilities, whether in DCs or the community.

Last year, in Report 2 of this series, we found a different result. For the 178 Movers who were included in that analysis, average weekly earnings dropped from $4.80 in the DCs to only $1.60 in the community. That drop was statistically significant. Now, a year later, the significant drop is gone. This means that a fair number of people among the 191 Movers either began earning some small amount of income, or increased what they were earning.

This could be interpreted as a positive finding, in the sense that a previously negative outcome has been reduced to no change.

As we have consistently stated in Reports 2, 3, 8, 12, and 18 of the previous series, and Report 2 of this series, the data support the strong conclusion that California's community

services system is sorely in need of attention to supported and competitive employment options, and to more innovative options for generation of income such as microenterprises.

Number of Close Friends Reported

In 1994 in the DCs, and in 2001 in the community, we asked people how many "close friends" they had. The answers were usually given by whomever knew the person best. We did not define "close friends" for the respondents, we asked them to use their own definitions. Hence this item must be considered to be largely subjective as an indicator of quality of life.

From 1994 to 2001, the average number of close friends reported fell from 3.3 to 2.2. The decrease of 1.1 was statistically significant.

Friendships are rapidly becoming recognized as a very important dimension of quality, and one that has often been under-emphasized or even ignored by traditional human service systems. Hence this negative finding should be interpreted to be an important one. We suggest that friendships, relationships, and community connections might be considered as a dimension for close monitoring by families, service providers, regional centers, advocates, and also for policy makers in DDS, the legislature, and the judiciary.

In our last annual report, Report 2, we also detected a drop in the average number of close friends from DC to community. However, that drop was not statistically significant (from 3.3 to 2.6). Now, measuring from 1994 to 2001, the decrease from 3.3 to 2.2 has become statistically significant. This suggests that some of the loss of friends may have taken place over the past year or two within the community. If so, that would be a very important finding, pointing to a rather urgent need to help people maintain and/or extend what relationships they have.

We suggest that the nature and depth of human relationships is an area in need of urgent concern and further investigation. Further investigations should study the proportion of friends in 1994 and in 2001 who were paid and unpaid, and friends with and without disabilities. A

study of those variables and others such as levels of retardation, age, gender, and living arrangement may help to explain the drop in close friends that we have detected.

Integration

Our measure of Integrative Activities is simply a count of "how many times the person went out" and went to places where any citizen might go. The Movers increased their levels of integration from 14.0 to 27.6, indicating an additional 13.3 community events per month. This near doubling of integrative activities was statistically significant.

Although integration is an expected result of movement to the community, this outcome is strong evidence that the Movers have sharply increased their opportunities to go to places in which they are in the presence of citizens without disabilities. Insofar as integration is a fundamental value in supporting people with disabilities, and a prominent issue in the Coffelt Settlement, this is a major outcome.

For future investigation, we would recommend a full analysis of the integrative activities in relation to the close friends scale and the individual goals. Such a simultaneous investigation might yield more insight about complex relationships among Individual Planning, relationships, and community activities. The present database is sufficiently rich to permit such a thorough analysis.

Qualities of Life Ratings (1994 and 2001)

The measures in this study include a scale of perceived qualities of life. Fourteen dimensions of quality of life are addressed including health, friendships, safety, comfort, etc. The person, or whoever knew the person best, gave numeric ratings of the person's qualities of life at the developmental center. (Back in 1994, there were only 10 dimensions of quality in the scale, so only 10 of the 14 can be compared pre and post.) In subsequent interviews, the person, or whoever knew the person best, gave ratings of the same qualities of life.

We compared the ratings given by people and/or DC staff back in 1994 to those given by people and/or community staff in 2001. (The overall 100-point scale for this analysis was composed of only the 10 items used in 1994, to keep the scales comparable in 1994 and 2001). The average score increased from 71.3 to 83.8, for an increase of 12.5 points. This indicates that the Movers, or the people closest to them, perceived lower quality of life back in the DC, and considerably higher qualities of life in the community.

To reveal the largest perceived changes, we broke down the scale into its component items. Table 7 shows the results, sorted by the size of the change.

Table 7
Perceived Qualities of Life Reported by Person or Closest Others, Pre-Post

Dimension of Quality	1994 at DC	2001 in Community	Change	Statistical Significance
Food	3.6	4.4	0.8	0.0000
Comfort	3.9	4.5	0.6	0.0000
Getting out	3.5	4.1	0.6	0.0000
Happiness	3.8	4.4	0.6	0.0000
Running my own life	3.2	3.8	0.6	0.0000
Seeing friends	3.2	3.7	0.6	0.0000
Safety	4.2	4.7	0.5	0.0000
What I do all day	3.7	4.2	0.5	0.0000
Health	3.9	4.2	0.3	0.0000
Family relationships	2.8	2.9	0.1	0.1708

The table shows that 9 out of 10 dimensions of quality of life were rated higher in the current community homes than they were back at the DCs. The largest difference was in quality of food. The next largest differences were in comfort, getting out, happiness, and running my own life.

It is worth noting that the perceptions of health and safety went up as well. This may be a surprise to those who believe that living in the community carries with it a price to be paid in

terms of diminished health and safety. These 191 Movers, and those closest to them, clearly do not agree with that contention.

The one element that did not change significantly was relationships with family. We speculate that those who had involved family members while at the DC continued to have them in the community, and those who did not have involved family members did not acquire them.

The proper conclusion from this is that the people and/or the staff closest to them reported their perceptions of quality back at the DC, and again 7 years later in the community – and the community ratings were considerably higher. These data strongly support the inference that the Movers are "better off" in their own eyes and the eyes of those close to them.

Staff Job Satisfaction

A critical factor in rating the quality of life in residential programs is staff. Do they like their jobs? Do they like working with this person specifically? Do they feel they receive sufficient support from administration to do their jobs effectively?

For "How much do you like your job?" on a scale of 1 to 10, the average response from developmental center staff was 8.9 and in the community it rose to 9.4. Community staff like their jobs more than did developmental center staff. This difference was significant.

Staff Like Working With This Person

The question "How do you feel about working with this person?" is believed to be very important for people with disabilities. Staff who like their jobs, and who like working with the individual, would seem likely to render better support.

On a scale of 1 to 10, the developmental center staff score averaged 8.2, and the community staff was significantly higher at 9.3. Community staff report enjoying working with each specific person significantly more than did the developmental center staff. We think

the proper conclusion is that relationships with close staff members are better in the community than they were back at the DCs for these 191 Movers.

Do Staff Get Sufficient Support?

When asked "Do you feel you receive sufficient support from administration to do your job?" the staff responses were fairly high in both settings. On a 5-point scale, the response was 4.1 from developmental center staff and 4.6 from community staff. Although both groups reported feeling supported, the ratings were higher in the community than they were in the developmental centers. The proper conclusion is that current community staff feel more supported than did DC staff back in 1994.

Number of Daily Medications

The average number of medications (including vitamins, minerals, and special supplements) administered daily stayed essentially the same, going from 4.9 to 5.0. This was not a statistically significant change (0.1). Incidentally, detailed analysis shows that the average number of "digestive, stomach, and bowel" medications has decreased significantly. This may be an indication of a change in dietary habits and medical management practices.

Number of Psychotropic Medications

The number of psychotropic medications remained the same. However, we must point out that in a sense this is a positive finding, because in our early studies, we found that the people who moved out of DCs in the mid-1990s actually experienced increases in psychotropic medications. This suggested that the community medical system was overmedicating people, perhaps out of lack of experience. Now we conclude that the 191 Movers are experiencing about the same probability of being given psychotropics in the community as they were in the DC.

Health by Days Ill in Past 30 Days

Another method used to measure general health is taken from national health surveys: "Number of days of restricted activity because of illness within the past 30 days." This health quality indicator did not change significantly, indicating that people's general health had neither improved nor diminished.

Quality of Health Care

The responses to the question "Overall, how good is the health care this person is getting?" revealed a negative and significant difference. Because this dimension was rated on a 1 to 5 scale, both the answers from 1994 in the DCs (4.7), and the answers from 2001 in the community (4.4), lie in the "Good" to "Excellent" range. However, the average rating in the community is significantly lower than the average rating back at the DCs.

One potential explanation for the decrease in the perceived rating of health care is problems with locating specialists and doctors in the community who have experience in working with people with disabilities. This is an area that has begun to be monitored closely via various DDS policies and actions, such as the Wellness Initiative. We interpret our finding as evidence that this attention to health care in the community needs to continue.

Doctor Visits Per Year

The Movers' number of doctor visits per year decreased sharply from 34.4 to 13.5 times per year. This pattern has been documented as fairly standard in moves from institutions to the community.[11] However, the fact that they saw the doctor 21 less times in the community does not necessarily mean that either their health care or general health was negatively affected.

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[11] Hayden, M. F., & DePaepe, P .A. (1991). ***Medical conditions, level of care needs, and health related outcomes of persons with mental retardation: A Review***. Journal of the Association of Persons with Severe Handicaps, 16(4), 188-206.

There is no evidence from any of the data that people in the community need to see doctors more often than 13 times a year. We therefore interpreted this finding as neither positive nor negative, but rather "Unclear."

Dental Visits Per Year

The Movers' number of dental visits per year decreased, from 2.2 to 1.5. Because the dental profession recommends 2 visits per year, we interpret the significant decrease as a negative finding. (Although the 1.5 times per year rate is believed to exceed the frequency of general public visits to dentists.)

Relative Visits Person Here At This Home

The frequency of family contacts increased from 8.4 to 11.2 per year. This was not a statistically significant change. Again, this might be interpreted as "those that had family contacts in the DC continued to have them; those that had no family contacts did not acquire the.". Proximity may also play a part in this increase as a number of people may have been placed in community residences that were close to their family home.

Individualized Practices Scale

This scale lists 15 items that are related to staff management practices, and it is designed to reveal the extent to which people are treated as individuals versus a management style in which "the same rules apply to everyone". The scale tends to reflect people's opportunities to engage in non-group activities and their options for making independent scheduling decisions within a group living arrangement.

The Movers increased their score on this quality dimension from 61.7 to 67.4, and this increase of 5.8 points on a 100 point scale was statistically significant, but not very large.

The topic of individualized supports may benefit from further investigation, because similar deinstitutionalizations in several other states have been associated with larger enhancements of individualized practices. A much larger increase on the Individualized Practices Scale occurred recently among 183 Indiana citizens who moved out of Developmental Centers. The Indiana Movers showed a statistically significant gain of 25 points on the Individualized Practices Scale after one year of life in the community.

Adaptive Behavior

For the first time in this body of work, the change in adaptive behavior between institution and community has become negative. Although the change is not statistically significant, this does represent a first. In more than 20 years of this kind of work in 10 states, this is the first time this research team has detected a skill loss, significant or not, for people who moved from institutional to community settings. We decided that this new finding was important enough to warrant a preliminary review of the entire California body of work since 1994. To follow up on this preliminary review, we will definitely need to investigate more deeply to try to understand the causes and the implications of these data.

Last year, in 2000, we conducted the same kind of pre and post analysis for 178 Movers whom we visited in the DC in 1994 and again in the community in 2000. In that analysis, there was an average gain of 0.6 points from the DC 1994 score in adaptive behavior. That was not significant. However, the fact that it was the first non-significant gain led us to wonder whether we might be seeing the leading edge of a trend. Hence we looked at the findings of all of our past pre-post comparisons for adaptive behavior change i.e., the results for each year of the study regarding the people that we interviewed in the DCs in 1994. The data are shown in Table 8. Although this table is complex, we believe it is necessary to present complete information because of the potential importance of the issues raised.

Table 8
Trends in Pre-Post Adaptive Behavior Findings Over the Years

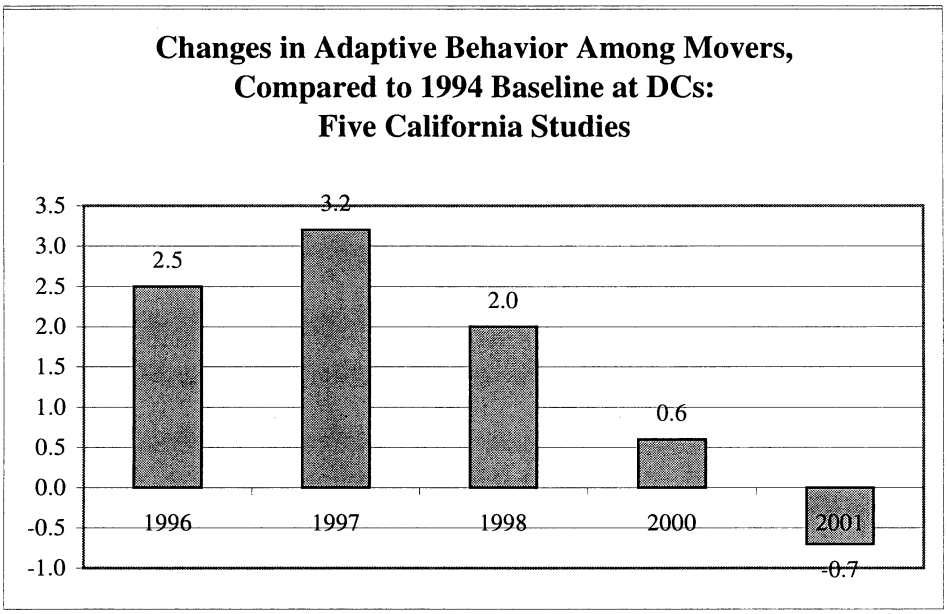
Adaptive Behavior Measure	Baseline DC 1994	Community 2001	Change	Significant?
Report 8, 1996 34 Movers	48.9	51.4	2.5	Significant
Report 12, 1997 64 Movers	45.1	48.3	3.2	Significant
Report 17, 1998 91 Movers	44.7	46.7	2.0	Significant
Report 2, 2000 178 Movers	45.0	45.6	0.6	Not significant (1st time)
Report 4, 2001 191 Movers	45.7	45.0	-0.7	Not significant (2nd time, first loss)

In our earliest studies at the top of the table, in 1996, 1997 and 1998, we found significantly increased adaptive behavior among the Movers after they left the institutions. This is consistent with a large number of studies by many research groups, as documented in the meta-analysis performed by Larson & Lakin (1989).[12]

Moving down the table to the larger and more recent analyses, we see a fairly consistent trend toward less and less benefit, until at the bottom, the average outcome for the 191 Movers in 2001 is that they appear to have actually lost slightly in adaptive behavior skills. Since the change is not statistically significant, we cannot be certain that the apparent loss is valid. Nonetheless, the trend seems worthy of note. A graphic presentation may make this issue more clear. Chart 1 shows only the amount of change in adaptive behavior detected in the five California studies.

[12] Larson, S., & Lakin, C. (1989). ***Deinstitutionalization of persons with mental retardation: Behavioral outcomes.*** Journal of the Association for Persons with Severe Handicaps, 14, 324-332.

Chart 1



It is the trend that is of greatest interest. The chart suggests rather strongly that the early Movers enjoyed considerable benefits in terms of learning new self-care skills and becoming more independent, but that the later Movers did not. In fact, the data suggest, but do not prove, that there might have actually been a loss in adaptive behavior in the past year, not between DC and community, but within the community. This hypothesis is tested in the next section, in which we analyze changes in quality indicators from the year 2000 community visits and the year 2001 community visits.

Another way to attempt to interpret the adaptive behavior data is to compare it with parallel data from other states.[13] Table 9 shows the adaptive behavior results from several studies conducted by this research group.

[13] As far as we are aware, only COA possesses a national database that permits such cross-state comparisons.

Table 9
Adaptive Behavior Results From Several Deinstitutionalization Studies

State	# of Years	Time-1 Average Adaptive Behavior Score	Time-2 Average Adaptive Behavior Score	Gain on 100 Point Scales
Pennsylvania	14 years	39.8	50.2	10.4
New Hampshire	8 years	53.0	62.3	9.3
Louisiana	7 years	56.2	64.2	8.0
California	**7 years**	**45.7**	**45.0**	**-0.7**
Oklahoma	6 years	41.3	47.4	6.1
Connecticut	5 years	49.5	54.0	4.5
North Carolina	2 years	52.7	54.8	2.1
Kansas	1 year	33.1	34.8	1.7
Indiana	1 year	48.1	50.2	2.1

At this point, the California experience is unusual. In prior years, the California data fit rather neatly into the general national pattern. Now, in 2001, something has changed. We think it is urgent to find out what has changed, and why, and also what can be done about it. It is important to again state that this change is not statistically significant and that it would certainly not have been detected without the mandate from the California legislature to monitor the progress of the Movers. This data, although alarming in its implications, presents an opportunity for all stakeholders to review current policies and practices and to assure that community services are being implemented according to the spirit and the letter of the law.

Challenging Behavior

This dimension was measured according to the person's ability to control challenging behavior and so a higher score is a positive outcome. The 9.9 point increase in our current pre-post analysis is very high.

It is possible that the decrease in adaptive behaviors (although not statistically significant) and the major improvement with regard to challenging behavior are related. Programs that focus on adaptive behaviors are often more formal and regimented. In contrast, state-of-the-art programming for people with challenging behaviors relies more on prevention and positive reinforcement to produce safe and nurturing environments. The data on these two dimensions appear to support the hypothesis that the community programs for these 191 Movers have been designed to meet their specific needs in these areas. This is an area that should be investigated further.

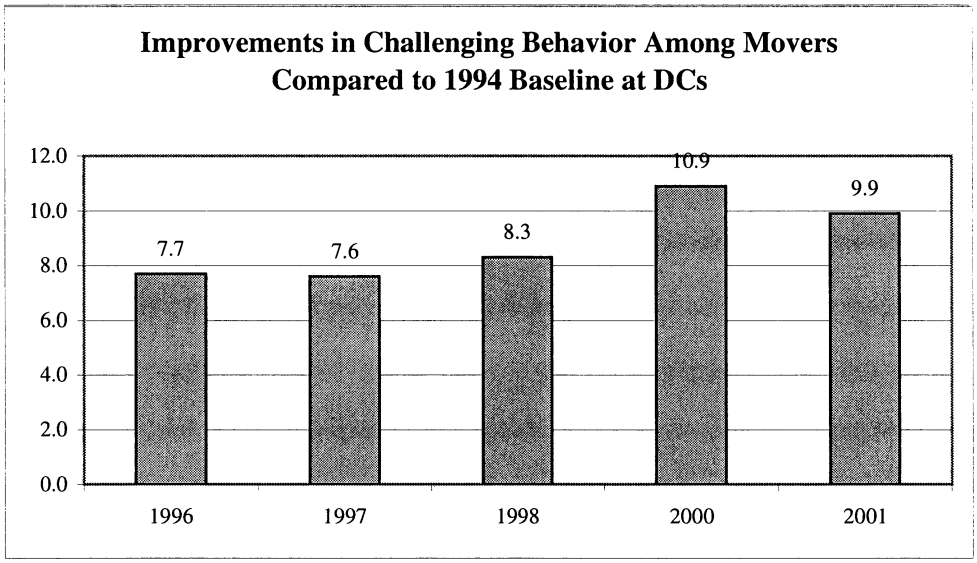
Because of the surprising findings in adaptive behavior, we decided to look at challenging behavior findings over the years in the same way. Table 10 shows the data.

Table 10
Trends in Pre-Post Challenging Behavior Findings Over the Years

Challenging Behavior Measure	Baseline DC 1994	Community 2001	Change	Significant?
Report 8, 1996 34 Movers	67.3	75.0	7.7	Significant
Report 12, 1997 64 Movers	69.7	77.3	7.6	Significant
Report 17, 1998 91 Movers	68.1	76.4	8.3	Significant
Report 2, 2000 178 Movers	67.6	78.4	10.9	Significant
Report 4, 2001 191 Movers	68.0	78.0	9.9	Significant Less than Year 2000

The table suggests that outcomes were progressively becoming more and more positive over the years, until this year. The 2001 average gain from deinstitutionalization has become less than the average gain we measured last year (10.9 to 9.9). Again, a chart may make this trend easier to see.

Chart 2



It is the downturn on the right that makes us suspect that there may have been very recent decrements in quality within the California community support system, at least for these 191 Movers.

To this research group, this finding is of major importance. As in the case of adaptive behavior, this gradual decline in the challenging behavior benefits associated with community placement may suggest that in the past year or two these 191 Movers have actually lost ground in this area. We decided to add a new chapter to this report, the chapter following this one, to explore this issue further. In the next chapter we present tests for changes in qualities of life between the Year 2000 visits and the Year 2001 visits, not just for the 191 Movers, but for all 2170 people in this study population.

Before leaving the challenging behavior dimension, it is important to underscore the fact that California's Movers appear to have experienced the largest improvements ever documented in such research. The following state comparison table shows this fact.

Table 11
Challenging Behavior Results From Several Deinstitutionalization Studies

State	# of Years	Time-1 Average Challenging Behavior Score	Time-2 Average Challenging Behavior Score	Gain on 100 Point Scale
Pennsylvania	14 years	77.7	87.3	9.6
New Hampshire	8 years	79.6	78.6	-1.0
Louisiana	7 years	80.9	84.1	3.2
California	**7 years**	**68.0**	**78.0**	**9.9**
Oklahoma	6 years	89.7	93.5	3.8
Connecticut	5 years	79.0	80.2	1.2
North Carolina	2 years	87.7	89.4	1.7
Kansas	1 year	78.6	81.3	2.7
Indiana	1 year	70.5	67.9	-2.6

The proper conclusion is that these 191 Movers are far better off now, in the community, in terms of being able to control their own potentially challenging behavior. Yet the data still lead to intense concern about possible recent declines in this important quality dimension.

Choicemaking

The scale for measuring opportunities for choicemaking is called the Decision Control Inventory. It is composed of 35 ratings of the extent to which minor and major life decisions are made by paid staff versus the focus person and/or unpaid friends and relatives. Each rating is given on a 10 point scale, where 0 means the choice is made entirely by paid staff/professionals, 10 means the choice is made entirely by the focus person (and/or unpaid trusted others), and 5 means the choice is shared equally. This is the same scale being used by the Robert Wood Johnson Foundation in its National Evaluation of Self-Determination in 29

states. In fact, the scale was originally created by COA in order to measure the impacts of self-determination in people's lives.

Choicemaking opportunities as measured by the Decision Control Inventory increased from 32.7 points back at the DCs in 1994, to 47.3 points in the community in 2001. This increase of 14.7 points was highly statistically significant.

This positive outcome may reflect major differences between institutional and community life. The Movers, despite their levels of disability, have shown a consistent pattern of growth in their ability to make choices. This outcome may also be an indication of provider and staff commitment to independence as a valued goal.

We are intrigued, however, that the large increases in choicemaking did not appear until recently in our studies. In the same format as in the two previous sections, Table 12 shows the choicemaking results of five pre-post analyses.

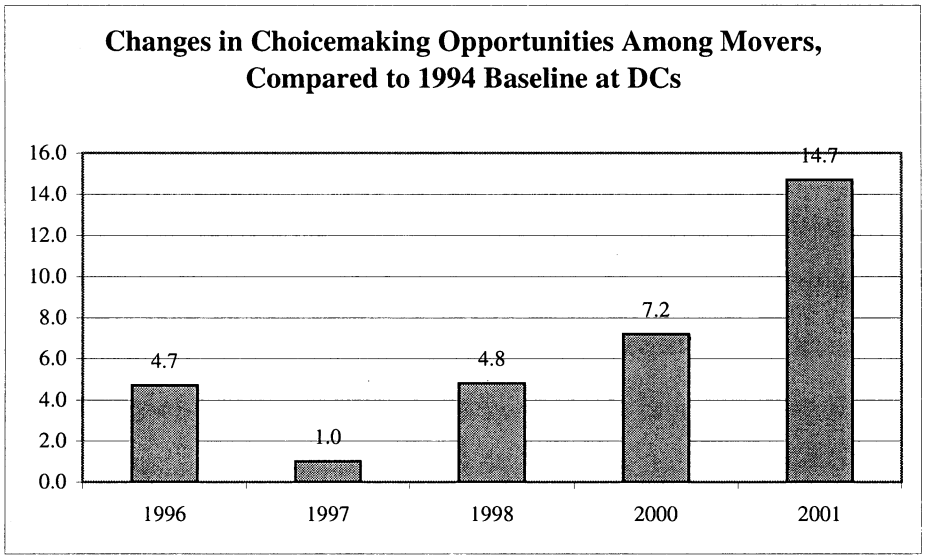
Table 12
Trends in Pre-Post Choicemaking Findings Over the Years

Choice Making Measure	Baseline DC 1994	Community 2001	Change	Significant?
Report 8, 1996 34 Movers	35.9	40.6	4.7	Not Significant
Report 12, 1997 64 Movers	33.6	34.6	1.0	Not Significant
Report 17, 1998 91 Movers	31.5	36.3	4.8	Significant (1st time)
Report 2, 2000 178 Movers	31.7	38.9	7.2	Significant (2nd time, larger)
Report 4, 2001 191 Movers	32.7	47.3	14.7	Significant (3rd time, still larger gain)

For the early Movers, the gains in opportunities to make choices were small and not statistically significant. In the third of the five studies, the gain was still small, but at least it

reached significance. By the time of the fourth study in 2000, the gain was larger. Then the average gain more than doubled in 2001. The pattern may again be made more clear by a chart.

Chart 3



What could explain such a dramatic recent increase in the choicemaking scale? Several competing possibilities are available. They will be discussed after new analyses in the next chapter: changes in qualities of life <u>within</u> the community, from Year 2000 to Year 2001, for <u>all</u> the movers.

Chart 3

Pre-Post Results 2: Last Year and This Year

For the first time, we now have the ability to explore changes in the lives of the Movers from one year to the next, while they are living in the community. In the previous section, we studied changes in the Movers' lives from institution to community. In this section, we investigate changes from last year to this year. Has anything changed? Are people growing and learning? Is individual planning becoming more person-centered? Are people making more choices now than they were last year? There are many questions that can be posed, all aimed at the question "Is the entire service system any different now than it was a year ago?"

And, the ideal way to test this question is to determine whether the qualities of life of the people served in the system have changed.

Using this approach, we have attempted to further investigate some of the major issues raised in the previous section. These major issues involve adaptive behavior, challenging behavior, and choicemaking. These areas will be the focus of this section.

Before proceeding into those three areas, we note that we did test the entire battery of quality indicators to see what had changed since last year. In brief, we detected statistically significant changes in:

- Perceived Progress Toward Individual Goals (up 1.3 points on the 100 point scale)
- Number of Services in the Plan (up .4 services per person)
- Time Spent in Day Program (up .4 hours per week)
- Individualized Practices Scale (up 4.3 points on the 100 point scale)
- Elements of the Planning Process (up 4 points on the 100 point scale)
- Number of Friends (down 1.3 friends, to 8.8)
- Number of Doctor Visits Per Year (down .8 visits per year, to 11.7)

Five of these changes are favorable, one is unfavorable (Number of Friends), and one is unclear (Number of Doctor Visits). We will offer to prepare a full report on changes from year 2000 to year 2001 as part of the existing contract with DDS, within existing resources. For the present report, we wish to focus on what we see as the largest and most pressing issues.

In the previous section, we examined five separate pre-post analyses over the years of our work. We found reason to suspect that people's adaptive behavior abilities (also called self-care skills or independent functioning) might have begun to decline. It is extremely important to find out if this is true.

Our statistical test includes 1,912 Movers who were visited both in 2000 and 2001, and for whom complete data on the selected issues was available. We use the Student's t-test to ask whether the average adaptive behavior score this year is any different from the average score from last year. The answer is "Yes".

Table 13
Average Adaptive Behavior Changes Among 1,912 Movers
Year 2000 to Year 2001

Average for Year 2000	Average for Year 2001	Change	Significance
49.064	47.350	-1.7	0.000

The average Mover experienced a loss of 1.7 points on the adaptive behavior scale. This was very highly statistically significant, as symbolized by the "0.000" at the right of the table. Any number below 0.050 would be considered significant. The lower the number, the higher the significance. The probability that this decrease of 1.7 points is just a chance variation in the numbers is very close to zero.

Because adaptive behavior is such a highly reliable,[14] valid, global, and strongly predictive measure of individual functioning, we think this finding should be taken very seriously.

One might wonder whether a mere 1.7 point loss on a 100 point scale is really that serious. The answer is found in the long run. What would happen to people if such losses continued each year for 10 years? If our service system consistently produces small losses, people would lose 17 points in the next decade. In old and generally outmoded terminology, that loss would be more than enough to push a person from the mental retardation label "moderate" to the label "severe." In our data set, the average person with the label "moderate" has an adaptive behavior score of 64; the average person with the label "severe" has a score of 51. A loss of 17 points over 10 years would be devastating to a person's functional status.

[14] In Report 7 of our earlier Coffelt series, we reported interrater reliability for the adaptive behavior scale as .97 or .98 depending on the calculation method. This is extremely high. It means that this is a very accurate measure. We also know that this measure correlates strongly with many other aspects of life, such as choicemaking, earnings, and integration. This means that it is an important measure that influences many aspects of people's lives.

That is why we feel a strong sense of urgency about this finding. Further investigation of causes and necessary actions are urgently needed.

Next, we performed the same kind of analysis for challenging behavior. Obviously, challenging behavior and its reduction is a very important aspect of people's lives. Challenging behaviors are also of great concern to service providers and families.

Table 14
Average Challenging Behavior Changes Among 1,912 Movers
Year 2000 to Year 2001

Average for 2000	Average for 2001	Change	Significance
78.614	77.106	-1.5	0.000

As seen in the table above, the average scores for the 1,912 Mover decreased by 1.5 points on the 100 point scale. On this scale, the higher the score the better the person is able to control challenging behavior. The 1.5 decrease means that people are displaying more challenging behaviors in 2001 than they were in 2000. The decrease was highly statistically significant.

This finding is also unusual in our experience. We have seen challenging behavior increase temporarily when people change homes, as happened in our 6-month post deinstitutionalization data in Indiana. However, those increases later vanished as people settled into their new homes. The increase we have measured in California, however, appears to be quite different. This is associated with people living in their homes, engaging in daily activities, and not obviously experiencing any major disruptions in their lives. It strongly suggests a systemic problem. In combination with the adaptive behavior finding, the evidence seems to us to be compelling. We do not know for certain, however, exactly what is (are) the nature of the problem(s).

At the same time that people were losing skills and increasing challenging behavior, a counterintuitive and paradoxical process was occurring. Average scores on the Decision Control Inventory, our measure of opportunities for choicemaking, were increasing rapidly. This scale is an important indicator of power shifting and progress toward self-determination.

Table 15
Average Decision Control Inventory Change Among 1,912 Movers
2000 to 2001

Average for 2000	Average for 2001	Change	Significance
43.077	47.345	4.3	0.000

The average score on the Decision Control Inventory increased significantly from 2000 to 2001, from 43.077 points in 2000 to 47.345 in 2001. The increase of 4.3 points is highly statistically significant, and it is also large. The entire self-determination movement has been at least partly fueled by the positive scientific findings from the original project in New Hampshire – and in that project, the observed gain on this same scale was only 4.1 points over an 18 month period. The observed increase among California's Movers is larger, and happened faster, than the power shift in New Hampshire. This too should be taken seriously, and on the surface, it appears to be a positive outcome.

Taken together, what do these three major changes over the course of 12 months mean? At this time, we can only brainstorm and speculate. It is urgent that we obtain explanations so that California can take action to halt any negative trends.

The first explanation that occurred to our team was a broad based acceptance of the principles of self determination which espouse personal choice and freedom. It is possible that in their zeal to convert the system, some people have moved too quickly and have decreased

their focus on skill development activities. This kind of scenario could explain behavioral losses and increased choice.

A second possible explanation is the widely acknowledged crisis in the direct care labor pool. Low salaries and high turnover rates translate into poorly motivated and poorly trained staff. Recognizing the antecedents of challenging behavior and providing positive supports to prevent such behavior requires caring and well-trained staff. A direct care worker who does not have the benefit of such skills, or complete knowledge of the principles of self determination and person centered planning, may find it convenient to adopt the rhetoric of consumer choice and "let the people do what they want."[15] This could explain the increase in the choicemaking scale.

Either explanation fits at least some of the facts. A reading of Appendix D, which contains the notes and comments written by relatives in the 2001 Family Survey, tends to support the second explanation. There are many comments about the poor quality and the short tenure of direct care staff.

The details of the power shift reflected in our choicemaking scale also seem to support the second explanation. The top 10 changes in power from 2000 to 2001 were:

- *When to go to bed on weekdays*
- *What to have for dinner*
- *When to get up on weekends*
- *What to have for breakfast*
- *Choosing to decline activities*
- *What to do with relaxation time*
- *When to go to bed on weekends*
- *Taking naps in evenings/weekends*
- *What foods to buy*
- *Express affection*

[15] Self-determination advocates would not favor the description given above. True self-determination is a very careful and responsible process of sharing power and control with a person and the person's allies. Genuine self-determination requires Freedom, Authority, Responsibility, and Support.

It is our opinion that these activities are mainly related to direct care staff attitudes and actions. We should also note that in general, the above kinds of choices do not entail significant cost increases. At the other end of the Decision Control Inventory are the things that did not change.

- *Who goes with you on outings*
- *Time spent working or at day program*
- *Choice of house or apartment*
- *Choice of case manager*
- *Type of work or day program*
- *How to spend residential funds*
- *Whether to have pets in the home*
- *How to spend day activity funds*
- *Choice of people to live with*
- *Choice of furnishings*

These items seem to us to be "big" aspects of life – where you live, with whom you live, what you do during the day. In most traditional service systems, these items are controlled by administrative policies and personnel. These items also have significant financial implications depending on the choices people make. This pattern of change in the scale tends to support the idea that what is going on among the Movers in California in the past year is not actually self-determination, but rather simply a relaxing of authority over several "small" aspects of daily life.

Because the behavioral results were both unusual and unexpected, we wanted to begin preliminary investigations at slightly deeper levels. Based on past research by this team,[16] we wondered whether outcomes differed for people who lived in ICF/MR versus Waiver settings. We collapsed the long list of residential categories into Community ICF/MR and Waiver

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[16] Conroy, J. (1996). The Small ICF/MR Program: Dimensions of Quality and Cost. *Mental Retardation, 34 (1),* 13-26. Conroy, J. (1998). Quality in Small ICFs/MR Versus Waiver Homes. *TASH Newsletter, Volume 2, Issue Number 3, March 1998.*

settings, and excluded people who lived in large congregate settings. Next, we excluded people who had changed their type of home between 2000 and 2001. This left us with about 800 people who had been living in an ICF/MR for the entire year, and about 950 who had been in Waiver settings.

Before showing these preliminary results, however, it is extremely important to caution readers that this analysis is exploratory only. The people who live in ICFs/MR and Waiver settings are different kinds of people, with distinctly different characteristics. To drive this point home, we produced Table 16 of measures from the year 2000 round.

Table 16
Characteristics of People in ICF/MR and Waiver Community Settings, 2000

	ICF/MR, N=808	Waiver, N=957
Adaptive Behavior	35.0	60.0
Challenging Behavior	83.2	74.9
Choicemaking Scale	31.9	52.6
Quality of Life Scale	85.8	83.4
Integrative Activities	21.4	36.9

Notice the large difference in adaptive behavior, with the Waiver recipients having far higher levels of ability – 60 points versus 35 points. The Waiver recipients also displayed considerably more challenging behavior than the ICF recipients. (Higher scores are favorable on this scale, meaning less challenging behavior.)

These differences between the ICF/MR and the Waiver recipients means, for one thing, that direct comparisons between the two groups must be done judiciously and interpreted with great caution and conservatism. We proceed with a comparison here, because we are "looking for clues". This is purely an exploratory attempt to see if any pattern might emerge that could lead toward an explanation of the recent findings.

With that caution, then, the following table breaks down changes in five quality indicators for the two groups.

Table 17

Changes In Quality Indicators, 2000 to 2001, for Two Groups: ICF/MR and Waiver

	ICF/MR, N=808	Waiver, N=957
Adaptive Behavior Change	-2.1	-1.0
Challenging Behavior Change	-1.6	-0.8
Choicemaking Change	5.5	3.4
Quality of Life Scale Change	-0.6	1.5
Integrative Activities Change	-2.6	3.0

While both groups lost some ground in adaptive behavior, the ICF/MR group's loss was twice the size of the Waiver group's loss. And because the ICF/MR group started out with much lower scores, their 2.1 point loss was a larger percentage of their skill repertoires.

Similarly, the loss in challenging behavior was about twice as large for ICF/MR recipients than Waiver recipients.

At the same time, the ICF/MR people gained more in Choicemaking, the opportunity to control many minor aspects of daily life and decisions, than did the Waiver people. This presents a pattern that is confusing to us. The mystery is only deepened when we note that the average Mover in an ICF/MR showed a slight decrease in overall quality of life ratings from our Quality of Life Changes scale, while the Waiver Movers showed an increase. Finally, Integrative Activities went down slightly for the ICF/MR Movers, while it went up for the Waiver Movers.

In the spirit of "looking for leads," then, we believe there is justification for much more in-depth and careful study of at least these two funding mechanisms. The funding mechanisms

are tied to quite different methods of monitoring, licensing, and regulation, and these differences may be causing different emphases in daily service and support practices.

This exploration has not determined that either model is better than the other, because the people in the two models are so different in the first place. What we have done, again, is shown that this is an area that merits investigation.

This section closes with a reminder and a warning. The evidence is very clear and strong that the Movers are in most ways "better off" than they were in DCs. Moving people from institutions to community homes in California has been excellent social policy that benefited thousands of people. That fact has been established not only by the present research group, but also has been replicated by researchers at California State University, Berkeley Planning Associates, and the Citygate consulting organization.

However, we now have evidence that something is changing in the service system. There are many positive measurable changes in people's lives over the past year, but for the first time, we have seen two negative impacts on people's lives. We think these two areas, adaptive and challenging behavior, are important areas. Hence we suggest treating these findings as an "early warning system." The behavioral losses have just begun, as far as we can determine, in the past year or two. Our view is that these findings give California a chance to investigate further and weigh options carefully.

Descriptive Results for the 2,170 Movers

Descriptive Results 1: Characteristics of the Movers

We completed visits with 2,170 people who moved out of Developmental Centers as a result of the Coffelt settlement agreement and who were still in the community when we visited. We refer to this group as "Movers," that is, people who moved out of Developmental Centers and into community living situations. Table 18 shows the distribution of basic characteristics among the 2,170 people, including gender, minority status, average age, and label for level of mental retardation.

Table 18
Characteristics

Percent Male	61.5
Percent Female	38.5
Percent Minority	30.2
Average Age	41.6
Percent not labeled MR	2.0
Percent Mild	19.5
Percent Moderate	10.7
Percent Severe	13.7
Percent Profound	54.0

The population is 61.5% male and 30.2% minorities. The average age is 41.6 years old. About 68% percent of the people interviewed are labeled severely or profoundly mentally retarded, while approximately 30% are labeled mildly and moderately mentally retarded.

Marital status is another characteristic that is often used to describe people in the general population. The majority of the people in this study (98%) have never been married, but 22 people who are now single, reported that they had been married at some point, while 14 people said they are married now. We also asked if people had any children. The majority answered "no", but 53 people said they have children. Only 12 of the 53 reported parents list their children as dependents.

Many people with mental retardation also have secondary disabilities. This information can be important for developing current and long-range community resources. The people we visited reported the conditions shown in Table 19 as major secondary disabilities.

Table 19
Percent of "Movers" who Reported
Major Secondary Disabilities

Ambulation	27.4
Autism	10.8
Aggressive Behavior	34.9
Brain Injury	7.2
Cerebral Palsy	17.9
Communication	60.7
Dementia	1.7
Major Health Problems	26.7
Hearing	5.3
Mental Illness	22.5
Physical Disability	15.7
Seizures	29.1
Self Abuse	23.5
Substance Abuse	2.3
Swallowing	7.9
Vision	13.1
Other	10.5

Communication, aggressive behavior, seizures, problems with ambulation, and major health problems are reported as the top five secondary disabilities. The least reported secondary disabilities were dementia, substance abuse, hearing problems, brain injury, and swallowing problems.

Descriptive Results 2: Family Contacts

A major concern in any deinstitutionalization initiative is the maintenance of family connections. In fact, planning for relocation and decisions regarding where people will live in the community are often made with the intent of reunifying families and providing opportunities for more contact. Our Visitors therefore ask how much and what kinds of family contact has occurred in the past year. The specific questions from page 11 of the PLQ are as follows:

10. What kinds of contact has this person had with any relatives during the past year, and about how many times? About how often in the past year?
(Zero if none)

_____ 10a. Telephone calls
_____ 10b. Mail
_____ 10c. Relative visits person here at this home
_____ 10d. Person goes out with relative(s)
_____ 10e. Program Planning Meetings
_____ 10f. Consent for medical care

The results are shown in Table 20.

Table 20
Frequency of Contact with Relatives

Type of Contact	% With No Contact	Median For Those With Any Contact
Telephone calls	64%	12.0
Mail	74%	3.0
Relative visits person here at this home	63%	4.0
Person goes out with relative(s)	70%	6.0
Program Planning Meetings	80%	2.0
Consent for medical care	86%	1.0

The column headed "% With No Contact" shows that the majority of people had no contact with relatives in all of the listed categories. For example, approximately 80% of people had no contact with relatives in the past year via program planning meetings. For the 20% who did have relatives involved in program planning, the average (median) number of contacts was 2 in the past year.

The most common kind of contact with relatives was made by telephone, at about 12 times per year for the people who had any contact. To repeat, however, only 36% of the people had any telephone contact with relatives. The median number of 12 contacts per year is for those same 36% of the Movers who had phone contact.

Taken across all the forms of contact, more than 49% of the Movers were reported to have had no family contact of any kind in the past year. This showed that many of the Movers had no one in their lives other than paid professionals and direct care workers. These people were, and are, dependent on the "system" to safeguard their rights and well-being. This is in sad contrast with the fact that one of the most frequent responses given by the Movers to "If you had one wish" (see Results: Personal Interview below) was the wish for more contact with relatives.

Descriptive Results 3: Friendships

Many people measure their quality of life according to the numbers of friendships they enjoy.[17] This measurement is even more important for people with disabilities, like the Movers, who have not had years of community schooling and jobs to develop friendships in the ways that most people do. The PLQ addresses this serious issue beginning on page 12:

> **11. Number Of Friends:** About how many people in this person's life would you describe as friends? Do not count mere acquaintances (people one might say "Hi to, or wave to, but with whom there is no other interaction). Friends might include housemates, co-workers, schoolmates, other people with disabilities served by the residential or day program agency, direct care workers, case managers, support coordinators, therapists, churchgoers, neighbors, merchants (workers in any commercial store), letter carriers, law officers, advocates, guardians, etc.
>
> 11a. _____ number of friends
>
> 11b. _____ number of "close" friends (see next section for explanation)

This question was often answered by whoever knew the person best, usually a staff person. The following Table provides the results for both 11a and 11b.

Table 21
Number of Friends and Close Friends

	None	Average
11a. Friends	11.6	8.6
11b. Close Friends	29.3	2.6

Among the 2,170 Movers, 29% reported no close friends at all. The other 71% reported having an average of 2.6 close friends. We did not define "friend" or "close friend" for the people being interviewed. It is our procedure to allow the people being interviewed to make

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17 R. Schalock and M. Begab (Eds.) ***Quality of life: Perspectives and issues*** (pp. 227-234). Monograph Number 12. Washington: American Association on Mental Retardation.

their own decisions regarding the definitions and degrees of friendship. The responses indicated that people have a clear understanding of friendship and that they do have friends.

The next section of the PLQ, the Close Friends Scale, begins on page 12 (see **Appendix B**). The matrix below was designed to capture the nature and intensity of relationships. Visitors asked people to describe their five closest friendships. Our analysis describes the percentages of friendships according to the type of relationship. The nature of these close friends was as shown in Table 22.

Table 22
Close Friends: Relationships

Relationship	Number	Percent of Responses
Relative	402	8.7
Staff of home	2066	44.6
Staff of day program	401	8.7
Other paid	145	3.1
Housemate	1094	23.6
Co-worker	185	4
Neighbor	78	1.7
Merchant	7	0.2
Other	257	5.5
Total responses	4635	100.0

The Table immediately reveals that most "close friends" were people who were paid to be in the person's life (56.4% when we add rows 2, 3, and 4). The second most common choice was housemates at 23.6%. The third largest group was relatives at 8.7%. Respondents listed 257 friends (5.5%) as "Other," the nature of the relationship was not known, and we could not tell whether they were paid or unpaid.

The data support an image of what the Movers considered to be close friends: mostly paid staff, and then the people they lived with (rarely by their own choice), followed by

relatives. Outside of paid people, housemates chosen by others, and relatives, these people tended not to have many friends such as neighbors, co-workers, churchgoers, or other general members of the community. On the other hand, almost three out of four Movers were considered to have at least one close friend, and that would seem to be a positive finding.

If the future brings an increase in real community membership and inclusion, then we should expect to see a gradual increase in friendships with other than paid staff and housemates. Our database will enable us to test this hypothesis over the years to come.

Descriptive Results 4: Individual Planning

Since the mid 1970s and the beginnings of the movement towards individualized services, a person's plan has been a critical measure of quality services. Federal regulations for residential, employment, and educational services began to require individual plans so that active treatment and progress could be monitored. Today, the state of the art for individual plans includes a high degree of person-centered thinking and the inclusion of family members and friends in the planning process. Table 23 shows the personal plan status for the 2,170 people interviewed this year.

Table 23
Does The Person Have An Individual Plan?

	Number	Percent
0 No (if No, skip this section)	47	2.2
1 Yes, but no copy of it is kept here	83	3.8
2 Yes, and normally a copy would be here, but is not now	59	2.7
3 Yes, and a copy of it is here	1975	91.3
Information missing	6*	
Total	2170	100.0

* For 6 people of the 2,170, this item was left blank or an incorrect code was entered

Our data show that 91.3% of the Movers have individual plans and that a copy was available at the time of our Visit. There were only 47 people who did not have plans and that information was reported immediately to the proper Regional Center as part of our Quality Feedback System.

The next scale, on page 23 of the PLQ instrument, is "Elements of the Planning Process". This scale measures the degree to which a person's plan is person-centered. The first item is about the primary respondent's participation in the planning process. The results are listed in Table 24.

Table 24
How Was the Primary Respondent
Involved in the Planning Process for This Person?

Value Label	# of People	% of People
Not at all	416	19.7
Somewhat	68	3.2
Half	43	2.0
Mostly	127	6.0
Completely	1459	69.0
Total	2113	100.0

*57 people left this question blank.

The first item asked whether the primary respondent, (the person or the person who knew the individual best) was involved in the individual planning process for the individual. The Table shows that the majority of our primary respondents (80%) were part of the planning team to some degree. However, approximately 20% were not involved at all. Those respondents were not asked to complete the rest of the items about the Elements of the Planning Process, because they would not have first hand knowledge of how things were done. For most people, then, we were able to find out a great deal about the nature of the planning process.

A review of the average scores on this five point scale provides an accurate summary of the status of the planning process for people with disabilities statewide. The results are shown in Table 25.

Table 25
Elements of the Planning Process:

Features of "Person-Centeredness"	Average
How involved in planning process?	3.0
Address long-term dreams?	3.5
Building a network of supports?	2.9
Meetings comfortable and relaxed?	3.7
Planning sessions scheduled as needed?	3.4
Process defined or regulated?	3.8
Process encourage creativity?	3.6
Process allow for conflict resolution?	3.6
Process flexible?	3.7
Does person have ultimate authority?	2.5
Process emphasize cooperation?	3.7
Process emphasize person's relationships?	3.1
Process consider money?	2.7
Does planning group have control over resources?	3.0
Do unpaid group members have real power?	2.6
Do you consider plan to be person-centered?	3.8

The data in Table 25 identify where the planning process was most "person-centered" and where it could use improvement. Two items were tied for the highest score at 3.8. They were: *Is the planning process defined or regulate*d? and *Do you consider the plan to be person-centered?*

The three lowest scores were recorded for: *Does the person have ultimate authority?* (2.5). *Do unpaid group members have real power?* (2.6). *Does the process consider money?* (2.7).

These answers seem to be contradictory in that the respondents feel strongly that the plans are person centered and yet they also report that the focus people do not have ultimate authority. The high score on the "defined or regulated" dimension also seems to be at odds with progressive notions of person-centered planning that are not governed by "one size fits all" rules and procedures. One explanation is that most respondents have accepted the philosophy of person centered planning and they see improvements from the past, even though the system needs to be more responsive to the actual preferences of the focus person.

The planning process was weakest on taking money into consideration, allowing the ultimate authority to reside with the person, and with the unpaid team members. These are three of the things that self-determination is specifically aimed at changing. Over the coming years, we will be looking for changes in these and other Elements of the Planning Process scale.

One of the most important aspects of a plan is the perception of the focus person, and those who are meant to implement it, regarding its utility. A plan is useless if the person and/or staff view it only as an annual requirement to be completed and filed away until the new year. Table 26 shows the percentages of how respondents rate a plan's usefulness.

Table 26
How Useful Is This Person's Plan?

Value	Number of People	Percent
Not at all useful	16	0.8
Not very useful	34	1.6
Somewhat useful	266	12.8
Very useful	1139	54.7
Extremely useful	600	28.8
Don't know or not applicable	27	1.3
Missing	88*	100.0
Total	2170	

* For 88 people of the 2,170, this item was left blank or an incorrect code was entered.

Table 26 shows clearly that the great majority of people (96.3%) consider their plan to be somewhat, very, or extremely useful. This is a credit to the system and to all stakeholders who participate in planning. Several other aspects of the planning process are of interest. For example, how many planning meetings took place during the past year for each person? The average (mean) was 3.3 and the median (half had more and half had less) was 4.0. More than three meetings per year can be viewed as a positive step because it can mean that a person's planning team is being flexible in responding to personal need, not solely the requirement for an annual meeting and an annual plan.

The approximate average length of these planning meetings was 1.5 (mean) and 1.0 (median) hours. The length of the meetings suggests adequate time to review progress and explore future goals and dreams. The planning teams were composed of about 6 people on the average (5.8 mean, 6.0 median). The average number of goals per plan was reported to be about 6 (6.2 mean, 5.0 median).

One of the basic principles of person-centered planning is to include the person in the meeting and to make accommodations to facilitate maximum participation. We measured the degree of participation for each person in the project, as shown in Table 27.

Table 27
Focus Person's Presence at the Planning Meetings

Response	Number	Percent
No	108	5.0
No, person chose not to be present	23	1.1
Yes, person present for small part	146	6.8
Yes, person present for most or all	1884	87.2
Total	2161	100.0

* For 9 people of the 2,170, this item was left blank or an incorrect code was entered.

As shown above, approximately 94% of the people visited had some level of participation in their plans. Non-participation was a relatively rare event. The Movers and the people who support them obviously place a high value on this element of the planning process.

On page 26 of the PLQ we ask about people's "Top 5 Goals" (**Appendix B**). In Table 28, the goals are listed in the order of how often they were included in individual plans.

Table 28
How Often Were Various Goals Included in Plans?

Type of Goal	Number of Goals Out of the 9,283	Percent of the 9,283 Goals	Percent of the People
Other self-care	798	8.6	38.0
Eating	565	6.1	26.9
Grooming	519	5.6	24.7
Other sensory, motor or communication	451	4.9	21.5
Reduction of physical violence to self	433	4.7	20.6
Domestic activities	415	4.5	19.7
Bathing and/or washing	382	4.1	18.2
Reduction of physical violence	353	3.8	16.8
Personal health care	344	3.7	16.4
Other goals regarding reduction of challenging behavior	304	3.3	14.5
Use of non-verbal communication	282	3.0	13.4
Arm use and hand-eye coordination	266	2.9	12.7
Toileting	239	2.6	11.4
Develop skills in sports/athletic activities	237	2.6	11.3
Dressing skills	229	2.5	10.9
Reduction of hostility or threatening behavior	206	2.2	9.8
Reduction of stereotyped behavior	197	2.1	9.4
Reduction of disruptive behaviors	189	2.0	9.0
Use of money and purchasing	171	1.8	8.1
Reduction of rebelliousness	170	1.8	8.1
Reduction of property damage	159	1.7	7.6
Other leisure time goals	162	1.7	7.7
Ambulation improvement	149	1.6	7.1
Reduction of inappropriate verbalization	150	1.6	7.1
Use of verbal language	127	1.4	6.0
Group interaction	127	1.4	6.0
Reduction of inappropriate sexual behavior	107	1.2	5.1
One-to-one interaction	111	1.2	5.3
Other social skill goals	113	1.2	5.4
Develop hobby(s)	108	1.2	5.1
Reduction of running away	104	1.1	4.9
Reduction of clothing problems	90	1.0	4.3
Increase motivation to work	94	1.0	4.5
Awareness of others	79	0.9	3.8
Other work goals	88	0.9	4.2
Reduction of theft, stealing	70	0.8	3.3

Table 28
How Often Were Various Goals Included in Plans?
(continued)

Type of Goal	Number of Goals Out of the 9,283	Percent of the 9,283 Goals	Percent of the People
Other education goals	72	0.8	3.4
Learn to use community resources more independently	76	0.8	3.6
Mobility/Travel	61	0.7	2.9
Reduction of inappropriate interpersonal manners	43	0.5	2.0
Family interaction	51	0.5	2.4
Reduction of lying, cheating	34	0.4	1.6
Achieve a new or better work placement	36	0.4	1.7
Improve motivation to participate and learn in school	33	0.4	1.6
Learn to plan excursions	35	0.4	1.7
Obtaining generic community services	29	0.3	1.4
Learn the concept of working for pay	30	0.3	1.4
Learn specific job skills	31	0.3	1.5
Achieve mastery of specific academic skills	24	0.3	1.1
Vision: using glasses, correction of eye problems	14	0.2	0.7
Use of written language	15	0.2	0.7
Reduction of withdrawal	16	0.2	0.8
Reduction of hyperactivity	18	0.2	0.9
Manners, customs, politeness	20	0.2	1.0
Handling emergencies	11	0.1	0.5
Civic and legal duties	8	0.1	0.4
Sexual interaction	6	0.1	0.3
Learn job-seeking skills	7	0.1	0.3
Learn to use television appropriately	8	0.1	0.4
Understanding and use of numbers	3	0.0	0.1
Telling time	3	0.0	0.1
Use of telephone	2	0.0	0.1
Hearing: using hearing aid, correction of ear problems	4	0.0	0.2
Learn appropriate classroom behavior	3	0.0	0.1
Transfer to a more appropriate school placement	2	0.0	0.1
Total Number of Goals Reported	**9283**	**100**	

Table 28 has two percentage columns. The first represents the goal's percentage of the total 9,283 goals. For example, the goal with the highest percentage in that column was "Other Self-Care", meaning that 8.6% of the 9,283 reported goals were "Other Self-Care". The second percentage column lists the number of people in the population of 2,170 who selected that particular goal. In the case of "Other Self-Care", 38% of the respondents included that goal in their plans. The top three types of goals selected by the focus people and their planning teams all relate to basic self care. The fourth most common kind of goal was in the area of sensory, motor, and communication skills. The fifth was behavioral, aimed at reducing or preventing self-abusive behaviors.

It is interesting to note that some goals that were previously seen as "standard" in professional circles were rarely selected for this group. Examples are "Handling emergencies," "Learn job-seeking skills", and "Manners, customs, politeness".

Descriptive Results 5: Day Activities, Employment, and Earnings

One of the most important ways to look at quality for all people, and especially for people leaving institutions, is to ask, "What do they do all day?" It is important that people stay engaged, that they have something to do that is fulfilling to some degree, to have something that they can "look forward to" each morning. Page 29 of the PLQ recorded information about each person's involvement in work, day activities, and school. Table 29 summarizes how many of the Movers were involved in each type of day activity.

Table 29
Number and Percent of Movers Involved in Each Type of Day Activity

Type of Day Activity	Number of People Involved	Percent of the 2,170 Movers	Average Number of Hours
Adult Development Program	1247	57.5%	27
Vocational Rehabilitation	382	17.6%	25
Community Experience	364	16.8%	18
Sheltered Employment	115	5.3%	22
Other Day Activities	113	5.2%	26
Supported Employment	58	2.7%	22
Public School, Center-based	29	1.3%	26
Volunteer Work	24	1.1%	12
Regular Job	16	0.7%	26
Public School, Regular	14	0.6%	24
Senior Citizen Program/RC Funded	12	0.6%	27
Private School, Center-based	7	0.3%	22
Self Employed	6	0.3%	5
Adult Education	6	0.3%	10
Partial Hospitalization Program	4	0.2%	13
Private School, Regular	4	0.2%	14
Senior Citizen Program Generic	2	0.1%	2

For the Coffelt Movers, the most common type of day activity was an Adult Development Program (57.5%), and the second was Vocational Rehabilitation (17.6%). As the Table shows, very few people were involved in supported employment (2.7% or 58 people) or a regular job (0.7% or 16 people). The issue of most concern regarding day activities is that 116 people reported having zero hours per week of day activities. This number is an increase from last year's data in which 99 people reported no day program hours. This information was reported to the Regional Centers immediately following the interviews along with the stated reasons that are listed in Table 30.

Table 30
Reasons Given for Lack of Day Program

Refuses (10)
They said I don't belong there.
On a list to get a new day program, old one scaled down. (2)
Chooses not to participate. (3)
In-home activity center.
Because of seizures, it's difficult for him to participate in a day program.
Retired (6)
Not in day program due to being on a tube feeder.
Just moved, none yet.
Behavior problems due to fecal smearing at the day program.
Kept falling at day program.
Lost job. (2)
In jail. (3)
Trying to get a day program through resource center.
Quit his job a couple of weeks ago.
Became too difficult to handle, combative.
None apparently offered.
School was too stressful.
Behavior problems. (10)
Starting business.
Elopement risk, family living.
Too retarded and no verbal skills.
Health wise is unable to tolerate a day program. (2)
Client's choice (5)
Just fired from job and is just "hanging out."
Does not want to attend.
Totally dependent for all care, Mother feels it's better if she's at home.
Kicked out of last two day programs, looking for a new one.
No local program for his level of disability.
Broken legs and cataracts prevented her from going to a day program.
Lives with mother and she feels he should stay with her.
Physically unable to be cared for at local facility.
Says she doesn't want or need to attend a day activity.
Refused to attend day activity at level available.
Was just admitted to a drug rehab.
Recently hospitalized, recuperating.
Regurgitates continually and was removed.
Medical issues that prevent her.
Says he hurt his back.
Nobody will accept him at a day program. Case manager trying to find a program.

She will be attending an activity within a couple of weeks.
He refuses all attempts, there have been many.
Wants to make money at a job, but can't work around kids because of sexual behaviors.
AWOL behaviors prevent.
Still looking for a job.
Recovering from surgery.
He has aggressive behaviors and no one wants to work with him.
Lost job - looking right now for an evening job.
Physical disabilities prevent him from participating. (2)
Not since surgery last year.
Takes care of her baby.
Client doesn't want to go, he wants to fish.
Case worker hasn't signed him up yet.
In-home tutorial due to being wheelchair bound and can't talk.
Kicked out of last program.
This facility is beginning to discuss providing a day program.
Dropped from day program because of non-compliance. (2)
Not willing to participate recently.
Funding for his old program stopped, case manager looking for a new one.
He hasn't wanted one, moved frequently.
Lives with parents, they see no need.
Left job recently, waiting for a new placement.
Looking for work.
Unable to work due to health problems.
He is on his own and comes and goes as he pleases. Does not want a day program.
Fell at day program, broke arm. Removed until arm heals then place in a different one.
Level of retardation and health issues.
On the waiting list.

Many of the listed reasons for no day activity hours are perfectly valid, e.g., "Fell at day program, broke arm. Removed until arm heals then place in a different one" and "Takes care of her baby." However, there are many responses that seem to indicate systemic problems. Many responses refer to challenging behaviors and an inability or unwillingness for these problems to be addressed in day programs. Examples of these responses are:

- Dropped from day program because of non-compliance
- He has aggressive behaviors and no one wants to work with him
- Nobody will accept him at a day program. Case manager trying to find a program that will
- Became too difficult to handle, combative

The next aspect of day activities that we examined was the level of integration that a person experiences during the day. One of the questions we use to measure integration is on page 30 of the PLQ:

5. DURING DAY ACTIVITIES, WORK, OR SCHOOL, HOW MUCH TIME DOES THE PERSON SPEND IN THE PRESENCE OF THE **PUBLIC**? (Do not count during transportation.)

Table 31
How Often In Integrated Settings During Day Activities

How Often Integrated	Number of People	Percent of People
None	279	13.5
Less than half	594	28.8
About half	650	31.5
More than half	273	13.2
All or nearly all	269	13.0
Total	2065	100.0
Response Missing	105	

As Table 31 shows, there was a fairly even distribution across the five levels of integration on this item. In all, about 58% of the Movers were reported to be "in the presence of" the public about half, or more than half, of the time.

When people move from institutions to the community there is an expectation that they will be able to engage in some form of income generating activities. We therefore ask people if they earned any money through their day activity. The average weekly earning figure, including all the people who made no money at all, was $5.93.

This year's data show that 470 of the 2,170 Movers (22%) earned money in the week preceding the visit (or a typical week). Of the 470 people who did make any money, the lowest weekly amount was 25 cents, and the highest was $260. We removed the data for the people who made no money at all, and looked at the averages again. The average (mean) for those who did make any money was $27.36. Another measure of the average is the median, which was $10.00. The median is the figure where half the earnings were below it and half were above it. For an unusual distribution, the median is a better measure than the mean, and earnings in this group were distributed very unevenly.

The picture that emerged was one of economic bleakness and scarcity. Less than a fourth of the Movers performed any work for pay, and for them, the amount of money earned was very small, the best indicator of the average was very low, about $10 per week or $520 per year.

Descriptive Results 6: Choicemaking and Self-Determination

The Decision Control Inventory, beginning on page 33 of the PLQ, measures who has power over 35 life areas such as clothes to wear, food to eat, places to go, and type of work or day program. The scale requires ratings from 0 to 10 on each dimension, with 0 meaning that paid staff made all decisions in that area, and 10 meaning that the focus person (and/or freely chosen unpaid allies) made the decisions in that area. A score of 5 or 6 means that decision making power is shared about equally. The 35 "0-to-10" scores can be combined into a single scale which we compute to a range from 0 to 100, with higher scores meaning more individual control over life choices, and therefore less professional domination. The Movers' average score on the Decision Control Inventory was 47.9 points out of 100.

Table 32 provides detail about which areas of choice people had more or less control over. Examination of these scores can provide guidance for provider agency staff and other support personnel who wish to enhance people's decision making skills.

Table 32
Details of Opportunities for Choicemaking

Life Control Area	Average Score
Taking naps in evenings	8.5
Freedom to decline activities	8.3
What to do with relaxation time	8.1
When to get up on weekends	7.8
When to go to bed on weekends	7.7
Express affection, including sexual	7.3
When, where and how to worship	7.3
When to go to bed on weekdays	7.0
Who you hang out with in and out of the home	6.7
What clothes to wear on weekends	6.2
What clothes to wear on weekdays	6.1
What to have for breakfast	5.2
What clothes to buy	5.1
What to have for dinner	5.1
Visiting with friends	5.1
Minor vices	4.9
Choosing restaurants	4.8
Choice of places to go	4.8
Time and frequency of bath	4.8
What to do with personal funds	4.6
Who goes with you on outings	4.0
What foods to buy	3.5
Type of work	3.4
Whether to have a pet in the home	3.2
Choice of house or apartment	3.1
Choice of furnishings	3.0
Amount of time spent working	2.9
How to spend day activity funds	2.8
Which service provider works with person	2.7
Choice of people to live with	2.5
Choice of support personnel: option to hire and fire	2.4
Choice of case manager	2.2
How to spend residential funds	2.1
Choice of agency's support person/staff	2.1
Type of transportation	1.9

These data showed that the highest average scores were in the choice to take naps in the evenings and to decline to take part in group activities. Following those were: what to do with relaxation time, when to get up on weekends and when to go to bed on weekends. These scores reflect the methods being used in community homes to support people who are in transition from hospital-like environments, with very strict medically oriented rules and regulations, to more flexible and individually tailored community homes.

The lowest scores in the table were equally informative. Movers in California do not yet participate very much in choices about hiring and firing support personnel, selecting case managers, spending residential funds, selecting what staff will work with them, or in types of transportation. These are major control issues that can shape lives in major ways. These are also areas that are targeted specifically in self-determination initiatives. If power shifts in future years in the California service system, data like these can reveal the change from the point of view of each individual service recipient.

Descriptive Results 7: Integrative Activities

The scale used to measure integration was taken from the Harris poll of Americans with and without disabilities (Taylor, Kagay, & Leichenko, 1986). Respondents were asked to report how often they engaged in a variety of community events in a typical month. Items on the scale included activities such as: visit with friends, go shopping, go to a place of worship, engage in recreation, etc. A second qualifier for our scale was events that involved the presence of people without disabilities. This tool simply counts the number of "outings" to places where there might be interaction with non-disabled citizens. It does not measure actual engagement or the degree of participation. Information regarding participation as well as presence might be revealed through an analysis of the close friends scale and types of individual goals.

Table 33
Types of Integrative Activities

Type of Outing	Average Number of Events Per Month
Visit with close friends	4.9
Go to a park or playground	4.7
Go to a shopping center	4.1
Visit a grocery store	4.0
Go to a restaurant	3.5
Use public transportation	1.9
Other kinds of getting out	1.8
Go to a movie	1.1
Go to church	0.8
Go to a library	0.7
Go to a bank	0.7
Go to a sports event	0.6
Go to a theater	0.6
Go to a post office	0.4
Go to a health or exercise club	0.3
Go to bars	0.1
Total	30.4

According to this scale, the Movers had opportunities for integrated activities an average of 30.4 times per month. The most frequent kind of integrated community activity reported by the focus people, or by those who knew them best, was visits to close friends, at an average of 4.9 visits per month. The next most frequent kind of outing was going to a park or playground, (4.7 times per month), followed by various kinds of shopping, to a shopping center (4.1 times per month) and to the grocery store (4.0 times per month). The least frequently reported activities were going to bars (0.1 times per month) and going to a health club (0.3 times per month). It will be interesting to track changes in this scale as people make more community connections and develop more individualized interests.

In the Integrative Activities section of the PLQ on page 34, we asked what kind(s) of transportation people had used during the past month. The results were as shown in Table 34.

Table 34
Types of Transportation Utilized

Type of Transportation	% of People
Car or van assigned to this home	72.9
Agency car or van	70.4
Staff member's car or van	49.4
Agency bus	30.9
Family member's car or van	24.7
Public transportation	19.9
Paratransit	18.3
Friend's car or van	7.7
Taxicab	4.8
Person's own car or van	1.7

The highest percentages of people had used a car or van assigned to their home (72.9%) or an agency car or van (70.4%) for transportation in the month preceding our visit. Many people (49.4%) had also been out in a staff member's vehicle. The next types of transportation used were an agency bus or a family member's car or van. Smaller groups of the Movers used public transportation (19.9%) and paratransit (18.3%). The least used forms of transportation were a friend's vehicle, a taxicab or one's own vehicle.

In one of the questions most indicative of freedom of movement, we asked:

18. ACCESS TO TRANSPORTATION: If this person wanted to go somewhere on the spur of the moment (beyond walking distance), how many times out of 10 would he/she be able to? If this person does not communicate such wants phrase the question as "If someone unpaid wanted this person to be able to go somewhere on the spur of the moment" Count only trips that are within 1 hour of home.

_____ times out of 10

The responses are listed in Table 35 and show a pattern of relatively high freedom to get out and about.

Table 35
Freedom to Travel at Will

# Times	# People	% of People
0	226	10.4
1	75	3.5
2	89	4.1
3	82	3.8
4	46	2.1
5	168	7.7
6	53	2.4
7	54	2.5
8	217	10.0
9	206	9.5
10	954	44.0
	2170	100.0

Remarkably, nearly half of the people (44%) were reported to be able to go out whenever they wanted to, even on the spur of the moment, 10 times out of 10.

The corresponding figure in an otherwise reasonably progressive service system in the Midwest was 19% for a total population of 786 people. The California Movers, then, enjoyed unusually high freedom of movement. This could be related to the cultural emphasis on vehicles in California, but the result was nevertheless intriguing and, in our view, positive.

Descriptive Results 8: Health, Health Care, and Medications

One of the strongest indicators of a quality support system is the maintenance of health and access to quality health care. Community capacity with regard to health care for people with disabilities is a vital factor in any deinstitutionalization initiative. The PLQ addresses these important issues in the Health Information section beginning on page 35. Table 36 shows the responses to the question "In general, how is this person's health?"

Table 36
How Is This Person's Health?

Rating	Number of People	Percent of People
Very poor	6	0.3
Poor	38	1.8
Fair	327	15.2
Good	1324	61.5
Excellent	457	21.2
Total	2152	100.0
Blank	18	

Almost 83% of the respondents felt that peoples' health was "Good" or "Excellent." Only 2.1% of the respondents felt that peoples' health was "Poor" or "Very Poor." Table 37 summarizes a series of analyses related to health care utilization.

Table 37
Indicators of Health Care Utilization

Health Care Dimension	
Average Dental Visits	1.50
Average Doctor Visits	6.07
Average Specialist Visits	4.77
Average Hospital Admissions	0.27
Average Emergency Room Visits	0.74
Receiving Antipsychotic Medication	581
Receiving Behavior Control Medication	812
Receiving Sleep Medication	182
Receiving Antidepressant Medication	217
Receiving Seizure Control Medication	924
Receiving Digestive Medication	1028
Receiving Chronic Health Condition Medication	827
Receiving Nutritional Supplements	1184
Receiving Other Daily Medication	751

Table 36 shows that the Movers had an average of 1.5 visits to a dentist and 6.07 visits to a doctor in the past year. Additional visits to specialists were made an average of 4.77 times in the past year. The table also shows the number of people receiving certain types of medications. Antipsychotic medication, for control of psychiatric symptoms, was received by 581 people. Behavior control medication was received by 812 people. Seizure control medication was received by 924 people. Another important health related question asked "How many errors in the administration of medications occurred in the past month?" Table 38 presents a list of responses.

Table 38
Number of Medication Errors in Past Month

Number of Medication Errors	Number of People	Percent of People
0	2080	98.3
1	26	1.2
2	4	0.2
3	2	0.1
5	1	0.0
6	2	0.1
20	1	0.0
Total	2116	100.0
Blank	54	

The great majority of Movers (98.3%) did not experience any errors in the administration of their medications in the month prior to our visit. However, there were 26 people who experienced at least one error in the past month. It is important to note that medication errors is one of the items that we include in our quality feedback summaries to the Regional Centers immediately following the visit. We also asked respondents to describe the most recent medication error. Their responses are presented in Table 39.

Table 39
Reasons for Most Recent Medication Errors

Describe most recent medical error
Didn't wake up in time for meds
He took medication at wrong time
There was a missed dosage in the afternoon, however there was no need for emergency room
Skipped giving an antibiotic for 5 days
Given a dose of pepsid when it had been discontinued
Gave coumadin 5 blood tests
There was a missed dosage in the afternoon. However, there were no significant problems
Received someone else's medications
He took someone else's medication at program
1 morning's doses missed, behaviors & trip to ER
Only 1/2 of regular dose given
New med order, missed on 1st dose
1 dose of propulsid missed
Missed one of her noon meds at cap
During day activity - did not receive depakote tablets
Client refused to take med. (resistive behavior)
Med. Omission
There was a missed dosage in the afternoon. No significant problems such as ER visit
There was a missed dosage in the afternoon
Not compliant when taking meds
PM doses given late
Forgot to give a pill, given soon after
Forgot to give one dosage
Refused meds 10/16 and 10/30 pm
Called pharmacy who instructed what to do
Forgot to take morning meds. Staff documented in chart
There was a missed dosage in the afternoon. There was no significant problem
There was a missed dose in the afternoon, no significant problems
He did not take 12 PM med. New staff did not send it to day program
Call the pharmacy to remind them that person is low on ibuprofen
He does not come back to the house for meds
Missed morning dose, nurse notified, no problems
Noon meds. Missed 1 week ago but given later

Table 40 illustrates the responses to the question "How easy is it to get health care?"

Table 40
Ease Of Getting Medical Care For This Person

Feeling	Number of People	Percent of People
Very difficult	65	3.1
Difficult	102	4.8
About average	372	17.7
Easy	974	46.2
Very easy	594	28.2
Total	2107	100.0

Table 40 show that over 74% of the respondents believed that it was "Easy" or "Very Easy" to obtain healthcare for the Movers. Only about three percent of the respondents felt that it was "Very Difficult." Table 41 shows the responses to the question "Overall, how good is this person's health care?"

Table 41
How Good Is The Health Care This Person Is Getting?

Feeling	Number of People	Percent of People
Very poor	4	0.2
Poor	5	0.2
Fair	97	4.6
Good	1207	56.7
Excellent	816	38.3
Total	2129	100.0

Table 41 shows that 95% of the respondents felt that the peoples' quality of health care was "Good" or "Excellent." Less than one percent of the respondent's felt that the peoples' quality of health care was "Very Poor."

A very important aspect of any quality tracking and assurance program is monitoring allegations of abuse. Table 42 lists the respondents' descriptions of allegations of abuse in the past year.

Table 42
Allegations of Abuse in Past Year

Describe most recent allegation of abuse
No knowledge of previous problems no records
Accused mom of slapping, but it all worked out
Picked up stick & threatened house manager
Allegations of staff yelling at her. Tendency to make false allegations.
Episode of bus driver hitting. Bus driver was fired
Reported that resident was rolled over by staff while changing
Staff drug her on carpet, left rug burns
Mom made derogatory comments to regarding staff care (unfounded)
Says that staff at his old home started a fight with him.
Suspected physical abuse by prior care provider
Report of neglect filed because night staff member deserted his position.
Abuse was alleged in previous home
When returning from shopping with a group from the day activity staff
Lost control & as a result there were abrasions when brought under control
Sexual abuse allegation
Abuse by prior care provider
Alleged abuse at previous home
Abuse by prior care provider
Sexual advances from brother and his friend in sister's home.
Alleges that the administrator at the day program made an advance.
Allegedly sprayed disinfectant in her face. Employee dismissed
Someone heard her screaming and someone slapping her. It was investigated
Incident of rape by attacker when she snuck out. She is very proud of herself
Staff person raised her voice
Lost her wallet and asked if she would be spanked for it. Investigated.
He was whipped with a cord. Investigation resulted in arrest and conviction
Refuses to go to doctor appointments. Case worker filed a licensing report.
Staff member alleged he was hit on the arm by another staff member.
Old residence using my ss money for drugs. Reported to RC
Housemate grabbed him & caused abrasions & a bump on his head.
I don't want to talk about it
Mother took him out, ended up in ER. Social services was called.
Says staff are beating her up, calling her names and hitting her
Abuse at the day program, employee was terminated
Said staff at day program hit him. This resulted into investigation.
Multiple allegations against staff when she first moved.
Suspected of being involved in the sexual abuse of another patient.
Job coach allegedly pushed him from chair. Job coach terminated
Claimed a male peer forced him to have oral sex
Claims that a teacher attacked him. Charges pressed.
Called 911, said he needed to be straightened out
TV was stolen from room staff member staff
Former staff member pulled him to the bathroom by his feet no apparent injury
Claimed that staff hit him in the head. Finding was inconclusive.
Staff member grabbed her by the throat to lead her, no physical injury.
Physical abuse by day program staff

Descriptive Results 9: Personal Interviews

The personal interview is one of the most interesting sections of the PLQ. It records the opinions and comments of people with disabilities in their own words. As possible, this interview is conducted privately. Prime requisites for COA Visitors are experience in working with people with disabilities and demonstrated sensitivity to disability related interviewing factors such as non-verbal communication, short attention spans, repetitive physical and verbal mannerisms, limited vocabulary skills, and tendencies to agree or disagree regardless of question content. Visitor training includes instructions on gathering pre-interview information on these kinds of issues and on requesting methods and strategies for individual communication preferences. The location, timing and presence of a person who knows the focus person very well are additional factors that are considered in designing an optimal interview environment.

Visitors begin with an explanation of the purpose of the interview and assurances regarding confidentiality. Simple language is used to stress the fact that there are no wrong answers, that the interview is not a test or a licensing inspection, and that the Visitor will not tell anyone else individual answers. For example, "I will ask you a question like *how do you like the food here?* I will write down your answer but I will not tell your staff, house manager, case manager or anyone else what you said. When we finish our report, there will be a section that says something like *most of the people like the food, or 25% of the people don't like the food,* but no one will know what you said."

Visitors then gather general information and try to develop a rapport with the focus person. The person is free to come and go during the interview and to participate as much as possible. Visitors, with the assistance of the person who knows the focus person very well, make a judgment decision about when to try the personal interview.

Following are individual discussions of the questions on the personal interview. In this year's visits, 667 Movers were able to communicate directly with the Visitor and answer these

questions. Most answers were recorded on a five-point scale, from very poor, poor, fair, to good, and very good. The remaining questions involved the use of a Likert scale, a yes, no or don't know choice. The respondents did not all answer every question so individual response numbers are presented. It is important to note that the PLQ often includes several questions on the same topic as a reliability tool. The questions do not follow each other in the personal interview but are grouped together in this report for ease of comparison.

Table 43
How do You Feel About Living Here?

Feeling	Number of People	Percent of People
Very poor	22	3.7
Poor	33	5.5
Fair	79	13.3
Good	259	43.5
Very good	202	33.9
Total	595	100.0

Table 43 shows that the majority of people (77.4%) answered good or very good to this question. This was followed by 13.3% who answered fair. The next level, poor, was the response of 33 people (5.5%). Only 22 people (3.7%) answered very poor. This question is very broad and of course may reflect a person's feelings about what occurred on the actual day of the interview. However, the percentage of positive responses indicates a significant level of satisfaction.

Table 44
Do You Want to Move Back to a Developmental Center?

Feeling	Number of People	Percent of People
Definitely not	312	67.0
Probably not	43	9.2
Maybe	42	9.0
Yes, probably	32	6.9
Yes, definitely	37	7.9
Total	466	100.0

The answers to this question were also significantly positive. Of the 466 people who answered, 76.2 % said they would definitely not or probably not choose to return to a developmental center. This majority was followed by 9 % of the respondents who answered maybe, and 14.8 % who answered probably or definitely yes. COA has found in other studies that people who consider a return to a developmental center often make that choice because of a personal connection that has been lost, either with staff or peers.

Table 45
Do You Want to Move?

Feeling	Number of People	Percent of People
No	301	55.2
Not sure	29	5.3
Yes	215	39.4
Total	545	100.0

This is a general question and a positive response could reflect a desire to move to a family home, to another community living arrangement, to a more independent community living arrangement or back to a developmental center. It is important to note that a desire to move does not necessarily reflect negatively on a provider or the service system. A desire to

move may indicate personal growth and independence and a stable support system that has provided opportunities for developing community connections, and for learning personal choice and decision making.

There were three choices for this question, yes, no, and not sure. A total of 545 people answered and 301 (55.2%) answered no, they did not want to move. There were 215 people (39.4%) who did want to move and 29 people (5.3%) who were not sure.

A recommendation for further measurement and monitoring of changes in this question would include comparisons with the decision control inventory, especially with the, *who chose where and with whom you live,* questions.

Table 46
How is The Food Here?

Feeling	Number of People	Percent of People
Very poor	9	1.6
Poor	23	4.0
Fair	57	9.9
Good	287	49.8
Very good	200	34.7
Total	576	100.0

Approximately 84.5% of the 576 people who answered this question answered good or very good. It is apparent that most people feel that food in community programs in California is generally good. A description of food as fair was reported by 57 people, and 32 people answered poor or very poor. The negative responses are low but further study of those responses could be done with comparisons by provider agency and the decision control inventory scores.

Table 47
Please Let me Check-Did You Say The Food Here is Good or Bad?

Feeling	Number of People	Percent of People
Very poor	14	2.8
Poor	14	2.8
Fair	48	9.6
Good	258	51.6
Very good	166	33.2
Total	500	100.0

The responses to this question are consistent with the answers to the earlier food question. Fewer people (500 versus 576) answered this question but 84.8% reported that the food was good or very good, compared to 84.5% in the first question. There were 28 answers of poor and very poor in this group and 32 in the other question. The largest difference in answers was in the fair category, 48 for this question and 57 for the other.

Table 48
How do You Feel About The People You Live With?

Feeling	Number of People	Percent of People
Very poor	9	1.6
Poor	28	5.0
Fair	110	19.5
Good	221	39.3
Very good	91	16.2
Not applicable	104	18.5
Total	563	100.0

A total of 563 people answered this question. Of that number, 104 answered not applicable, most likely because they live alone. A majority (55.5%) felt good or very good

about the people they live with. Unfortunately, there were 26.1% of the respondents who answered fair, poor or very poor to this question. It is hoped that future personal interviews will reflect an increase in satisfaction with housemates as people make more personal connections and are able to change their living arrangements through the individual planning process.

Table 49
Do You Have Enough Privacy?

Feeling	Number of People	Percent of People
Definitely not	21	4.2
Probably not	33	6.6
Maybe	49	9.8
Yes, probably	179	35.9
Yes, definitely	216	43.4
Total	498	100.0

An increase in privacy is an early and significant quality of life change for most persons moving from developmental centers to the community, and the 498 Movers who responded to this question reflect that trend. A significant majority (79.3%) reported that they definitely or probably have enough privacy. The next group of 49 people (9.8%) answered maybe and only 54 people (10.8%) said that they definitely, or probably, did not have enough privacy. This issue may be related to feelings about housemates and their levels of challenging behavior. This is another quality of life factor that would be expected to show positive growth in future surveys.

Table 50
How do You Feel About The People Who Work With You Here (the Staff)?

Feeling	Number of People	Percent of People
Very poor	8	1.6
Poor	7	1.4
Fair	66	13.2
Good	250	50.0
Very good	169	33.8
Total	500	100.0

Satisfaction with direct and indirect support staff is very important in measuring the overall life quality for a person moving from a developmental center to the community. This factor can make or break the development and implementation of individual plans and have a major impact on a person's general motivation and attitude toward community life.

The answers to this question were significantly positive. A total of 500 people answered this question and 419 of them (83.8%), answered that they felt good or very good about the people who support them. There were 66 respondents who answered fair (13.2%), and only 15, (3%) who felt poor or very poor about the people who work with them.

This level of satisfaction is very encouraging and is often an indication of quality staff recruitment and training. Further study of this issue would compare satisfaction levels by providers and staff job satisfaction.

Table 51
Are There a Lot of Rules You Have to Obey Here?

Feeling	Number of People	Percent of People
Definitely not	50	11.4
Probably not	49	11.2
Maybe	57	13.0
Yes, probably	138	31.6
Yes, definitely	143	32.7
Total	437	100.0

Rules, and an emphasis on compliance to rules, play a major role in congregate living arrangements. There is a need for structure in any specialized living arrangement, especially with regard to health, safety and preservation of personal privacy and property. However, a homelike atmosphere should incorporate these safeguards without the appearance of rigidity. This question was used to elicit a general feeling regarding the amount of rules.

The majority of the 437 respondents (64.3%) felt that there were definitely or probably a lot of rules. A smaller number (22.6%) reported that there definitely or probably were not a lot of rules. The remaining 57 respondents (13%) answered that maybe there were a lot of rules to obey.

Table 52
Are There Some Rules You Don't Like?

Feeling	Number of People	Percent of People
Definitely not	87	23.0
Probably not	94	24.9
Maybe	72	19.0
Yes, probably	81	21.4
Yes, definitely	44	11.6
Total	378	100.0

The transition from a large congregate facility to a small community home involves significant change. A total absence of rules, after many years of institutional life could be confusing and stressful. COA therefore included a follow up question to gauge the general attitude regarding existing rules. A majority of the 378 respondents (47.9%) stated that there were definitely not or probably not any rules that they did not like. There were 125 people (33%) who said yes, there definitely or probably were rules they did not like, while 72 people (19%) answered maybe.

Table 53
How do You Feel About Your Job, Day Program, Workshop, Etc.?

Feeling	Number of People	Percent of People
Very poor	17	3.6
Poor	27	5.7
Fair	65	13.7
Good	219	46.0
Very good	148	31.1
Total	476	100.0

The level of satisfaction with jobs and day programs has a strong impact on overall life quality. A significant number of the 476 respondents (77.1%) answered that they felt good or very good about their jobs. They were followed by 65 people (13.7%) who answered fair, and only 44 people (9.3%) who answered poor or very poor. A recommendation for further study is to compare this positive response rate with the number of people engaged in competitive employment, pay rates, and progress toward vocational goals.

Table 54
Do You Have Friends?

Feeling	Number of People	Percent of People
No friends	23	4.3
Just one	27	5.1
A few	137	25.7
Yes, some	161	30.2
Yes, a lot	185	34.7
Total	533	100.0

The PLQ asks several questions regarding friends because the answers yield rich information about a person's level of integration and satisfaction with the transition to community life. In the personal interview section, 64.9% of the 533 respondents stated that they had a lot, or some, friends. There were 50 people (9.4%) who reported having only one or no friends and 137 (25.7%) who said they had a few friends.

Table 55
Who is Your Best Friend?

Feeling	Number of People	Percent of People
Direct care staff	59	13.3
Paid professional	89	20.1
Advocate, guardian	1	0.2
Family member	49	11.1
Peer with a disability	201	45.4
Unpaid person without a disability	44	9.9
Total	443	100.0

It is interesting to note the categories of the people who are reported as best friends. For most people in the general population, a best friend is not someone who is paid to be in their

lives. This is consistent with the friends noted by 55.3% of the 443 respondents, if the peer with a disability and the unpaid person without a disability categories are combined. A large number, (33.4%) of the people, listed direct care or paid professional staff as their best friend. The remaining 11.3% of respondents listed a family (including foster family) member, advocate or guardian as best friends.

Table 56
Do You Have a Special Friend, Like a Girlfriend or Boyfriend?

Feeling	Number of People	Percent of People
Definitely not	178	39.0
Probably not	30	6.6
Maybe	21	4.6
Yes, probably	68	14.9
Yes, definitely	159	34.9
Total	456	100.0

There were slightly more people who reported having a special friend than those who did not have a special friend. There were 227 people who answered probably yes or definitely yes to this question, and 208 who answered probably not or definitely not. The remaining 21 of the 456 respondents answered maybe. The opportunity to form intimate relationships was not widely available to people living in developmental centers. A future increase in the number of people reporting special friends could be viewed as a positive sign of community integration and personal independence. This is another area that would be interesting to study further, e.g., differences according to other variables such as levels of disability or employment status.

Table 57
Do You Get Lonely?

Feeling	Number of People	Percent of People
Yes, often	64	14.0
Yes, sometimes	166	36.2
In between	44	9.6
No or very rarely	57	12.4
No, never	127	27.7
Total	458	100.0

Many professionals and parents worry about the potential for loneliness in small community homes, especially for people who spent many years in an environment that included large numbers of peers and staff. A small majority of the 458 respondents (50.2%) felt that yes, they were often or sometimes lonely. There were 184 people (40.1%) who felt that they were never or very rarely lonely. Future trends with regard to this question should be monitored closely and cross-referenced with the sections on community outings and friendships.

Table 58
Do You Have a Pet?

Feeling	Number of People	Percent of People
No	364	71.0
Not sure	6	1.2
Yes, shared with others	86	16.8
Yes, my own	57	11.1
Total	513	100.0

Person centered plans, especially the sections that refer to wishes or dreams, often refer to pets. The opportunity to own a pet is sometimes the first obvious sign of choice, and for many it is a major element in creating a homelike environment. There are many reasons why it

is difficult to include pets in community living arrangements, allergies, cost, and housemate preferences. The data indicate a low frequency of pet ownership. Only 57 of the 513 respondents (11.1%) had their own pet, while an additional 86 people (16.8%) shared pets. The great majority (72.2%) did not have a pet or were not sure.

Table 59
How Important is Having This Pet?

Feeling	Number of People	Percent of People
Not at all important	12	7.5
Not much	6	3.8
In between, not sure	16	10.1
Yes, some	39	24.5
Yes, very important	86	54.1
Total	159	100.0

The people who had pets (143) were asked to rate their pet's importance. The majority (78.6%) answered that having their pet was either very important or of some importance. A smaller group (11.3%) felt that their pet was not at all important or not of much importance. Finally, 10.1% of the pet owners were unsure of how they felt about their pet's importance.

Table 60
Would You Like To Have A Pet?

Feeling	Number of People	Percent of People
Definitely not	76	23.2
Probably not	22	6.7
Maybe	28	8.6
Yes, probably	70	21.4
Yes, definitely	131	40.1
Total	327	100.0

This question sought more information regarding choice and pets. The data would appear to indicate that there are people who want pets who do not have them. When asked if they want to have a pet, 201 of the 327 respondents (61.5%) answered probably or definitely yes. An additional 28 people (8.6%) said maybe they would like a pet and 29.9% answered probably or definitely not.

Table 61
When You Go Places (Field Trips, Shopping, Movies, Parks, Walks, or Any Other Outings), Who Picks Where You Go?

Feeling	Number of People	Percent of People
Others choose	59	13.9
Person has some say,	19	4.5
Person has little say	36	8.5
Person has major say	139	32.7
Person chooses	172	40.5
Total	425	100.0

The answers above are related to community integration and choice. The majority of the 425 respondents (73.2%) answered that they either choose where to go in the community or

have a major say in where to go. There were 55 people (13%) who answered that they have little or some say in where to go and 59 people (13.9%) who reported that others choose where they go. Choices for community outings are often dependent on cost, transportation, staff ratios and housemate preferences. This is an important measure to be monitored and cross referenced with the decision control inventory and integration questions that appear elsewhere in the PLQ. A further recommendation would be to identify the 59 respondents for whom others make the choices and check their annual goals for training in choice making.

Table 62
Do You Like Going Out To Those Places?

Feeling	Number of People	Percent of People
Not at all	3	0.6
Not much	4	0.8
In between	20	4.1
Yes, some	92	19.1
Yes, very much	363	75.3
Total	482	100.0

The point of this question is to double-check the issue of choice making. Some people may report that they choose to go certain places. However, if they do not really like where they are going then the apparent choice may be the result of limited options. In this case, the data appear to support the fact that the 482 respondents are choosing to go to places they like. Their overwhelming (94.4%) answers were yes, some, or yes, very much. The remaining 5.5% of the answers were in between, not much or not at all.

Table 63
Would You Like To Go Out More Often, Or Less Often?

Feeling	Number of People	Percent of People
More often	358	74.7
About the same	91	19.0
Less often	30	6.3
Total	479	100.0

It seems that the residential providers are doing such a good job at identifying places that people like to go that the 479 respondents want to go out even more. The majority, (74.7%) want to go out more often and 19% are content with about the same amount of outings. There were only 30 people (6.3%) who answered that they want to go out less often.

Table 64
Do You Have Someone Who Visits You
Called a Regional Center Case Manager?

Feeling	Number of People	Percent of People
No	30	6.1
Not sure	79	16.1
Yes	381	77.8
Total	490	100.0

Case management services are a crucial factor in community transition and stability. The majority of the 490 respondents, (77.8%) answered that yes, they are visited by a regional case manager. There were 79 people (16.1%) who were not sure and 30 people (6.1%) who said no. Further study of the 22.2% of these Movers who were not sure, or said no, could include cross-references to discharge dates and regional centers.

Table 65
Can You Call (reach) This Case Manager if You Need To?

Feeling	Number of People	Percent of People
No	44	9.1
Not sure	105	21.7
Yes	334	69.2
Total	483	100.0

It is important for people living in the community to understand that they can contact their case manager. For many people, the case manager may be the only contact that is independent of the residential provider agency. Although the majority of the 483 respondents (69.2%) said yes, they can reach their case manager, it is a concern that 105 people (21.7%) were not sure and 44 people (9.1%) said no. This may be a training issue, assuring people that they can contact their case manager and providing them with assistance with the phone to do so. It may also be indicative of a confusion between regional center case management and provider staff who may have similar titles, or who may perform functions that these Movers associate with case management.

Table 66
Does the Case Manager Help You?

Feeling	Number of People	Percent of People
Not at all helpful	11	2.8
Not helpful	18	4.7
Somewhat helpful	74	19.2
Helpful	167	43.3
Very helpful	116	30.1
Total	386	100.0

It is important that Movers view their case managers as helpful, as the kind of person they can turn to for support. Approximately 73.4% of the 386 respondents felt that their case managers were either helpful or very helpful. Only 7.5% of these people answered that their case managers were either not helpful or not at all helpful. The remaining 19.2% felt that their case managers were somewhat helpful. The responses to this question could also be further analyzed according to time in the community and by regional center.

Table 67
How Was This Interview Conducted?

Present	Number of People	Percent of People
Staff person was present	150	22.5
In private with the focus person	489	73.3
Other situation	28	4.2
Total	667	100.0

The final question on the personal interview asks if a staff person was present for the interview, if it was conducted privately, or if there were some other situation such as the presence of a friend or family member. There were 667 respondents, 73.3% of whom were

interviewed privately. Staff were present for 22.5% of the interviews and 4.2% of the interviews were described as being conducted under some other situation.

If You Had One Wish....

The answers to the one wish question range from funny to heart breakingly sad. It is perhaps the one response that best illustrates how much the Movers are just like anyone else in our society. The wishes can be categorized in many ways, and many wishes fit more than one category. In general, they break down according to wealth or possessions (stuff), relationships, adventures, and homes. Within each category there is a wide range of wishes that may reflect levels of disability. The wishes that seem most related to being a Mover have to do, appropriately, with moving and being more independent. The best way to share the responses to these questions is with direct quotes. Below are selected wishes from the PLQs.

Wealth/Stuff

Brand new bowling ball and bag- I want to get a computer
Catalogs, to see what I'll get for Xmas & birthday
I want a car
Candy bars, cigarettes, box of candy, 6 pack of coke
A dollar and an alarm clock
I wish that I had one million dollars
Bigger refrigerator
A lot of money
To have a lot money
Millionaire
To go to Reno, gamble and make a lot of money
Radios, telephones, watch
Money lots of money
Wish I could have some cocoa
To get $100,000 and spend it on junk food
A new radio
Lots of money

I like to watch TV I like music
I wish that I had my own car
For a joint
Chocolate peanut cups, chocolate candy
A guitar
A car
A bike & a VCR
PJs with no buttons and pull over tops
I want to have a car, can you get me a car?

Relationships and Family
To be with my sister-in-law, go shopping and eat out and go to another school
To visit my family
I want to live with my sister
To take my girlfriend out someplace and talk to her
Get married
I wish I could have my kids back
To be with my parents
To have even more friends

House
A house out in the country
My own place
To be with my girlfriend and get an apartment
To buy a house of our own in Modesto
I wish that I could get my own place
For me and my family to get completely out of debt and to buy a mansion
Get own apartment with kids

Adventure and Experiences
I want to visit my friend in Hawaii
To go to another country (Mexico or something)
Meet Elvis
To meet Connie Francis
I wish for Alice in Wonderland
Wish I could have a vacation to Disneyland where I wouldn't have to worry
A letter from England and to go to England
To meet Aretha Franklin
To fly a hot air balloon

Go to the Bahamas
To get laid in Hawaii
To visit the city of Washington

Self Improvement
Get better job
Better job- more money
To be back on my own
To get out, to be released, to be a free man

Sad
Wants baby girl back
That I could walk
To have his brother & aunt come back (they both passed away)

Descriptive Results 10: Perceived Quality of Life Changes

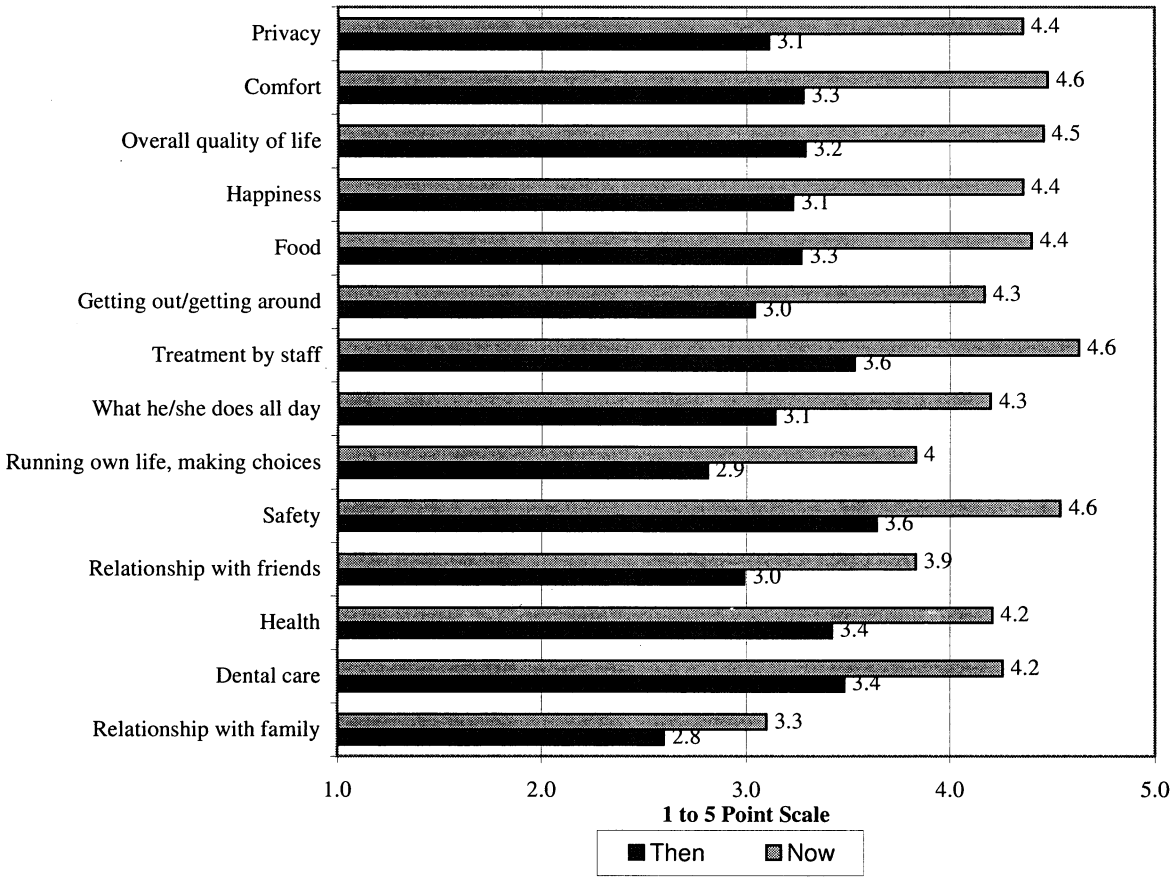
This scale addressed fourteen dimensions of quality of life, including health, friendships, safety, and comfort. The person, or whoever knew the person best, gave numeric ratings of the person's qualities of life at the developmental center (then) and in the community home (now). If the respondent did not have first hand knowledge of conditions at the developmental center, we accepted their perceptions based on what they had read, heard, and been told by the person and others close to the person. It is important to note that this scale measured perceptions only.

Table 68
Perceived Changes in Qualities of Life "Then" to "Now"

Quality of Life Dimension	Now	Then	Change	p
Relationship with family	3.3	2.8	0.5	0.000*
Dental care	4.2	3.4	0.8	0.000*
Health	4.2	3.4	0.8	0.000*
Relationship with friends	3.9	3.0	0.9	0.000*
Safety	4.6	3.6	1.0	0.000*
Treatment by staff	4.7	3.6	1.1	0.000*
Food	4.4	3.3	1.1	0.000*
Running own life, making choices	4.0	2.9	1.1	0.000*
What he/she does all day	4.3	3.1	1.1	0.000*
Getting out/getting around	4.3	3.0	1.2	0.000*
Overall quality of life	4.5	3.2	1.2	0.000*
Comfort	4.6	3.3	1.3	0.000*
Happiness	4.4	3.1	1.3	0.000*
Privacy	4.4	3.1	1.3	0.000*

Table 68 shows that the perceived changes in the fourteen quality of life areas were all positive and significant. The largest perceived changes were in privacy, happiness and comfort. The change in the perception of privacy was an expected result with a move from a large congregate living facility to a small community home, but it is interesting to note that along with the increased perception of privacy, people perceived increases in their levels of comfort and happiness. The next highest changes were in overall quality of life and getting out and getting around. The smallest recorded perceived change was in relationship with family. This is fairly consistent with our findings in other studies, and our findings in California as shown in Report 2. Family relationships may improve slightly with a move to the community, mainly due to proximity and improved access. However, people who had strong family ties while living in the developmental centers tended to maintain those same relationships. Unfortunately, the same pattern held true for those who had little family contact prior to their community move. Finally, it is important to note that there were also perceived positive changes in health and safety, two areas that are of great concern in planning and implementing deinstitutionalization initiatives.

Chart 4
Qualities of Life, Then and Now
(Perceptions of Community Staff)



Descriptive Results 11: Qualities of the Homes

There are three general measures of environmental quality in this study: the Individualized Practices scale, the Environmental Ratings scale and the Visitor's Subjective Impressions ratings. These scales are generally completed after the visit, based on the interview, observation, and a tour of the home. Table 69 shows the average scores on the Individualized Practices scale.

Table 69
Individualized Practices Scale

Weekend/Holiday Schedule	**Average Score**
Waking time	1.8
Bed time	1.9
Dinner time	0.9
TV, Radio and Music time	1.9
Weekday/Workday Schedule	
Waking time	1.0
Bed time	1.4
Dinner time	0.7
TV, Radio and Music time	1.7
General Activities	
Going to work/day program	1.1
Recreational trips	1.1
Shopping for food	1.4
Doctor, dental, psychiatric	1.7
Restaurants	1.0
Worship	1.3
Birthdays	1.8

The level of Individualized Practices was measured on a three-point scale ranging from 0 to 2. For weekend/holiday and weekday/workday schedules, a response of "0" indicated the selected time was fixed-same for all persons in the home. A response of "1" indicated the selected time was fixed-but with exceptions. A response of "2" indicated the selected time was flexible allowing for individual choice. On the weekend/holiday schedule, the average scores leaned toward a flexible environment with the exception of dinnertime. It seems that dinner was served at a fixed time during both weekend and weekday schedules but exceptions were permitted. During the weekday/workday schedule, the average scores were not quite as flexible as the weekend/holiday schedule but again, exceptions were allowed.

Under general activities, we found that on average, people celebrated birthdays and attended health care appointments individually. Going to work, recreational trips and going to

restaurants tended towards being group activities, while shopping for food and attending worship services were more individualized.

Table 70 shows the average scores on the Environmental Ratings scale.

Table 70
Environmental Ratings

Location	Average Score
Describe person's own room	2.6
Describe the outside of the home	2.7
Describe the inside of the home	2.7
Describe the home's grounds	2.7
Describe the area around the home	2.7

The Environmental Ratings scale was measured on a five-point scale which ranged from 1 to 5, from very unpleasant, unpleasant, ordinary, pleasant, to very pleasant. On average, the scores rated between ordinary and pleasant.

On the Visitor's Subjective Impressions section, we asked five questions that were measured on a ten-point scale. The range was from 0 to 10 with a low score indicating a negative response and a high score indicating a positive response. A response of "5" indicated a neutral or in between position. The average ratings of the Visitors are shown below in Table 71.

Table 71
Visitor's Subjective Impressions

Question	Average Score
How happy do you think this person is?	7.3
Quality of staff/consumer interactions	7.9
Quality of consumer/consumer interactions	6.5
Staff attitudes and expectations	7.5
Want relative to live here?	6.6

The first question asked was "How happy do you think this person is?" The average score was a 7.3, indicating that the Visitors felt that the people were "happy". On the second question, "What is the quality of staff-consumer interactions?" the average score was a 7.9, indicating that the Visitors believed the quality of interactions was positive leaning towards "warm and personal".

The third question "What is the quality of consumer-consumer interactions?" was scored at 6.5, indicating "tolerant". The fourth question concerned staff attitudes and expectations about growth, progress, and development. Here, the average score was a 7.5 indicating optimism. The last question was, "If you had a close relative with a major disability, how would you feel about him or her living in this home?" The average score was a 6.6 indicating a more neutral position in reference to this question.

Returnees

In every deinstitutionalization project there are some people who do not have a successful transition to the community. In some cases, usually very few, the problems are resolved by the person returning to live at a developmental center. In this quality tracking project, COA continues to visit the people who have returned to developmental centers so that we can learn more about what caused the return and perhaps identify the kinds of community

resources that may have prevented that return. In this year's study, there were 47 people that we visited at Developmental Centers. The numbers and current places of residence are listed in Table 72.

Table 72
People who Returned to
Developmental Centers from the Community

Number	Developmental Center
9	Agnews
10	Fairview
1	Lanterman
17	Porterville
10	Sonoma
47	

A comparison of the characteristics of the returnees and the people who remained in the community reveals very few differences. Table 73 compares their major characteristics.

Table 73
Characteristics of the Returnees

Characteristic	Community		Back in DC	
Gender	N	%	N	%
Male	1335	60.3%	29	61.7%
Female	835	37.7%	16	34.0%
Ethnicity				
White	1512	68.3%	33	70.2%
African American	216	9.8%	6	12.8%
Hispanic	338	15.3%	6	12.8%
Native American	10	0.5%	0	0.0%
Asian	48	2.2%	0	0.0%
Filipino	12	0.5%	0	0.0%
Other	31	1.4%	0	0.0%
Level of MR Label				
Not labeled MR	42	1.9%	1	2.1%
Mild	413	18.6%	20	42.6%
Moderate	227	10.2%	8	17.0%
Severe	291	13.1%	6	12.8%
Profound	1144	51.6%	10	21.3%

The distributions by gender and ethnicity vary very little. The area that does appear to show differences is the levels of mental retardation. Note that 60% of the returnees are labeled mildly or moderately mentally retarded while only 29% of the Movers are similarly labeled. The trend is reversed for people with severe and profound mental retardation with only 34% of the returnees carrying that label compared to 65% of the Movers.

Do these numbers mean that the community system is designed to better support people with severe and profound disabilities? Further investigation shows that the returnees share additional distinguishing characteristics. Table 74 compares their status to that of the Movers who remained in the community with regard to major secondary disabilities.

Table 74
Secondary Disabilities Reported as Major

Secondary Disabilities	Community		Back in DC	
	N	%	N	%
Ambulation	593	26.8%	8	17.0%
Autism	233	10.5%	6	12.8%
Aggressive Behavior	757	34.2%	30	63.8%
Self Abusive Behavior	510	23.0%	14	29.8%
Brain Injury	156	7.0%	4	8.5%
Cerebral Palsy	387	17.5%	5	10.6%
Communication	1317	59.5%	14	29.8%
Dementia	37	1.7%	1	2.1%
Health Problems	579	26.1%	18	38.3%
Hearing	115	5.2%	3	6.4%
Mental Illness	489	22.1%	24	51.1%
Physical Disabilities	341	15.4%	4	8.5%
Seizures	631	28.5%	12	25.5%
Substance Abuse	50	2.3%	5	10.6%
Swallowing	172	7.8%	4	8.5%
Vision	285	12.9%	6	12.8%
Other(s)	227	10.2%	7	14.9%

The differences are not quite as stark as in the previous table but there is a discernible pattern. The returnees appear to have higher percentages of those kinds of disabilities that usually result in challenging or disruptive behavior. They include autism, aggressive and self-abusive behavior, brain injury, dementia, mental illness, and substance abuse.

Finally, we examined the comparative scores of the returnees and the Movers who stayed in the community on various other dimensions. The results are shown in Table 75

Table 75
Comparative Scores on Various Dimensions

Dimensions	Community Mean	Back in DC Mean
Age	41.74	38.21
Adaptive Behavior	48.42	58.95
Challenging Behavior	77.30	67.86
Progress on Goals	78.69	78.65
Number of Services	8.33	7.66
Day Program Hours	26.87	23.45
Earnings	5.93	21.66
Number of Friends	8.73	10.71
Decision Control Inventory	47.93	41.43
Integrative Events	29.62	15.68
Quality of Life Now	84.35	73.14
Staff Satisfaction	1.76	1.27
Like Working w/Person	9.31	9.00
Sufficient Support	4.55	4.64
Number of medications	4.84	4.79
Antipsychotic Meds	0.41	0.47
General Health	4.03	3.73
Illness Past 30 Days	0.87	2.73
Health Care Rating	4.33	4.68
Dentist Visits Past Year	1.50	1.78
Doctor Visits Past Year	11.84	45.80
Relative Visits to Home	8.30	9.57
Individualized Practice Scale	68.61	66.03

The scores on the dimensions listed in Table 75 reveal more information about the returnees. Their adaptive behaviors are higher than those of the larger Mover group. This can probably be explained by the fact that they are generally "higher functioning" as predicted by their mental retardation levels. They exhibit less control of their challenging behavior, have less opportunities for decision making, less integrative activities, and they report that their qualities of life are lower than in the past. On the positive side the returnees report having more friends and they make more money than the Movers in the community. The amount of

doctor visits is also higher for the returnees. These differences are most likely a function of living in a congregate facility with daily interactions with large numbers of people. We can only assume that their higher earnings are due to large government contracts that are often available to Developmental Center contract workers. The amount of doctor visits is often higher in congregate care facilities since there is often on-site medical staff.

The respondents to our interview reported the following reasons for returns to developmental centers.

Table 76
Reasons for Return to Developmental Centers

Physical decline/ behaviors/ police involvement
Behavior
Due to health problems
Got out of jail
Progressive weight loss
Assaulted mother
Improved medical care
Health became too fragile
To Agnews to stabilize medically
Behavior and med problemss
Longer term placement / court ordered
Med and behavioral problems
Decompensation at previous home
AWOL & inadequate support for seizures
Aggression and destroying property
Behavior & running away
Increase in behavior
Aggressive behavior & destructive behavior
Aggressive behavior/ non-compliance
Aggression / self injury behavior increased
Unable to control in group home
Assaulted care provider
Had behavioral issues
Due to out of control community behavior
AWOL
Less restrictive environment
Behavioral problem
Behaviors too much to deal with in community
Behaviors became too much
Sexual behaviors were too much to deal with
Increased behavioral problems in community setting
Behaviors, put in psychiatric hospital
Family moved to Santa Rosa
Behaviors became too much/severely underweight
Needed better medical care
4 in home, could not accommodate health problems
Aggressive and self abusive behaviors

Reading the above list gives an overall impression of challenging behavior as the primary reason for failure to succeed in a community placement. There are Movers in the community who exhibit challenging behaviors and in many cases they are learning to control those behaviors. However, our overall findings regarding some loss of ability to control challenging behavior become even more serious if a major predictor for possible return to a developmental center is challenging behavior. A fuller analysis appears to be necessary. It would be interesting to pair these returnees with Movers who exhibit similar characteristics and to identify the differences in the supports they received in the community.

Family Survey

Participants

At the time of this writing, we have received survey responses from 291 of the 711 families for whom we received valid addresses (40.9%). Mothers completed the survey on their own almost half of the time (49.6%) and jointly with fathers on an additional 10.7% of the responses. The respondents were distributed as shown in Table 77.

Table 77
Relationship of Family Survey Respondents to Movers

Relation to Focus Person	Number	Percent
Mother	139	49.6
Father	40	14.3
Mother and Father	30	10.7
Sister or Brother	45	16.1
Other	26	9.3
Total	280	100.0

* Eleven families did not answer this question.

Legal guardianship was claimed by 61 respondents (23.6%), legal conservatorship by 106 (41.1%), and no legal status by 91 (35.3%). This item was left blank by 33 respondents who were unsure. The family respondents' ages ranged from 30 to 90, with a mean age of 63. The families reported that their relatives had lived in DCs between 0 and 65 years, with an average of 22 years.

Of the 243 family members who responded to the question of how often their relative had changed addresses since moving to the community, the average number of times reported was 1. The average number of times family members reported being able to visit their relative in the past year was 22 times, or roughly twice a month.

Perceptions of Quality

The primary purpose of the family survey was to determine if the families believed the Movers were better off in the community than they had been in the Developmental Centers. We asked the families to describe their relatives' quality of life "Then" while living in a Developmental Center, and "Now" while living in the community. The results are shown in Table 78.

Table 78
Families' Perceptions of Qualities of Relative's Life

Quality of Life Dimension	Now in Community	Then at DC	Change	p
Privacy	4.2	2.4	1.8	0.000*
Getting out and getting around	4.4	2.7	1.6	0.000*
Happiness	4.3	2.8	1.5	0.000*
Comfort	4.4	3.0	1.4	0.000*
Making choices	3.9	2.5	1.4	0.000*
Overall Quality of Life	4.3	3.0	1.4	0.000*
What he or she does all day	4.2	2.9	1.3	0.000*
Food	4.3	3.2	1.1	0.000*
Treatment by staff/attendants	4.5	3.5	1.0	0.000*
Safety	4.3	3.3	1.0	0.000*
Relationship with friends	3.9	2.9	1.0	0.000*
Dental	4.1	3.1	1.0	0.000*
Health	4.1	3.3	0.9	0.000*
Relationship with family	4.4	3.6	0.8	0.000*

* Indicates significance at the .05 level.

Table 78 provides the p values for the statistical test, which was the t-test. The p values represent the probability that changes of these magnitudes could have happened by chance. The value "0.000" means the probability was less than 1 in 1,000. The column labeled "Change" shows the average amount of change on the 5 point scale of quality. From this column we can see that the largest perceived change in quality was a gain of 1.8 points in

"Privacy". The next largest was in "Getting Out and Getting Around" with a gain of 1.6 points. These were followed by "Happiness" with a gain of 1.5 points, and "Comfort" with a gain of 1.4 points.

Questions 8 and 9 in the Survey were about family reactions to the idea and the reality of community placement. Question 8 was: "When you first heard about the idea for your relative to move to a new home in the community, were you 'for' it or 'against' it?" Question 9 asked: "Now that it has happened, how do you feel about your relative living in a new home in the community?" Responses could range from Strongly Against to Strongly For, on a 5-point scale. The results of these two questions are presented in Table 79.

Table 79
Families' Opinion About Community Placement
When First Heard Idea, Versus Now

Response Category	At First	Now
Strongly against	16.1%	1.1%
Against	15.4%	2.6%
In between	17.6%	5.5%
In Favor	22.7%	31.0%
Strongly in favor	28.2%	59.9%
Total	100.0%	100.0%

Table 79 shows that opposition to community placement decreased, and support increased. Before the move, 16.1% of the families strongly opposed the idea, and after it happened, the figure dropped to 1.1%. The shift from opposition to support is clear in these data. Only 3.7% now say they are against, or strongly against, community living. Before the move, the percentage opposed was 31.5% (16.1%, "Strongly Against" and 15.4% "Against"). Similarly, the percentage of families who support, or strongly support, community living is up from 50.9% to 90.9%. The trend is obviously toward increased family support for the idea of

community living for their relatives. The trend appears to get stronger the longer their family members are out of the Developmental Center.

To get the families' opinions about the Movers' happiness in a different way, we asked "How happy do you think your relative is with his/her living situation?" Table 80 shows how many families answered with each rating.

Table 80
How Happy Do You Think Your Relative Is With His/Her Living Situation?

Response Category	Number	Percent
Neither happy nor unhappy	31	11.0
Happy	102	36.3
Very happy	122	43.4
Don't know	26	9.3
Total	281	100.0

* Ten families left the item blank.

Not one family responded to this question with either "Very unhappy" or "Unhappy". Almost 80% said their relative was either "Happy" (36.3%) or "Very Happy" (43.4%). There were 10% of the respondents who did not know how to rate their relative's happiness or unhappiness. In a very direct question, we asked "If you could, would you have your relative leave his/her new community home and move back to a Developmental Center?" The results are shown in Table 81.

Table 81
Would You Like Your Relative to Move Back to a DC?

Response Category	Number	Percent
Yes, definitely	7	2.7
Yes, probably	3	1.1
In between	11	4.2
No, probably not	70	26.7
No, definitely not	171	65.3
Total	262	100.0

* Nineteen families left the item blank.

These responses clearly show that the preference of the families is to continue with community living. Ninety-two percent of the respondents said either "No, probably not" (26.7%) or "No, definitely not" (65.3%) in response to this question. There were only 10 families (3.8%) who said they probably or definitely would like to see their relatives move back to a DC. The situations of these 10 individuals, and the opinions of their families, may require further investigation by DDS or the responsible Regional Centers.

Satisfaction with Supports

Satisfaction with the Case Manager or Service Coordinator assigned to their relative is a major factor in a family's overall satisfaction with supports. Table 82 provides a "report card" on this issue.

Table 82
How Satisfied Are You with Your Relative's Case Manager or Service Coordinator?

Response Category	Number	Percent
Very dissatisfied	16	6.5
Dissatisfied	9	3.6
In between	27	10.9
Satisfied	104	41.9
Very satisfied	92	37.1
Total	248	100.0

* Forty-three families did not answer this question.

When asked the question, "How satisfied are you with your relative's case manager or service coordinator, 79% of the families reported being either "Satisfied" (41.9%) or "Very Satisfied" (37.1%). A little over 10% of the families who responded to this question reported being either "Dissatisfied" (3.6%) or "Very Dissatisfied" (6.5%).

We asked family members to report how happy they felt their relative was with their job or other day program, Table 83 below shows the distribution of responses.

Table 83
How Happy Do You Think Your Relative is with Their Job or Other Day Program?

Response Category	Number	Percent
Very unhappy	2	0.7
Unhappy	3	1.1
In between	48	17.5
Happy	104	38.0
Very happy	78	28.5
Don't know	39	14.2
Total	274	100.0

*Seventeen families did not answer this question.

The responses were extremely positive with 66.5% of the families reporting that they felt their relative was either "Happy" (38.0%) or "Very happy" (28.5%). Only 1.8% of families responded that they felt their relative was "Unhappy" or "Very unhappy". An additional 17.5% said they felt their relative was "in between", neither happy nor unhappy with their job or other day program.

Person-centered planning has become a key element in providing services and supports for people with developmental disabilities across the nation. We asked the families to tell us whether or not they felt that their relative's individual plan was "person-centered".

Table 84
Is Your Relative's Plan a Result of a "Person-Centered" Process?

Response Category	Number	Percent
Yes	156	62.4
No	20	8.0
Don't know	74	29.6
Total	250	100.0

* Forty-one families did not answer this question.

The majority of family members (62.4%) reported that "Yes", their relative's individual plan was the result of a person-centered planning process. Eight percent responded "No" to this question, while almost 30% responded to this question with "Don't know". Perhaps families in California, as is true of families in other states we have studied, need more information about the shift in service planning from a program-centered model to the newer person-centered approach.

Verbatim Comments

At the end of the family survey, we asked three open-ended questions:

- Please list one or more thing(s) that you like about your relative's current situation
- Please list one or more thing(s) that you are most concerned about with regard to your relative's current situation
- If you had one wish for your relative, what would it be?

These responses add substantial insight to the survey data. Some of the things that families liked about their relative's current situations were how home-like their relative's homes were, that the staff at the homes were caring and affectionate, that their relatives seemed very happy, that their relatives were closer to home, and that their relatives were in homes with less people then the situations they were in before.

Things that caused concern for family members about their relative's current situation included such things as the perception that staff turnover was a problem, that the direct care staff in the community made less money than the developmental center staff for more work, worries about the long-term stability of the homes, concerns about their relative's safety and health needs, and the lack of community activities and employment.

In terms of what families wished for their relatives, most of the wishes reflected a desire for their relatives to be safe and happy, for adequate community care to be continued, for the current placement and supports for their relatives to remain stable, and for their relatives to achieve their highest potential. Many families expressed the desire that their loved one would overcome their disability, be "normal", or be able to communicate verbally.

The verbatim responses of family members to these questions are presented in **Appendix D** and are grouped by family, in other words, in a glance across the three columns, one can see each family's responses to the three questions.

APPENDIX A

PRIOR REPORTS OF THE CENTER FOR OUTCOME ANALYSIS ON THE WELL BEING OF PEOPLE WHO MOVED FROM DEVELOPMENTAL CENTERS TO COMMUNITY HOMES IN CALIFORNIA

APPENDIX B

THE YEAR 2001 PERSONAL LIFE QUALITY PROTOCOL

APPENDIX C

THE YEAR 2001 FAMILY SURVEY

APPENDIX D

RESPONSES TO OPEN-ENDED QUESTIONS IN THE YEAR 2001 FAMILY SURVEY

COA

Reports To Federal, State, And Local Agencies

Revised: December 18, 2006 .

Dr. Conroy has directly participated in the preparation of more than 270 formal deliverable research reports to government agencies, service agencies, and private foundations since 1970. Each of the reports below was formally reviewed and accepted by the recipient organization.

R272. Conroy, J., Brown, M., & Mitman, T. (2006, February). *Who Are the Young People Involved in the Youth Advocate Program in Pennsylvania , and How Are They Doing?* Brief Report #1 of the Youth Advocate Programs Outcomes Project. Havertown , PA : Center for Outcome Analysis.

R239. Conroy, J., Fullerton, A., Brown, M., & Garrow, J. (2002, December). *Outcomes of the Robert Wood Johnson Foundation's National Initiative on Self-Determination for Persons with Developmental Disabilities: Final Report on 3 Years of Research and Analysis*. Narberth, PA: Center for Outcome Analysis.

R238. Conroy, J., Brown, M., Fullerton, A., & Garrow, J. (2002, November). *Assessment and Analysis of Self-Determination Efforts for People with Developmental Disabilities in New Jersey.* Submitted to New Jersey Council on Developmental Disabilities. Narberth, PA: Center for Outcome Analysis.

R236. Brown, M., Conroy J., Fullerton, A. (2002, July). *How Are They Doing? Year 2002 Evaluation of the Delaware County Self-Determination Initiative.* Submitted to: Delaware County Office of Mental Retardation. Narberth, PA: Center for Outcome Analysis.

R235. Conroy, J., Fullerton, A., & Brown, M. (2002, June). *Final Outcomes of the 3 Year California Quality Tracking Project.* Report #6 of the Quality Tracking Project for People with Developmental Disabilities Moving from Developmental Centers into the Community. Narberth, PA: Center for Outcome Analysis.

R234. Garrow, J., Vasile, F., & Conroy, J. (2002, April). *Progress Report: Quality of Life Evaluation of People with Developmental Disabilities Moving from Developmental Centers into the Community.* Semi-Annual Report (Year 3) Submitted to Community Services Division, Department of Developmental Services, California. Narberth, PA: Center for Outcome Analysis.

R233. Conroy, J., Brown, M., Fullerton, A., Beamer, S., Garrow, J., & Boisot, T. (2002, March). *Independent Evaluation of California's Self-Determination Pilot Projects: Final Report.* Submitted to: Eastern Los Angeles Regional Center and California Department of Developmental Services. Narberth, PA: Center for Outcome Analysis.

R232. Conroy, J., Beamer, S., Brown, M., Fullerton, A., & Garrow, J. (2001, September). *Independent Evaluation of California's Self-Determination Pilot Projects: Second Year Interim Findings.* Submitted to Eastern Los Angeles Regional Center and the California Department of Developmental Services. Narberth, PA: Center for Outcome Analysis.

R231. Center for Outcome Analysis (2001, July). *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 Moving from Developmental Centers into the Community (The "Quality Tracking Project").* Final Report (Year 2) submitted to The Honorable Gray Davis, Governor, State of California, California Legislature. Narberth, PA: Center for Outcome Analysis.

R230. Center for Outcome Analysis (2001, June). *Arizona's First Self-Determination Participants: Descriptive Data from the Personal Life Quality Protocol.* Narberth, PA: Center for Outcome Analysis.

R229. Center for Outcome Analysis (2001, January). *Progress Report: Quality of Life Evaluation for People with Developmental Disabilities Moving from Developmental Centers into the Community.* Semi-Annual Report (Year 2) submitted to Regional Centers Branch, Community Services Division, California Department of Developmental Services. Rosemont, PA: Center for Outcome Analysis.

R228. Conroy, J., Seiders, J.X., Brown, M., Fullerton, A. (2000, December). *Independent Evaluation of Tri-Alliance/Arc of North Carolina Self-Determination Project.* Rosemont, PA: Center for Outcome Analysis.

R226. Conroy, J.W., Beamer, S., Seiders, J.X., Brown, M, & Fullerton, A. (2000, November). *Independent Evaluation of California's Self-Determination Pilot Projects: First Year Findings.* Report submitted to the Department of Developmental Services and the Legislature of California. Rosemont, PA: Center for Outcome Analysis.

R225. Fullerton, A., & Conroy, J. (2000, July). *Integrated Employment for People with Developmental Disabilities Who Moved from Institutions to Community Placements in the Nineties: A Comparison of Two States.* Brief Report Number 19 of the Oklahoma Outcomes Series. Submitted to the Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R224. Conroy, J.W., Seiders, J.X., & Brown, M. (2000, June). *How Are They Doing? Year 2000 Report of the Quality of Life Evaluation Of People with Developmental Disabilities Moving from Developmental Centers into the Community (The "Quality Tracking Project").* Final Report (Year 1). Submitted to California Department of Developmental Services. Rosemont, PA: Center for Outcome Analysis.

R223. Conroy, J., & Seiders, J. (2000, May). *Outcomes of Community Placement at One Year For the People who Moved From New Castle and Northern Indiana State Developmental Centers.* Report Number 6 of the Indiana Community Placement Quality Tracking Project. Submitted to the Division of Disability, Aging, and Rehabilitative Services, Indiana Family and Social Services Administration. Rosemont, PA: Center for Outcome Analysis.

R222. Center for Outcome Analysis (2000, March). *Progress Report: Quality of Life Evaluation for People with Developmental Disabilities Moving from Developmental Centers into the Community.* Semi-Annual Report (Year 1) submitted to Regional Centers Branch, Community Services Division, California Department of Developmental Services. Rosemont, PA: Center for Outcome Analysis.

R220. Conroy, J., & Spreat, S. (2000, April). *Provision of Nursing Home Services to Oklahoma Residents who have Mental Retardation: 1992 through 1996.* Brief Report Number 15 of the Oklahoma Outcomes Series. Submitted to the Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R219. Conroy, J., & Spreat, S. (2000, March). *Comparison of Health Care Services in a Congregate Care Setting and in Supported Living Arrangements in Oklahoma.* Brief Report Number 14 of the Oklahoma Outcomes Series. Submitted to the Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R218. Conroy, J., Brown, M., Seiders, J., & Sweitzer, J. (2000, February). *Impact Assessment of the "Self-Determination For Persons with Developmental Disabilities" Initiative, Year 2 Annual Report.* Submitted to the Robert Wood Johnson Foundation under contract number 31891. Rosemont, PA: Center for Outcome Analysis.

R217. Spreat, S., & Conroy, J. (2000, February). *Community Placement for Persons with Significant Cognitive Challenges: An Outcome Analysis.* Brief Report Number 13 of the Oklahoma Outcomes Series. Submitted to the Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R216. Conroy, J. (2000, January). *Positive Outcomes of Self-Determination in Michigan After One Year.* PowerPoint presentation and document provided to the Michigan Department of Community Health. Rosemont, PA: Center for Outcome Analysis.

R215. Seiders, J., & Conroy, J. (2000, January). *Outcomes of Community Placement at Six Months For the People who Moved From ResCare Intermediate Care Facilities.* Report Number 5 of the Indiana Community Placement Quality Tracking Project. Submitted to the Division of Disability, Aging, and Rehabilitative Services, Indiana Family and Social Services Administration. Rosemont, PA: Center for Outcome Analysis.

R214. Conroy, J., Yuskauskas, A., Seiders, J., & Brown, M. (1999, September). *Community Based Supports in Rhode Island: 1999 Findings of the Quality Tracking Project.* Submitted to: Rhode Island Department of Mental Health, Retardation, and Hospitals. Rosemont, PA: Center for Outcome Analysis.

R213. Spreat, S., & Conroy, J. (1999, September). *Consumer Satisfaction in the Oklahoma Mental Retardation Service System.* Report Number 12 in the Oklahoma Outcomes Series. Submitted to: Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R212. Spreat, S., & Conroy, J. (1999, September). *Use of Psychotropic Medications by People Who Transfer from Institutions to Community Programs.* Report Number 11 in the Oklahoma Outcomes Series. Submitted to: Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R211. Spreat, S., & Conroy, J. (1999, September). *The Impact Of Deinstitutionalization On Family Contacts.* Report Number 10 in the Oklahoma Outcomes Series. Submitted to: Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R210. Conroy, J. (1999, September, Revised October). *Seven Years Later: A Satisfaction Survey of the Families of the Former Residents of Hissom Memorial Center.* Report Number 9 in the Oklahoma Outcomes Series. Submitted to: Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R209. Conroy, J., & Seiders, J. (1999 July). *Outcomes of Community Placement at Six Months For the People who Moved From New Castle and Northern Indiana State Developmental Centers.* Report Number 4 of the Indiana Community Placement Quality Tracking Project. Submitted to the Indiana Family and Social Services Administration, Division of Disability, Aging, and Rehabilitative Services. Rosemont, PA: Center for Outcome Analysis.

R208. Spreat, S., Conroy, J., & Jones, J. (1999, June). *Costs of Support for the Former Residents of Hissom Memorial Center.* Report Number 8 in the Oklahoma Outcomes Series. Submitted to: Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R207. Jones, J., & Conroy, J. (1999, March). *The Hissom Outcomes Study: An Update on the Well Being of Balance Class Members.* Report Number 7 in the Oklahoma Outcomes Series. Submitted to: Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R206. Conroy, J. (1999, February). *The Hissom Outcomes Study: 1998 Update.* Report Number 6 in the Oklahoma Outcomes Series. Submitted to: Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R205. Conroy, J., & Seiders, J. (1999, February). *The Indiana Quality Tracking Project on DC Closures: Preliminary Findings.* Report Number 2. Submitted to the Indiana Family and Social Services Administration, Division of Disability, Aging, and Rehabilitative Services. Rosemont, PA: Center for Outcome Analysis.

R204. Wilson, L., & Conroy, J. (1998, December). *Interviews with Community Leaders on the Closure of Winfield State Hospital and Training Center.* Report Number 7 of the Hospital Closure Project Required by Substitute House Bill 3047. Submitted to: The Kansas Council on Developmental Disabilities and The Legislative Coordinating Council. Rosemont, PA: Center for Outcome Analysis.

R203. Conroy, J. (1998, December). *Are People Better Off? Outcomes of the Closure of Winfield State Hospital.* Final Report (Number 6) of the Hospital Closure Project Required by Substitute House Bill 3047. Submitted to: The Kansas Council on Developmental Disabilities and The Legislative Coordinating Council. Rosemont, PA: Center for Outcome Analysis.

R202. Conroy, J., & Spreat, S. (1998, November). *People Who Moved From Oklahoma's Public Institutions to Community Homes in the Nineties: Outcomes and Costs.* Report Number 5 in the Oklahoma Outcomes Series. Submitted to: Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R201. Conroy, J. (1998, October). *Patterns of Coffelt Placement Practice and Indicators of System-Wide Quality. Report Number 20 of the Coffelt Quality Tracking Project.* Submitted to: the California Department of Developmental Services and Protection & Advocacy Inc. of California. Rosemont, PA: Center for Outcome Analysis.

R200. Crowley, R., Bustow, S., Conroy, J., & Yuskauskas, A. (1998, September). *Independent Review of Developmental Services of Sullivan County, New Hampshire.* Submitted to: The Board of Directors of Developmental Services of Sullivan County, Region II Area Agency. Rosemont, PA: Center for Outcome Analysis.

R198. Conroy, J., & Seiders, J. (1998, July). *The People Moving from Newcastle State Developmental Center: Baseline Data on Characteristics and Quality of Life.* Report Number 1. Submitted to the Indiana Family and Social Services Administration, Bureau of Aging and In-Home Services.

R198. Conroy, J., & Seiders, J. (1998, June, revised October). *The Coffelt Quality Tracking Project: The Results of Five Years of Movement From* Institution *to Community. Final Report (Number 19) Of the Coffelt Quality Tracking Project California Department of Developmental Services.* Submitted to: the California Department of Developmental Services and Protection & Advocacy Inc. of California. Rosemont, PA: Center for Outcome Analysis.

R197. Dudley, J.R., Calhoun, M.L., Jones, J., & Conroy, J. (1998, June*). The Progress Made by Thomas S. Class Members, 1993 to 1998.* Monograph 18 of the Thomas S. Longitudinal Research Project. Charlotte, NC: University of North Carolina at Charlotte.

R196. Conroy, J., Seiders, J. (1998, June,). *Selected Findings of the Coffelt Quality Tracking Project. Report (Number 18) Of the Coffelt Quality Tracking Project.* Submitted to: the California Department of Developmental Services and Protection & Advocacy Inc. of California. Rosemont, PA: Center for Outcome Analysis.

R195. Conroy, J., & Seiders, J. (1998, May). *Recent Results of the Six-Month Visits.* Report Number 3 of the Indiana Quality-Tracking Project. Submitted in PowerPoint format to the Indiana Family and Social Services Administration, Division of Disability, Aging, and Rehabilitative Services. Rosemont: Center for Outcome Analysis.

R194. Spreat, S., Conroy, J., & Rice, M. (1998, March). *Improve quality in nursing homes, or institute community placement? Implementation of OBRA for individuals with mental retardation.* Report Number 4 of the Oklahoma Outcomes Series. Submitted to: Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R193. Spreat, S., & Conroy, J. (1998, February). *Use of psychotropic medications for persons with mental retardation who live in Oklahoma nursing homes.* Report Number 3 of the Oklahoma Outcomes Series. Submitted to: Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

R192. Conroy, J., Seiders, J., & Yuskauskas, A. (1998, January, revised April). *Patterns of Community Placement IV: The Fourth Annual Report on the Outcomes of Implementing the Coffelt Settlement Agreement.* Report Number 17 of the 5-Year Coffelt Quality Tracking Project. Submitted to: the California Department of Developmental Services and Protection & Advocacy Inc. of California. Rosemont, PA: Center for Outcome Analysis.

R191. Wilson, L, Conroy, J. & Wear, P. (1998, January). *Executive Summary of Four Reports of Center for Outcome Analysis' Reports on The Closing of Winfield State Hospital and Training Center, March 1997 through October 1997. Report Number 5 of the Evaluation of the Closure of Winfield State Hospital and Training Center.* Submitted to the Kansas Council on Developmental Disabilities and the Kansas Legislative Transition Oversight Committee. Rosemont, PA: Center for Outcome Analysis.

R190. Conroy, J., Nerney, T, & Bowen, J. (1998, January). *Connecticut's Special Education Labeling and Placement Practices: Patterns of Out of District Placement.* Submitted to: The Connecticut Developmental Disabilities Council. Rosemont, PA: Center for Outcome Analysis.

R189. Wilson, L., & Conroy, J. (1998, January). *The Premovement Survey of Relatives/Guardians of Winfield State Hospital & Training Center Residents. Report Number 4 of the Evaluation of the Closure of Winfield State Hospital and Training Center.* Submitted to the Kansas Council on Developmental Disabilities and the Kansas Legislative Transition Oversight Committee. Rosemont, PA: Center for Outcome Analysis.

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California foes of community living fight de-institutionalization

FIGHTING TO KEEP 'EM IN

By Josie Byzek

The headlines are startling:

Selah, Washington: "Unattended Woman Dies of Brain Injury"

Chicago, Illinois: "Retarded Woman Alone In Apartment Dies of Seizures"

Omaha, Nebraska: "Retarded Man Dies After Moving to Community Care"

Fourteen pages of news clips documenting accidents and mishaps at group homes around the nation.

These form the centerpiece of a report put out by the California Association of State Hospital Parent Councils for the Retarded (CASH/PCR). This report, and a study by University of California statistician David Strauss, are the big cannons in the war to stop the exodus of Californians labeled with severe mental retardation from institutions to the community.

Besides CASH/PCR, and the usual unions representing institution workers such as the California Association of Psychiatric Technicians, the institutions have the backing of the California Medical Association, the California ARC, the San Francisco Chronicle -- which ran an anti-community series of articles last winter -- and Senator Diane Feinstein, usually noted as a liberal supporter of civil rights.

They want a two-year moratorium on all moves out of the institutions, called Developmental Centers.

Feinstein "was against the transfer of developmentally disabled out of care. They were being kicked out into the streets. She expressed her outrage," said a staffer for Senator Feinstein in her Washington, DC office. Even though no one has been able to cite a single example of someone actually being 'kicked out" of California's Developmental Centers "onto the streets," Sen. Feinstein's reaction is typical.

California has had the fastest deinstitutionalization of any state so far -- 2,300 people since 1994. This exodus was the result of what is called the "Coffelt Lawsuit," brought by parents of people living in the Developmental Centers, who charged that over 2,000 people in these centers wanted community services instead. When the parents won the suit, the exodus began.

The Strauss report was published in July 1996. Dr. David Strauss, a statistician for the University of California, Riverside, found that people with developmental disabilities had a 72 percent higher chance of dying in the community than in an institution. The report was funded primarily by the federal government; some money came from what Strauss calls "allied groups" -- the California Association

Exhibit 4

of Psychiatric Technicians is named as the primary union underwriter.

Fear of people with mental retardation living on the streets, coupled with the Strauss report, has stirred up worries of a repeat botched deinstitutionalization process like the one California experienced under Gov. Ronald Reagan when thousands of psychiatric survivors were freed from institutions without adequate funding or community supports and many became homeless.

Repercussions from what's currently happening in California have been felt across the nation from Tennessee to Pennsylvania. The Strauss report is being touted by such pro-institution groups as Voice of the Retarded (VOR), a parent organization, as definitive proof that people with mental retardation are much better locked up than loose in the community.

Had there been no Strauss report, most likely there'd be no move for a California moratorium on people with disabilities moving out of institutions into the community. Senator Feinstein would not so firmly believe that lives are at stake, or that people with mental retardation are being forced out onto the streets. The San Francisco Chronicle's series on community versus institution wouldn't have had the same bite -- it probably wouldn't have even been written.

But the report, coupled with the anecdotal evidence of community placement gone wrong, has brought the exodus from California institutions to a virtual halt, even without a formal moratorium on moves into the community.

"There is no credible evidence of a mortality crisis among those who are placed in community care settings," writes Dr. Jane Mercer in her report, "Statistics Should Not Undermine Freedoms for Development-ally Disabled Californians." Mercer, a sociologist, is also from the University of California at Riverside. Her report, compiled in the wake of the Strauss report, was released last July, a year after the Strauss report. "The statistics on death rates are incomplete and certainly misunderstood," it says. Mercer's report received no press at all, in stark contrast to the Strauss report.

Mercer's report outlines the history of California's most recent move from institutions: that in the 1980s, a group of parents grew tired of waiting for the state to create placements for their children with developmental disabilities in the community and sued the state of California. This resulted in the 1993 Coffelt settlement, in which the California Department of Developmental Services agreed to move at least 2,000 people with developmental disabilities from state developmental centers into the community in five years. California lived up to its agreement -- which sparked the backlash documented and supported by the Chronicle.

Mercer's report insists there's "encouraging evidence that the community placement has enriched the lives of many developmentally disabled persons." As part of the Coffelt agreement, Dr. James W. Conroy, Ph.D., an independent evaluator, has been conducting a study of the effects of community placement on those moved into the community. The Conroy study did not receive any mention in the Chronicle series either.

Conroy matched 118 "movers" with 118 "stayers" of the same age and sex and with similar levels of disability and found, not surprisingly, that the movers indeed were now able to get out more and socialize; that they had friends, went to church, attended school, went to the mall and other places people socialize.

"The great victory is that 2,300 people have gotten a shot at life outside an institution," says Conroy. "Those who can speak to us are very happy about it. Those who can't speak -- we've measured every quality of their lives: behavioral progress, physical aspects of homes, integration, employment, and so on. I've talked to thousands of people. Everybody says they're doing great, they'd never go back. So what is this commotion about? It's bizarre!"

Conroy thinks the Strauss report will be debunked. "The essence of science is replication," he says. "No one has replicated his findings, certainly not I."

The Strauss report, he said, found a 72 percent higher mortality rate in folks who moved out of institutions -- whether they lived in group homes or with mom and dad made no difference This finding seems very odd to people like Conroy. In his own research, Conroy said, "I get the total opposite." That's why, he said, "you can't just depend on one researcher. Other researchers have to find it out in other states."

He compares the Coffelt settlement with the 1978 Pennhurst case in Pennsylvania, which moved over 1100 people into the community, and which he evaluated. "I tracked all those [Pennhurst] people every year right up to today. There's no question of 'in the community' or 'institution,' because everyone went to the community. Based on past years, 15 per thousand people per year die in institutions. By 1990 182 people would have died. Instead, all those people moved into the community and only 132 people actually died."

Originally the project Strauss worked on was run by Dr. Richard Eyeman. He retired, and the project was continued by Strauss, who was advised to do a mortality investigation. "He did so," says Conroy, "but with very complicated mathematical models. After his adjustments, he claimed that the rate of death is higher in the community than in institutions."

Another researcher with the same data would get very different results, Conroy thinks. "Cold fusion was published," he points out, "and found to not be true. It was a great stir, a huge controversy, widely published, but never replicated."

Yet the Strauss report remains a powerful gun. The finger on the trigger of that gun is the Voice of the Retarded, a small but potent pro-institution group that has strong ties with unions representing institution workers. California CASH/PCR is allied with VOR.

"The attempt at reconciliation and finding common ground has failed because of bad faith with VOR and CASH/PCR," says Conroy. "They come to the table, negotiate compromises, then betray them behind your back. They've done this in Pennsylvania, Montana, Tennessee, Florida and Connecticut. They have us running scared right now, but the facts are so far in our favor, so clear. Thirty years of research, there has never been a contradictory finding."

Conroy spoke with Ed Bradley from 60 Minutes a few years ago, during filming of a story on state institutions. He says Bradley told him that as of 1995, VOR had a $1.3 million war chest. Yet the group appears to have only have 600 members nationwide. Some VOR leaders, such as Polly Spare in Pennsylvania, are open about receiving funds from unions that support workers in institutions. Some disability rights advocates have wondered whether groups such as VOR and CASH/PCR are merely fronts for the unions and not representative of parents at all.

Even with foes like VOR, pro-community family members are still confident that the battle against California's institutions will be won. "What we have done is almost completely stop new admissions to the Developmental Centers. That's a major step forward," says Bob Little, whose daughter with mental retardation lives in the community. Bob is also a member of People First, a self-advocacy group. "Parents of young children with disabilities no longer think about putting their children in Developmental Centers." The only pro-institution group, he says, are the older parents "who are afraid of what they did fifty years ago. They regret it, and they feel guilty about it. Now they have to face the fact that they made a bad decision about it."

In order for people with disabilities who move out of institutions to be full members of the community, the community must change, says Little. "How do you change the attitudes of communities so people are more welcome when they come? Some of us think we have to go out and sell this idea to the city council, the mayor; let them know there are some changes that are occurring. Things like sheltered workshops are no longer appropriate, and so on. That there needs to be access and transportation. A whole infrastructure that needs to be in place. That there's a need for ADAPT, People First and Senior groups, and they need to work together."

Maybe someone needs to tell that to the California Medical Association. They're one of the groups who passed a resolution for a moratorium.

"There's been a lot of reflection in the CMA over the resolution they passed," says Mark Polit, President of the Alameda County Developmental Disabilities Planning and Advisory Council. "They probably realized it was passed with incomplete information, only hearing one side of the story, as well as putting them in the uncomfortable position of suggesting we keep people in Developmental Centers because of lack of adequate medical care in the community. If that is true, they need to not be the cause of inadequate care."

And the resolution passed by the ARC? "A lot of people in the ARC don't even realize they have a moratorium resolution," says Polit. "It was drafted by CASH/PCR members on ARC's board and then presented to the group." He says ARC has "since issued a clarification" but that they're still "divided" over the matter.

The division exists in part because those fourteen pages of headlines about community-living-gone-bad are true stories. Of course, there are also thousands of true torture tales about life inside institutions, but it is clear that institutions do not hold a monopoly on horror stories.

"The most important things that lead to abuse are when people are isolated from their communities or other people, and when people are put in a position of lack of power; when their caretakers have lots of power over their lives, and when they're taught to obey," says Polit. "Those are the key factors that lead to abuse. Those factors exist disproportionately in institutions." But, he goes on, "There are also some group homes that are isolated, where the caretakers have a disproportionate amount of power."

Abuse can happen both in institutions and in the community. But there's one clear difference, says Polit: It is possible in the community to be free. "Moving people into our communities is about freedom. It's about civil rights. It's about access to enjoyable and stimulating things. None of us would choose to live in an institution."

The argument for or against community has been framed as being between institutions and group homes. But some advocates don't see it that way. Take institutions completely out of the picture, they say; group homes will be the next dinosaur to disappear.

"Most people don't want to live in a group home either," says Wendy Wolfe, an advisor to Bay Area People First. "Like nobody's ever heard of owning your own home, or shared housing? If you think about the possibilities, you can work with your community and create them."

Many advocates are pushing beyond the group-home model to supported living, which is very similar to the personal assistance services used by people with physical disabilities.

"The person could have an arrangement where they could live on their own," says Wolfe. "They could choose the supports they want. Maybe a neighbor, a best friend, or someone from a service provider. The Supported Living agency is more like a service broker. The consumer would get the in-home services they need. It's happening here in California. A lot of people who are coming out of the institutions are going into supported living. It's more creative."

"We're just getting a toehold on supported living," says Ellen Goldblatt, Senior Attorney for Protection and Advocacy, Inc. of California. "The idea is that people with disabilities control their homes and the service providers come and go, and the level of service goes up and down as people need it. Supported living separates housing from services; you rent your apartment, buy your home, and then get a provider. If the provider changes, you don't have to move."

"We need to get more into supported living," says Bob Little. "We must have the dollars from the institutions flow into the community, with the person. In Tennessee, people have control of their own dollars."

"Look at what happened in Oklahoma," says Conroy. "The Hisom Memorial Center closed, and no one was placed in a group home. Everyone went to supported living." They picked where they lived and picked their staff, he said. "If they couldn't, then a strong attempt was made to get unpaid circles of support including family members, neighbors, churchgoers, and so on to help make those choices. In Oklahoma, absolutely the strongest, most positive outcomes were from supported living."

If groups like CASH/PCR, VOR and unions representing the workers inside institutions get their way, thousands of Californians will never get the chance to live on the other side of the wall. The outcome of the battle in California will most likely foreshadow similar battles in other states.

Unfortunately, the message that has been sent across the nation from California is that deinstitutionalization wasn't working. But the message is wrong. It is working, and California disability rights advocates are already eyeing the next battle: getting more consumer-controlled support services, creating a system where the money follows the person, so that person can live the way she wants to live, like every other American.

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TALK TO US!

Write to The Ragged Edge

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Thomas M. Cooley Law Review
Hilary Term, 2000

Disability Law Symposium Legal and Treatment Issues

*53 "I AIN'T GONNA WORK ON MAGGIE'S FARM NO MORE:" INSTITUTIONAL SEGREGATION, COMMUNITY TREATMENT, THE ADA, [FN1] AND THE PROMISE OF OLMSTEAD V. L.C. [FN2]

Michael L. Perlin [FN3]

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I. Introduction

If you are of a certain age, there is a fairly good chance that you remember, perhaps hazily, perhaps with pinpoint accuracy, the day that Bob Dylan plugged in his guitar and changed the course of rock 'n roll forever. [FN4] Now, it is true that I have been accused by some otherwise very good friends of being a bit too Dylan-centric, a charge to which I gleefully demur. But even if this allegation has a soupcon of truth, the point is an important one. Dylan's decision to abandon (or at least, radically transform) the folk music tradition and replace it with a new sort of literary, poetic, angry, passionate, lyrical rock music truly revolutionized popular culture. [FN5] For those of you fortunate enough to have seen him in recent years, that revolution continues. [FN6]

Why do I start this way (other than the obvious, which is that I really enjoy talking about him)? Well, there are two interlocking reasons. First, I believe that the United States Supreme Court's decision in June of 1999 in Olmstead v. L.C. [FN7] and the impact of the Americans With *54 Disabilities Act [FN8] on persons institutionalized by reason of mental disability [FN9] has the capacity to be as legally revolutionary as Dylan's decision to alter his performance style thirty-four years ago was culturally revolutionary (although I am, frankly, not at all certain that this will be so). Second, when Dylan did go electric, one of the first songs came from his famous Bringing It All Back Home album, Maggie's Farm. [FN10]

Maggie's Farm, like most of Dylan's important songs from this period, was not without its ambiguities. Critics have variously suggested that it is a metaphor for slavery and/or plantation life, for the ravages of Darwinian capitalism, for the oppression of family life, and for the suffocation of the human spirit. [FN11] Who knows which one, if any, is right? Bob sure has not told us. [FN12] We do know that Maggie's Farm has had a remarkable shelf life. Bob has sung it some 563 times on his current extended series of tours, most recently on July 30, 1999, at Jones Beach, NY. [FN13]

I tell you all this-trust me, it really is not as self-indulgent as it may *55 seem-because, when I read Olmstead and spent some time thinking about it, Maggie's Farm popped immediately into my mind. In her brilliant, Pulitzer Prize-winning report on life at Creedmoor Psychiatric Hospital in New York City, Is There No Place on Earth For Me?, [FN14] Susan Sheehan wrote carefully and thoughtfully about the regime of a then-recently-retired Creedmoor Superintendent who ran Creedmoor like a plantation, and treated Creedmoor staff like plantation workers (even to the grotesque length of calling African-Americans "darkies"). [FN15] When I

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Exhibit 5

first read Sheehan's book, [FN16] the "plantation" metaphor jumped out at me, and resonated with so many of my experiences as a lawyer representing patients at New Jersey mental hospitals from the mid 1970s to the early 1980s, and with observations that I had made over the years at mental hospitals in other states across the country. The sagas of right-to-treatment cases such as Wyatt v. Stickney, [FN17] or right-to-refuse-treatment cases such as Rennie v. Klein, [FN18] bespoke a plantation mentality, often on the parts of both the keepers and the kept. [FN19]

So, when I first read Olmstead, [FN20] one of the images that immediately ***56** came to my mind was Dylan singing, snarling:

> I ain't gonna work on Maggie's farm no more.
> No, I ain't gonna work on Maggie's farm no more.
> Well, I wake in the morning,
> Fold my hands and pray for rain.
> I got a head full of ideas
> That are drivin' me insane.
> It's a shame the way she makes me scrub the floor.
> I ain't gonna work on Maggie's farm no more. [FN21]

Maggie's Farm spoke to emancipation. [FN22] The ADA, as I will discuss later, speaks to emancipation; and Olmstead, when read (from my perspective, at least) optimistically, speaks to emancipation. It is this question of potential emancipation that I wish to address today. For I believe that Olmstead is potentially the most important civil mental disability law case since the Supreme Court decided Youngberg v. Romeo [FN23] in 1982. Olmstead potentially has the capacity to transform and revolutionize mental health law in the same profound ways that Bob Dylan transformed and revolutionized popular culture. If Olmstead is taken seriously, it may change the debate on institutional mental health care, on community treatment, on deinstitutionalization, on the segregation of persons with mental disabilities, on the future of the "least restrictive alternative" doctrine, and perhaps most importantly, on how we feel about persons with disabilities.

This paper will proceed in this manner. First, I will briefly discuss the ADA so as to better contextualize the Olmstead case. [FN24] Then, I will consider the sparse pre-Olmstead litigation that dealt with questions ***57** affecting persons institutionalized because of mental disability. [FN25] Then, I will address the Eleventh Circuit's decision in Olmstead, [FN26] a case far broader, and, to my mind, more visionary than the Supreme Court's ultimate decision. [FN27] Next, I will look at all the Olmstead opinions (for there is much to learn from all of them). [FN28] Following this, I will briefly discuss the concepts of "sanism" and "pretextuality," two concepts that I am convinced beyond a reasonable doubt explain much about the incoherence of so much of mental disability law. [FN29] Finally, I will explain what I see as the overarching significance of Olmstead, and how it may truly give institutionalized persons across the nation the capacity to say, maybe even optimistically to sing, "I ain't gonna work on Maggie's Farm no more." [FN30]

II. The Americans With Disabilities Act [FN31]

The Americans With Disabilities Act [FN32] has been hailed by advocates for persons with disabilities as "a breathtaking promise," [FN33] "the most important civil rights act passed since 1964[,]" [FN34] and as the "Emancipation Proclamation for those with disabilities." [FN35] It is, without question, Congress's "most innovative attempt to address the pervasive problems of discrimination against physically and mentally handicapped

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citizens" [FN36] by providing, in the words of a Congressional committee, "a ***58** clear and comprehensive national mandate to end discrimination against persons with disabilities." [FN37] The ADA provides basically the same bundle of protections for persons with disabilities as the Civil Rights Acts of the 1960s [FN38] did for citizens of color with clear, strong, and enforceable standards. [FN39]

The language that Congress chose to use in its introductory fact finding is of extraordinary importance. [FN40] Its specific finding that individuals with disabilities are a "discrete and insular minority . . . subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness" [FN41] is not just precatory flag-and-apple-pie rhetoric. [FN42] This language, granted "the force of law," [FN43] was carefully chosen; and it comes from the heralded footnote four of the United States v. Carolene Products case [FN44] that has served as the springboard for nearly a half century of challenges to state and municipal laws that have operated in discriminatory ways against other minorities, [FN45] and reflects a Congressional commitment to provide ***59** protected class categorization for persons with disabilities. [FN46] This in turn forces courts to employ a "compelling state interest" or "strict scrutiny" test in considering statutory and regulatory challenges to allegedly discriminatory treatment. [FN47] The law's invocation of the full "sweep of congressional authority, including the power to enforce the Fourteenth Amendment" [FN48] simply means that any violation of the ADA must be read in the same light as a violation of the Equal Protection Clause of the Constitution, [FN49] guaranteeing, for the first time, that this core constitutional protection will finally be made available to persons ***60** with disabilities. [FN50]

Individuals in in-patient psychiatric hospitals comprise a population that is classically voiceless and friendless, with few contacts in the "free world." It is a population whose disenfranchisement starkly mirrors the sort of powerlessness and marginalization spoken to by the Supreme Court in the Carolene Products case and, of course, spoken to by Congress in the ADA's initial findings section. [FN51]

By its terms, the entire ADA applies to persons with mental disabilities, including persons with mental illness. [FN52] Yet, very little of the final statute, the legislative history, or floor debate focused on the "grotesque" history of discrimination and mistreatment suffered by such individuals; [FN53] the crushing economic, social, and psychological burdens borne by such persons in their day-to-day lives; the conditions faced by such persons when institutionalized in public facilities, or when discharged from such facilities to lives of misery on our cities' streets without adequate transitional mental health, medical, or social services; or the pernicious legal effects that flow from the badge of mental disability. [FN54]

The legislative history is remarkably skimpy and speaks to only two relevant considerations. First, it reflects Congressional awareness of the danger of stereotyping behavior. [FN55] It makes this clear through its heavy reliance on the Supreme Court's language in School Board of Nassau County v. Airline [FN56] that "society's accumulated myths and fears about ***61** disability and disease are as handicapping as are the physical limitations that flow from the actual impairment." [FN57] Congress stressed that its inclusion in the definition of a disability of an individual who is regarded as being impaired [FN58] acknowledges this teaching about the power of myths. [FN59]

Thus, employment decisions cannot be based on "paternalistic views" of what is best for a person with a disability. [FN60] The employment title of the ADA was thus designed, in significant part, to prevent employers from relying "on presumptions, stereotypes, misconceptions, and unfounded fears" in making employment decisions, [FN61] and as a means of breaking the chain of misperception that individuals with disabilities are a "permanently helpless and separate class, unable to work or otherwise contribute to society." [FN62]

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Second, the history of the "direct threat" section, again relying on the Airline case, specifies that, for persons with mental disabilities, the employer must identify "the specific behavior on the part of the individual that would pose the anticipated direct threat," and that the determination must be based on such behavior, "not merely on generalizations about the disability." [FN63] In such a case, there must be ***62** "objective evidence . . . that the person has a recent history of committing overt acts or making threats which caused . . . or which directly threatened harm." [FN64]

While these two excerpts are praiseworthy and important, that is all there is. Nowhere else in any of the lengthy Congressional reports are the specific biases (one of which is sanism) and prejudices faced by persons with mental illness discussed. Although there is recognition that much of the discrimination faced by disabled persons flows from "unfounded, outmoded stereotypes and perceptions and deeply imbedded prejudices," [FN65] the legislative history in no way illuminates the specific prejudices and biases faced by mentally disabled persons, especially those who were formerly institutionalized. [FN66]

Earlier, I alluded to the impact of "sanism" and "pretextuality" on developments in this area. What do I mean by these terms? [FN67] Simply put, "sanism" is an irrational prejudice of the same quality and character of other irrational prejudices that cause (and are reflected in) prevailing social attitudes of racism, sexism, homophobia, and ethnic bigotry. [FN68] It infects both our jurisprudence and our lawyering practices. [FN69] "Sanism" [FN70] is largely invisible and largely socially acceptable. It is based predominantly upon stereotype, myth, superstition, and deindividualization; and it is sustained and perpetuated by our use of alleged "ordinary common sense" and heuristic reasoning in an unconscious response to events both in everyday life and in the legal process. [FN71]

***63** "Pretextuality" means that courts accept (either implicitly or explicitly) testimonial dishonesty and engage similarly in dishonest, frequently meretricious, decision making, specifically where witnesses, especially expert witnesses, show a "high propensity to purposely distort their testimony in order to achieve desired ends." [FN72] This pretextuality is poisonous: it infects all participants in the judicial system; breeds cynicism and disrespect for the law; demeans participants; and reinforces shoddy lawyering, blase judging, and, at times, perjurious and/or corrupt testifying.

In a paper I published in 1997, [FN73] I questioned whether:

> If and when cases are brought seeking to apply the ADA to individuals institutionalized in psychiatric hospitals, will federal courts interpret the ADA as it was written (in the light of Congress's clear statutory intent) or will the key language to which I have already alluded be seen as little more than hortatory shibboleths? Will courts say, "No, Congress really didn't mean what it said."? Would they say, "Well, Congress may have meant it, but only in an aspirational way, and there's really nothing for us here."? [FN74] Or will they say, "Yes, Congress said it, Congress meant it, and, dammit, we're gonna enforce it!"? [FN75]

Olmstead begins to answer these questions.

Persons with mentaldisabilities have faced the brunt of discrimination for years. Surveys show that mental disabilities are the most negatively perceived of all disabilities. [FN76] Individuals with mental disabilities have been denied jobs, refused access to apartments in public housing or entry to places in public accommodation, and turned down for ***64** participation in publicly-funded programs because they appear "strange" or "different." [FN77] A series of behavioral myths has emerged suggesting that persons with mental disabilities are deviant,

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worth less than "normal" individuals, disproportionately dangerous, and presumptively incompetent. [FN78] Yet, putting aside the two exceptions that I have discussed, nothing in the ADA speaks directly to these myths or to the special problems faced by persons with mental disabilities in attempting to combat them. [FN79]

A. Early Case Law [FN80]

The ADA title most important to institutionalized psychiatric patients is Title II. [FN81] Under Title II, "no qualified individual with a disability shall, by reason of such disability, be excluded from 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." [FN82] The legislative history stresses that discrimination continued in "such critical areas as institutionalization." [FN83] Although this title has not been the subject of much consideration in institutional cases, courts have held that allegations of restraint, isolation, and segregation could constitute ***65** discriminatory treatment under the ADA, [FN84] and that the Act requires that a psychiatric patient "be placed in the most integrated setting . . . which meets the needs of [his] disability but which gives [him] the most freedom." [FN85]

Most of the ADA/mental disability case law has focused on questions of professional licensing and examinations and on the range of accommodations necessary in employment situations. [FN86] Several courts have enjoined bar committees from inquiries into applicants' history of having been treated for mental disorders, but others have declined to do so. [FN87] Yet, other courts have considered the application of the ADA to conditions under which professional licensing exams are to be taken. [FN88] On whether accommodations are reasonable in the employment context, courts are split, and it appears that most decisions have been fact-based, turning on the individual judge's perception as to whether the plaintiff could perform the job tasks satisfactorily, even with the statutorily-mandated "reasonable accommodation." [FN89]

There is a smattering of other mental disability cases that focus on issues somewhat closer to the ones that are at the heart of this section. ***66** For instance, a federal district court in Florida found an ADA violation when a town's budget cuts eliminated community recreational programs that were solely for persons with disabilities, [FN90] as did a federal district court in Massachusetts considering a state law that required state hospital residents to contribute to the costs of assigned counsel. [FN91] On the other hand, a District of Columbia district court ruled that mentally disabled residents of a homeless shelter failed to state a claim in their allegations that restrictions on their freedom of expression were in violation of the same Act. [FN92]

The most important of these cases is Helen L. v. DiDario, [FN93] finding that a state welfare department regulation that forced certain patients to receive required care services in the segregated setting of a nursing home, rather than in their own homes, violated the ADA. [FN94] Helen L. is significant for several reasons. First, the Third Circuit read the Act's antidiscrimination language broadly and loudly. [FN95] It cited Congressional findings that "[h]istorically, society has tended to isolate and segregate individuals with disabilities . . . such forms of discrimination . . . continue to be a serious and pervasive social problem." [FN96] Furthermore, "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals." [FN97] Next, it read the ADA as being intended to insure that "qualified individuals receive services in a manner consistent with basic human dignity rather than a manner which shunts them aside, hides, and ignores them[,]" and declared that it would "not eviscerate the ADA by conditioning its protections upon a finding of intentional or overt 'discrimination[,]'" [FN98] focusing specifically on Congress's finding that "discrimination against individuals with disabilities persists in such critical areas as . . . institutionalization." [FN99] Finally, it rejected the state's

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argument that it could not change the plaintiff's regimen of care because the two ***67** programs in question were funded on separate budgetary lines. [FN100] In language that has potential impact on all cases assessing the potentially discriminatory basis of the provision of public hospital service benefits, the court was clear:

> [T]he ADA applies to the General Assembly of Pennsylvania, and not just to DPW [Department of Public Welfare]. DPW can not rely upon a funding mechanism of the General Assembly to justify administering its attendant care program in a manner that discriminates and then argue that it can not comply with the ADA without fundamentally altering its program.
>
> . . . .
>
> Because the Commonwealth, including all its branches, is bound by the decree, the argument of inability to comply rings hollow. Even if the executive branch defendants were physically or legally incapable of complying with the decree, those Commonwealth officials sitting in the General Assembly certainly are not incapable of insuring the Commonwealth's compliance [[citation omitted]. The same applies here: since the Commonwealth has chosen to provide services to [plaintiff] under the ADA, it must do so in a manner which comports with the requirements of that statute. [FN101]

B. The Literature [FN102]

By far, the most important analytic piece discussing the ADA and its potential impact here has been Timothy Cook's "The Americans with Disabilities Act: The Move to Integration" article in Temple Law Review. [FN103] Cook explicitly argued that the ADA meant an end to what he termed the segregation of institutions for persons with mental disabilities. [FN104] He read Congressional intent through the legislative history to abolish, in Senator Weicker's words, "monoliths of isolated care in institutions and in segregated educational settings . . . . Separate is not equal. It was not for blacks; it is not for the disabled." [FN105] The House Judiciary Report here was equally explicit: "[i]ntegration is fundamental to the purposes of the ADA. Provision[s] of segregated accommodations and services relegate persons with disabilities to ***68** second-class citizen status." [FN106] Cook read the act to bar intentional and unintentional discrimination, [FN107] and quoted researchers who concluded that "institutions and other segregated settings are simply unacceptable." [FN108] He concluded that the Act's invocation of the Fourteenth Amendment effectively overruled the "substantial professional judgment" standard of Youngberg v. Romeo. [FN109]

Can these same arguments be made about cases involving persons institutionalized because of mental illness? Are there clear differences? Do police power considerations inherent in the involuntary civil commitment process make a difference? Does the invocation of the Fourteenth Amendment and the use of "discrete and insular minority" language truly alter the Youngberg standard? [FN110]

I wrote more than five years ago that "[t]hese are difficult questions for which there are no ready or apparent easy answers," [FN111] and little has changed my mind since then. Cook's article has been cited in a number of federal court decisions in cases, mostly decided by the same judge, [FN112] involving a range of ADA topics, from a case brought by a child with a severe respiratory condition who sought to ban exceptions to a city's ban on open burning [FN113] to employment discrimination cases brought by persons suffering from asthma, [FN114] shoulder injury, [FN115] carpal tunnel ***69** syndrome, [FN116] spinal injury, [FN117] and a challenge to fees for disability parking placards. [FN118] Besides Helen L., one case involving the sort of "big issue" that Cook's methodology might eventually reach, Kathleen S. v. Dept. of Public Welfare, [FN119] held that a state's decision to close a state hospital violated the ADA by depriving residents of their right to receive services in the most integrated setting appropriate to their needs. [FN120] Nonetheless, Cook's article provides litigators with a

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blueprint for frontal attacks on Youngberg-based caselaw [FN121] that limits patients' civil and treatment rights. The unanswered question here, of course, is whether institutional plaintiffs' litigators will take the challenge.

C. Olmstead v. L.C. [FN122]

In retrospect, all of these developments, with the exception of Helen L. and possibly Kathleen S., may appear to be little more than the prelude to Olmstead. In Olmstead, the Court qualifiedly affirmed a decision by the Eleventh Circuit that had provided the first coherent answer to the question of the right of institutionalized persons with mental disabilities to community services under the ADA. [FN123] There, the court of appeals had found that the ADA entitled plaintiffs, residents of Georgia State Hospital, to treatment in an "integrated setting" as opposed to an "unnecessarily segregated" state hospital. [FN124]

Plaintiffs L.C. and E.W. challenged their placement at Georgia State Hospital, arguing that Title II of the ADA entitled them to "the most integrated setting appropriate to [their] needs." [FN125] The district court granted summary judgment to plaintiffs, finding that the state's failure to place them in an "appropriate community-based treatment program" ***70** violated the ADA, [FN126] and the state appealed. [FN127] On appeal, the Eleventh Circuit affirmed the judgment that the state had discriminated against the plaintiffs, but also remanded "for further findings related to the State's defense that the relief sought by plaintiffs would 'fundamentally alter the nature of the service, program, or activity.'" [FN128]

The court began its opinion by reviewing the pertinent statutory sections [FN129] and the relevant regulations promulgated by the Attorney General pursuant to statutory authority. [FN130] Under these regulations, "[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities," [FN131] and placement is required "in a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." [FN132] The court found that "[p]lacement in the community provides an integrated treatment setting, allowing disabled individuals to interact with non-disabled persons-an opportunity permitted only in limited circumstances within the walls of segregated state institutions such as [the state hospital]." [FN133] It thus concluded that the "express terms" of the regulation, "supported by the Attorney General's consistent interpretation, plainly prohibit a state from treating individuals with disabilities in a segregated environment where a more integrated setting would be appropriate . . . ." [FN134]

It then looked at the Congressional findings and legislative history that "make clear" Congress's aim "to eliminate the segregation of individuals with disabilities:" [FN135]

> In enacting the ADA, Congress determined that discrimination against individuals with disabilities persists in a wide variety of areas of social life, including "institutionalization," 42 U.S.C. § 12101(a)(3)(1995), and that "individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion . . . [and] segregation . . . ." 42 U.S.C. § 12101(a)(5); see also 42 U.S.C. § 12101 (a)(2) ("[H]istorically, society has tended to isolate and segregate individuals with disabilities, and . . . such forms of discrimination against ***71** individuals with disabilities continue to be a serious and pervasive social problem.").
>
> Indeed, the legislative history makes clear that Congress considered the provision of segregated services to individuals with disabilities a form of discrimination prohibited by the ADA. See S.Rep. No. 101-116 at 20 (1989) (noting "compelling need to provide a clear and comprehensive national mandate . . . for the integration of persons with disabilities into the economic and social mainstream of American

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life"); H.R.Rep. No. 101-485, pt. 2 at 29 (1990), reprinted in 1990 U.S.C.C.A.N. 267, 310 (listing "segregation" as a form of "[d]iscrimination against people with disabilities")[.] [FN136]

On this point the court concluded, "[c]ertainly, the denial of community placements to individuals with disabilities such as L.C. and E.W. is precisely the kind of segregation that Congress sought to eliminate." [FN137]

The court continued with its focus on the "basic goal" of the ADA:

> The ADA does not only mandate that individuals with disabilities be treated the same as persons without such disabilities. Underlying the ADA's prohibitions is the notion that individuals with disabilities must be accorded reasonable accommodations not offered to other persons in order to ensure that individuals with disabilities enjoy "equality of opportunity, full participation, independent living, and economic self-sufficiency . . . ." [FN138]
>
> It described the "reasonable accommodation duty" as requiring the state to "place individuals with disabilities in the most integrated setting appropriate to their needs[,]" [FN139] and relied on language from both the Third Circuit's decision in Helen L. v. DiDario [FN140] and Justice Marshall's separate opinion in City of Cleburne v. Cleburne Living Center [FN141] stating that "[t]he ADA is intended to ensure that qualified individuals receive services in a manner consistent with basic human dignity rather than a manner that shunts them aside, hides, and ignores them." [FN142]
>
> The court found that malevolent intent is not required. The state's "indifference to L.C. and E.W.'s needs, manifested by their refusal to ***72** place them in the community while recognizing the propriety of such a placement, is exactly the kind of conduct that the ADA was designed to prevent." [FN143] Here it drew on Supreme Court language from a § 504 case, Alexander v. Choate: [FN144]
>
> Discrimination against the handicapped was perceived by Congress to be most often the product, not of invidious animus, but rather of thoughtlessness and indifference-of benign neglect. Thus, Representative Vanik . . . described the treatment of the handicapped as one [of] the country's "most shameful oversights," which caused the handicapped to live among society "shunted aside, hidden, and ignored."
>
> . . . . Federal agencies and commentators on the plight of the handicapped similarly have found that discrimination against the handicapped is primarily the result of apathetic attitudes rather than affirmative animus. [FN145]
>
> Importantly, the court rejected the state's argument that plaintiffs' claims must fail because the denial of community-based placements was based on lack of funds. [FN146] "[T]he plain language of the ADA's Title II regulations, as well as the ADA's legislative history, make clear that Congress wanted to permit a cost defense only in the most limited of circumstances . . ." only where those accommodations "would fundamentally alter the nature of the service, program, or activity." [FN147] The court cited a House Judiciary report explaining:
>
> The fact that it is more convenient, either administratively or fiscally, to provide services in a segregated manner, does not constitute a valid justification for separate or different services under Section 504 of the Rehabilitation Act, or under this title . . . . The existence of such programs can never be used as a basis to . . . refuse to provide an accommodation in a regular setting. [FN148]

The court stressed that its holding did not "mandate the deinstitutionalization of individuals with disabilities." [FN149] Instead, it clarified:

> [W]e hold that where, as here, a disabled individual's treating ***73** professionals find that a community-based placement is appropriate for that individual, the ADA imposes a duty to provide treatment in a community setting-the most integrated setting appropriate to that patient's needs. Where there is no such finding, on the other hand, nothing in the ADA requires the deinstitutionalization of that patient. [FN150]

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The court pointed out that experts, including one of E.W.'s treating physicians, were unanimous that E.W. could be treated in a community setting, provided she were given "the level of care and supervision she needed." [FN151] Again, it underscored:

> We do not suggest that should a trial court find that a patient, for medical reasons, needs institutionalized care, it must nonetheless order placement in a community-based treatment program. We recognize that the determination whether a patient can be appropriately placed in a community-based treatment program is a fluid one, subject to change as the patient's medical condition improves or worsens. Over the course of litigation, there may be times that a patient can be treated in the community, and others where an institutional placement is necessary. But where, as here, the evidence is clear that all the experts agree that, at a given time, the patient could be treated in a more integrated setting, the ADA mandates that it do so at that time unless placing that individual would constitute a fundamental alteration in the state's provision of services. Nothing in the ADA, however, forbids a state from moving a patient back to an institutionalized treatment setting, as the patient's condition necessitates. [FN152]

The court then turned to the state's lack of funds argument. The duty to provide services is not absolute, it noted, and the state need not provide the services in question "if to do so would require a fundamental alteration in its programs." [FN153] However, the plaintiffs adequately demonstrated to the court that the state could "reasonably modify its provision of services by providing treatment to them in an integrated [community] setting." [FN154] It continued by noting that "the ADA does not ***74** permit the State to justify its discriminatory treatment of individuals with disabilities on the grounds that providing non-discriminatory treatment will require additional expenditures of state funds." [FN155]

However, because the trial court did not consider the question of whether the additional expenditures necessitated by community treatment would "fundamentally alter the services [the state] provides," the Eleventh Circuit remanded the case for the trial court to consider:

> (1) whether the additional expenditures necessary to treat L.C. and E.W. in community-based care would be unreasonable given the demands of the State's mental health budget; (2) whether it would be unreasonable to require the State to use additional available Medicaid waiver slots, as well as its authority under Georgia law to transfer funds from institutionalized care to community-based care, to minimize any financial burden on the State; and (3) whether any difference in the cost of providing institutional or community-based care will lessen the State's financial burden. [FN156]

On appeal, the Supreme Court, in a split opinion per Justice Ginsburg, [FN157] qualifiedly affirmed. [FN158] After setting out the provisions of the ADA that focused on the institutional segregation and isolation of persons with disabilities, and the discrimination faced by persons with disabilities (including "exclusion . . . [and] segregation"), [FN159] the Court reviewed the key Department of Justice regulations, including the "integration [mandate] regulation," [FN160] pointing out that the case, as presented, did not challenge their legitimacy. [FN161] It then set out its holding:

> ***75** We affirm the Court of Appeals' decision in substantial part. 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 diverse mental disabilities, and the States' obligation to administer services with an even hand. Accordingly, we further hold that the Court of Appeals' remand instruction was unduly restrictive. In evaluating a State's fundamental-alteration defense, the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others

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with mental disabilities, and the State's obligation to mete out those services equitably. [FN162]

The Court endorsed the Department of Justice's position that "undue institutionalization qualifies as discrimination, 'by reason of . . . disability,'" [FN163] and then characterized the ADA as having "stepped up earlier measures to secure opportunities for people with developmental disabilities to enjoy the benefits of community living[,]" [FN164] stressing how much more comprehensive the ADA was than had been "aspirational" or "hortatory" laws, such as the Developmentally Disabled Assistance and Bill of Rights Act. [FN165] It then focused on what it saw as Congressional judgment supporting the finding that "unjustified institutional isolation of persons with disabilities is a form of discrimination[:]" [FN166]

> 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. Cf. Allen v. Wright, 468 U.S. 737, 755, 104 S.Ct. 3315, 82 L.Ed.2d 556 (1984) ("There can be no doubt that [stigmatizing injury often caused by racial discrimination] is one of the most serious consequences of discriminatory government action."); Los Angeles Dept. of Water and Power v. Manhart, 435 U.S. 702, 707, n. 13, 98 S.Ct. 1370, 55 L.Ed.2d 657 (1978) ("In forbidding employers to discriminate against individuals because of their sex, Congress intended to strike at the entire spectrum of disparate treatment of men and women resulting from sex stereotypes.") (quoting ***76**Sprogis v. United Air Lines, Inc., 444 F.2d 1194,1198 (C.A.7 1971)). 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. See Brief for American Psychiatric Association et al. as Amici Curiae 20-22. Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice. See Brief for United States as Amicus Curiae 6-7, 17. [FN167]

The majority immediately clarified some qualifications in its opinion. It emphasized that the ADA did not "condone[ ] termination of institutional settings for persons unable to handle or benefit from community settings," [FN168] that the states "generally may rely on the reasonable assessments of its own professionals in determining whether an individual" is eligible for community-based programs, [FN169] and that there was no "requirement that community-based treatment be imposed on patients who do not desire it." [FN170] None of these issues, however, were present in the case before it: "[Georgia's] professionals determined that community-based treatment would be appropriate for [the plaintiffs]," both of whom desired such treatment. [FN171] The Court added one additional word of caution here:

> We do not in this opinion hold that the ADA imposes on the States a "standard of care" for whatever medical services they render, or that the ADA requires States to "provide a certain level of benefits to individuals with disabilities." . . . We do hold, however, that States must adhere to the ADA's nondiscrimination requirement with regard to the services they in fact provide. [FN172]

The Court then turned to the questions of remedy and enforcement. [FN173] It rejected the Eleventh Circuit's construction of the "reasonable-modification regulations" as "unacceptable" in that "it would leave the ***77** State virtually defenseless" if the plaintiff demonstrates she is qualified for the program or placement she seeks. [FN174] Rather, the Court concluded:

> Sensibly construed, the fundamental-alteration component of the reasonable-modifications regulation would allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treat-

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ment of a large and diverse population of persons with mental disabilities." [FN175]

The ADA, it concluded, "is not reasonably read to . . . phase out institutions, placing patients in close care at risk," nor is the law's mission "to drive States to move institutionalized patients into an inappropriate setting, such as a homeless shelter[.]" [FN176] "For other [[patients], no placement outside the institution may ever be appropriate." [FN177] Because of these factors, Justice Ginsburg concluded that the state must have more leeway than offered by the Eleventh Circuit's remedy:

> If, for example, 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 to keep its institutions fully populated, the reasonable-modifications standard would be met. [FN178]

She summarized in this way:

> [U]nder Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account there sources available to the State and the needs of others with mental disabilities. [FN179]

***78** Justice Stevens concurred, stating that he would have preferred simply affirming the Eleventh Circuit's opinion, but because there were not five votes for that disposition, he joined in all of Justice Ginsburg's opinion, except for the remedy-enforcement portion. [FN180] Justice Kennedy concurred, urging "caution and circumspection" in the enforcement of the Olmstead case. [FN181] After stressing that "persons with mental disabilities have been subject to historic mistreatment, indifference, and hostility[,]" [FN182] he traced what he saw as the history of deinstitutionalization: that, while it "has permitted a substantial number of mentally disabled persons to receive needed treatment with greater freedom and dignity[,]" it has "ha[d] its dark side" as well. [FN183] Here he quoted extensively from the writings of E. Fuller Torrey:

> For a substantial minority . . . deinstitutionalization has been a psychiatric Titanic. Their lives are virtually devoid of "dignity"or "integrity of body, mind, and spirit." "Self-determination" often means merely that the person has a choice of soup kitchens. The "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. [FN184]

"It would be a tragic event," Justice Kennedy warned, if states read the ADA, as construed in Olmstead, in such a way as to create an incentive to states, "for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision[,]" [FN185] and he thus emphasized that "opinion[s] of a responsible treating physician [should] be given the greatest of deference." [FN186] He underscored what he saw as a "common phenomenon:"

> It is a common phenomenon that a patient functions well with medication, yet, because of the mental illness itself, lacks the discipline or capacity to follow the regime the medication requires. This is illustrative of the factors a responsible physician will consider in recommending the appropriate setting or facility for treatment. [FN187]

Because of these concerns, and his fear that "[s]tates may be ***79** pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition," Justice Kennedy again urged "caution and circumspection" and "great deference to the medical decisions of . . . responsible, treating physicians." [FN188]

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He continued [FN189] by articulating what he saw as the necessary elements of a discrimination finding, [FN190] and then raised federalism concerns: "[g]rave constitutional concerns are raised when a federal court is given the authority to review the State's choices in basic matters such as establishing or declining to establish new programs. It is not reasonable to read the ADA to permit court intervention in these decisions." [FN191]

Finally, he parted company from Justice Ginsburg on the weight she gave to the Congressional findings. The findings in question, he concluded, "do not show that segregation and institutionalization are always discriminatory or that, by their nature, are forms of prohibited discrimination." [FN192] "Instead, they underscore Congress's concern that discrimination has been a frequent and pervasive problem in institutional settings and policies and its concern that segregating disabled persons from others can be discriminatory." [FN193]

Justice Thomas dissented, criticizing the majority opinion for its interpreting "'discrimination' that encompassed disparate treatment among members of the same protected class[,]" [FN194] arguing that the Congressional findings on which the majority premised its conclusions were "vague" and written in "general hortatory terms," [FN195] that its "approach impose[d] significant federalism costs," [FN196] and warning that states "will now be forced to defend themselves in federal court every ***80** time resources prevent the immediate placement of a qualified individual." [FN197] He concluded, "[c]ontinued institutional treatment of persons who, though now deemed treatable in a community placement, must wait their turn for placement, does not establish that the denial of community placement occurred 'by reason of' their disability. Rather, it establishes no more than the fact that petitioners have limited resources." [FN198]

Olmstead is significant for several reasons. First, it is the first time that the Supreme Court has ruled on the applicability of the ADA to community-based treatment programs. [FN199] Second, it breathes important life into the Congressional findings on questions of institutional segregation, discrimination, and exclusion. [FN200] Third, it specifically focuses on the way that "unjustified isolation . . . is properly regarded as discrimination based on disability." [FN201] Fourth, it comprehends how, in its own words, the ADA had "stepped up" prior Congressional efforts in this area. [FN202] Fifth, it underscores how institutional isolation "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," [FN203] and how such isolation "severely diminishes the everyday life activities of institutionalized individuals." [FN204]

On the other hand, the Court's "qualifiers" are equally important. It sanctions reliance on state professionals in determining community-treatment eligibility, thus, implicitly endorsing a perpetuation of Youngberg v. Romeo's "substantial professional judgment" standard, [FN205] notwithstanding the fact that the Court had stressed that there was no constitutional issue presented in the case. [FN206] It emphasizes that Olmstead cannot be read as an opinion designed to "phase out" institutions or to move patients to inappropriate community settings. [FN207] Its "reasonable modification" formula, by which a state must be able to "demonstrate that it had a comprehensive, effectively working plan for placing ***81** qualified persons with mental disabilities in less restrictive settings[,]" [FN208] provides an early partial blueprint for the resolution of similar future litigation.

Justice Kennedy's concurrence may turn out to be of critical importance for several reasons. First, he focuses squarely on the specter of inappropriate deinstitutionalization, relying on Fuller Torrey's powerful critique. [FN209] Second, he raises the concern that the fear of litigation may lead the state to prematurely and inappropriately release patients "with too little assistance and supervision." [FN210] Finally, he links institutional release with patients' subsequent failure to self-medicate in community settings, an argument that resonates in the current debate over involuntary outpatient commitment laws that premise community treatment on medication

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compliance. [FN211] It can be expected that these arguments of Justice Kennedy's will be as much a factor in the subsequent debate on community treatment questions as will Justice Ginsburg's majority opinion.

In short, Olmstead has the capacity to be a truly transformative ADA case, and one which may serve as the template for future developments in this area. [FN212] Although the Youngberg "substantial professional judgment" standard has been an important underpinning of mental disability law jurisprudence for nearly two decades, courts have rarely given much thought to its dimensions, its limits, and its implications for ***82** institutional life. [FN213] Olmstead's implicit endorsement of the standard is likely to rekindle interest in this standard. This will clearly have an impact on all aspects of institutional mental health practice. The Court's focus on institutional segregation and the deleterious effects of institutional isolation will likely lead to greater attention being paid to the way institutions are run, and the ways institutional mental health professionals provide treatment in institutional settings. If Olmstead leads to more ADA litigation on behalf of institutionalized persons seeking community treatment, it is likely that, notwithstanding the cases's implicit endorsement of the Youngberg standard, this will also lead to far greater scrutiny of mental health professionals' institutional practices. Although Olmstead deals solely with civil patients, there is nothing in the opinion or the ADA or the supporting regulations that suggests that the basic principles would be inapplicable to forensic populations. [FN214]

III. Sanism, Pretextuality, and the ADA [FN215]

Any analysis of ADA developments must be undertaken contextually in light of the role of sanism and pretextuality. The "direct threat" language in the ADA [FN216] is a potential laboratory for sanist and pretextual experimentation. [FN217] What sort of "behavior" will allegedly pose such a threat? If an employee starts to discuss obscure political conspiracies, is that a threat? If an individual taking psychotropic medication develops side effects that creates an agitated or a "zombie-like" condition, is that a threat? If an employee appears to be fixated with, ***83** say, frogs or turtles, and talks to customers about their importance to the world, is that a threat? To what extent can we expect that employers will tolerate [FN218] "aberrant" behavior on the part of workers? Let one local news station pick up a story that a group of schoolchildren stopped going to a downtown luncheonette because an employee was "acting odd," and that anecdote will become the centerpiece of the next debate on amending the ADA.

If the plain language of the ADA conflicts with what trial judges think is "best" for mentally disabled persons, will judges enter pretextual decisions (and encourage pretextual testimony)? Michael Saks reported a trial judge's explanation as to why he ordered civil commitment of individuals notwithstanding his overt acknowledgment that the state failed to meet its burden of proof; and the judge did so because he felt compelled "to do what [he thought was] right." [FN219] Should we expect judges to be less pretextual in ADA decisionmaking? [FN220]

Interestingly, in at least one section, the ADA drafters seem to acknowledge the dangers of pretexts. While the Act explicitly does not restrict the ability of insurance companies to limit mental-illness-disability benefits, [FN221] it specifies that this non-restriction section may not be used as a "subterfuge" to evade the purposes of either the employment or public accommodations titles. [FN222] This expectation of pretextual ***84** behavior on the part of an industry subject to regulation under this act is both realistic and troubling, for it reflects the extent to which pretexts can color the way we treat persons with mental disabilities.

The potential superimposition of "morality" was raised explicitly in the floor debate on the ADA by Senator Jesse Helms. His revealing comment, asking about the consequences if an employer's "moral standards" prevent

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him from hiring a manic-depressive, [FN223] reflects the reality that sanist behavior may be seen as moral behavior. [FN224] Will this lead to a spate of literature suggesting that the ADA be subverted in the same way that psychiatrists have written articles suggesting that strict involuntary civil commitment laws be subverted? [FN225]

I believe that one of the many reasons why society reacts in different ways toward persons with mental disabilities than it does when it discriminates against other minorities is that the distinguishing ***85** characteristics of the latter groups are frequently immutable. [FN226] With rare exceptions, few people change gender or change race. When individuals change religion, it is generally a voluntary act undertaken with some knowledge of the dimensions and consequences of the decision. On the other hand, each one of us can become mentally ill (and none of us chooses it volitionally). This phenomenon may help explain the level of virulence we often show toward persons with mental disabilities. [FN227]

The ADA floor debate on this question of what I will call the non-immutability of mental illness was illuminating. Senator Armstrong made this point graphically in his arguments on behalf of a narrowed law:

> A person is or is not a man or a woman. A person is or is not a Catholic, a Jew, a Mormon, whatever . . . . That is something we can readily determine. A person either is or is not Irish, Italian and so on.
>
> This bill proceeds from an entirely different point of view. . . . [FN228]
>
> On the other hand, Senator Domenici, a co-sponsor and ardent supporter, used the same information in an entirely different context. Said Domenici:
>
> It is very simple to say that it is only a matter of sex discrimination and perhaps race, and perhaps religion, as some have suggested. Those are easy ones.
>
> But they just scratch the surface in terms of the suffering that goes on in the lives of people who are assumed disabled because of some of the niches that they are put in, especially when it comes to serious mental illness . . . . [FN229]

Our discomfort and lack of clarity as to who exactly is disabled and who is not is, at base, sanist. Just as we wish to be able to categorize ***86** individuals in the criminal law as sane or insane, competent or incompetent, [FN230] we wish for a "real world" without tinges and shades of gray, especially on the question of who is "mentally disabled" for purposes of an act such as the ADA.

The ADA, if enforced, forces us to abandon sanist stereotypes in this area of the law. [FN231] It makes us reject presumptions of incompetence, broadly-drawn, non-individualized pictures of mentally disabled persons, and policy rationales that are premised on prejudice and bias. The ADA, if enforced, gives institutional plaintiffs a litigational vehicle to bring some coherence to the state/federal morass in right-to-refuse-treatment law and to seek to force courts to confront issues about personal autonomy and sexuality that judges have been all too happy to avoid for years.

Olmstead provides some powerful anti-sanist ammunition. Its focuses on the ravages of isolation (and its linkage of that isolation to the perpetuation of stereotypes, stigma and the diminution of everyday life) is the Supreme Court's strongest language yet in a majority opinion that implicitly acknowledges the corrosive impact of sanist behavior. On the other hand, there may be reason for concern in Olmstead's willingness ***87** to be deferent to institutional professionals. [FN232] The history of institutional treatment of persons with mental disabilities is, to be charitable, a checkered one. [FN233] By no means is it at all clear that the "shock the conscience" scenarios uncovered in cases ranging from Wyatt v. Stickney [FN234] to Halderman v. Pennhurst State School and Hospital [FN235] are all mere historical artifacts. [FN236] The potential for pretexts here is real and is worthy

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of careful scrutiny in the next inevitable generation of Olmstead-like cases.

At least three other concerns flow from the other Olmstead opinions. As I have already suggested, Justice Kennedy's endorsement of Torrey's florid description of deinstitutionalization as a "Titanic-like" disaster [FN237] may (perhaps unwittingly) serve to frame the continuing debate as to the success and failures of differing approaches to deinstitutionalization. The pages of journals such as American Psychologist or Psychiatric Services are regularly filled with reports of successful deinstitutionalization programs that have "worked," [FN238] and Torrey's vivid heuristics should not serve to preempt the terms of this important debate. [FN239]

Next, Justice Kennedy's connection between deinstitutionalization and refusals to take medication is perplexing on two independent levels. Concurring in 1992 in Riggins v. Nevada, [FN240] Justice Kennedy wrote eloquently about the dangers of drug side effects, dangers that so worried him that he concluded he would not allow the use of antipsychotic medications to make a defendant competent to stand trial absent an "extraordinary showing," a showing he doubted was possible to make ***88** "given our present understanding of the properties of these drugs." [FN241] None of these concerns is present in his Olmstead opinion. This is even more surprising, given the attention paid by the Court to antipsychotic drug side effects in Sutton v. United Air Lines. [FN242] In Sutton (an opinion joined by Justice Kennedy), the Court discussed, in dicta, the fact that "antipsychotic drugs can cause a variety of adverse effects, including neuroleptic malignant syndrome and painful seizures [[.]" [FN243] Again, there is no reference to this in Justice Kennedy's Olmstead concurrence.

Finally, both Justice Kennedy and Justice Thomas speculate as to the possibility of state-motivated improper release due to a fear of litigation. This assumes a major fact not in evidence: that competent, qualified counsel is widely available to represent institutionalized persons in such litigation. [FN244] This fear, certainly related to the critique that has scapegoated patients' rights lawyers as the villain in the deinstitutionalization movement, [FN245] is a potentially pernicious one, and must be carefully rebutted by responsible advocates who provide legal services to persons with mental disabilities.

Olmstead was limited to the question of community-based treatment. [FN246] Its powerful language about institutional segregation, [FN247] and about the permanent and irreversible effects of stereotyping, [FN248] however, goes far beyond the modest holding of the case. In acknowledging the ways that institutional placement can "perpetuate unwarranted ***89** assumptions" [FN249] about persons with mental disabilities and the way that such confinement can "diminish . . . the everyday life activities of [such] individuals," [FN250] the Olmstead court acknowledges the hidden prejudice that contaminates all mental disability law. [FN251] The majority, for the first time in United States Supreme Court history, [FN252] raises and implicitly confronts the issue of sanism. By acknowledging that the state needs to maintain a "range of facilities," [FN253] it rejects rigid, all-or-nothing, dyadic views of institutional/non-institutional life and of mental health/mental illness. [FN254] By its decision, it explicitly warns us of the danger of stereotyping and implicitly of "slotting" [FN255] (use of the typification heuristic by which treating doctors slot "patients into certain categories and prescribes a similar regimen for all"). [FN256] By considering the corrosive effect of perpetuated assumptions, it reminds us, in the words of Judge David Bazelon, to be vigilant about "overgeneraliz[ing] about citizens whom it is easy to overgeneralize about." [FN257]

IV. Conclusion

Olmstead, to be sure, is not a "deinstitutionalization decision" and cannot and should not be interpreted as supporting the proposition that all inpatient institutions must be closed down. [FN258] Cases such as Kathleen

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S. v. Department of Public Welfare, [FN259] holding that a state's decision to close a state hospital violated the ADA by depriving residents of their ***90** right to receive services in the most integrated setting appropriate to their needs, [FN260] will likely build on Olmstead and construe some of the decision's more ambiguous language. One of the most intriguing, and still unasked, questions is the extent to which Olmstead will eventually be read as a therapeutic or antitherapeutic decision. This therapeutic jurisprudence inquiry [FN261] is beyond the scope of this paper, but cries out for future analysis. I am convinced, however, that therapeutic jurisprudence investigations are incomplete if they do not "factor in" the impacts of sanism and pretextuality. [FN262] Again, the Court's focus on segregation and isolation forces us to consciously add these considerations to our analysis. But what Olmstead does tell us though, with finality, is that the Maggie's Farm mentality of the past is gone forever.

The analogy to Maggie's Farm, of course, is not a perfect one. No one would characterize Olmstead, as the critic Tim Riley characterized Maggie's Farm, as "the counterculture's war cry." [FN263] But the music critic Andrew Muir's vision of Maggie's Farm, as "representing any restricting, corrupt society or system," and a critique of the "personal prisons we all create by denying the freedom of the individual," [FN264] may be closer to the mark. In Olmstead, for the first time the Supreme Court spoke of isolation and segregation and stereotypes and stigma. For this Court at this point in time, those references were fairly revolutionary. Only time will tell us the extent of Olmstead's true legacy.

[FN1]. The ADA, mentioned throughout the paper, refers to the Americans With Disabilities Act, which can be found at 42 U.S.C.A. § 12101 (West 1995). This paper was presented on October 30, 1999, at Thomas M. Cooley Law School's Symposium on Mental Disability Law. Portions of this paper are adapted from Michael L. Perlin, The Hidden Prejudice: Mental Disability on Trial (2000).
[FN2]. 119 S. Ct. 2176 (1999).

[FN3]. Professor of Law, New York Law School. J.D., Columbia University School of Law; A.B., Rutgers University. The author wishes to thank Jennifer Burgess, Christine Morton, and Jenna Anderson for their invaluable research help, and Michael Feuerstein for bringing him back into the world of Bob Dylan's music.

[FN4]. See The Dylan Companion: A Collection of Essential Writing About Bob Dylan 15-16 (Elizabeth Thompson & David Gutman eds. 1990); Tim Riley, Hard Rain: A Dylan Commentary 116-17 (1992); Wanted Man: In Search of Bob Dylan 57-66 (David Bauldie ed. 1990).

[FN5]. See, e.g., Riley, supra note 4, at 4-27.

[FN6]. Readers of this article are cordially invited to visit me in my New York office. My door now is festooned with the set lists of the last twelve Dylan concerts I've attended (from November 1994, at Roseland in New York City, to November 1999, at the Meadowlands Arena in East Rutherford, NJ).

[FN7]. 119 S. Ct. 2176 (1999).

[FN8]. 42 U.S.C.A. § 12101 (West 1995).

[FN9]. See generally Perlin, supra note 1; Michael L. Perlin, Mental Disability Law: Civil and Criminal (1998, 1999 & 1999 Cum. Supp.).

[FN10]. Probably Dylan's most controversial early electric performance was at the Newport Folk Festival on Ju-

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ly 25, 1965. See Joe Boyd, Newport '65, in Wanted Man, supra note 4, at 64 ("[B]y [the musical standards of 1965, Maggie's] was the loudest thing that anybody had ever heard."). See, e.g., Riley, supra note 4, at 116-17. Maggie's was the first electrified song that he sang that afternoon. This will be my last burst of self-referentiality. I may have seen Bob sing Maggie's at a concert at Rutgers University in April 1965 (my memory is good, but not that good). In recent years, I've heard him sing it three times: Roseland in New York City in 1994, the Electric Factory in Philadelphia in 1995, and Irving Place in New York City in December 1997. I expect that there will be future times as well.

[FN11]. See, e.g., Andrew Muir, Detailed Study of Maggies [sic] Farm, (visited Oct. 8, 1999) <http://www.geocities.com/Athens/Forum/2667/maggiesf.html>; Riley, supra note 4, at 105 ("'Maggie's Farm' is a list of complaints, from everyday chores and employer hassles to bureaucratic oppression." The song's opening line-"I ain't gonna work on Maggie's Farm no more"-has been used epigrammatically to illustrate academicians' adoption of Critical Legal Studies as "Urban Guerrilla Warfare" in David Fraser, If I Had a Rocket Launcher: Critical Legal Studies as Moral Terrorism, 41 Hastings L.J. 777, 789 (1990)).

[FN12]. On the unexplained ambiguity in Dylan's lyrics, see Robert Shelton, No Direction Home: The Life and Music of Bob Dylan 306-39 (Da Capo ed. 1997). The song title may have come from Silas Magee's Farm in Greenwood, Mississippi, where Dylan, on July 6, 1963, played his early civil rights anthem, Only a Pawn in Their Game, at a civil rights rally. See also Greenwood Mississippi Rally, (visited Oct. 11, 1999) <http://www.punkhart.com/dylan/tapes/63-jul6.html>. See generally Muir, supra note 11.

[FN13]. See Bill Pagel, Bob Dylan's 1999 Summer Tour Guide, (visited Oct. 15, 1999) <http://www.execpc.com/°billp61/073099s.html>.

[FN14]. Susan Sheehan, Is There No Place on Earth For Me? (Vintage ed. 1983).

[FN15]. See id. at 13.

[FN16]. I have been assigning it to my Mental Health Law students yearly since 1985, so I have probably reread it more than any other book in my lifetime.

[FN17]. 325 F. Supp. 781 (M.D. Ala. 1971) (subsequent citations omitted).

A few of the atrocious incidents cited in [the supplementing] case include the following:

(a) a resident was scalded to death by hydrant water; (b) a resident was restrained in a straitjacket for nine years in order to prevent hand and finger sucking; (c) a resident was inappropriately confined in seclusion for a period of years; and (d) a resident died from the insertion by another resident of a running water hose into his rectum. Each of these incidents could have been avoided had adequate staff and facilities been available[.]

344 F. Supp. 387, 393-94 n.13 (M.D. Ala. 1972); see 2 Perlin, supra note 9, § 3A-3.1 at 24-32 (2d ed. 1999).

[FN18]. 462 F. Supp. 1131 (D.N.J. 1978) (subsequent citations omitted).

On November 17, 1977, plaintiff reported that evening shift attendants beat him with sticks while he was tied to a bed. The next day he pointed out the sticks, which were hidden at the nurses' station. The investigation that followed resulted in the suspension of one employee for three days. Plaintiff and the attendant remained together in the same ward.

Id. at 1136. See generally 2 Perlin, supra note 9, § 3B-5.1 at 190-91 (2d ed. 1999).

[FN19]. See generally Rennie, 462 F. Supp. 1131 (D.N.J. 1978); Wyatt v. Stickney, 344 F. Supp. 387 (M.D. Ala. 1972); and Wyatt, 325 F. Supp. 781 (M.D. Ala. 1971).

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[FN20]. I should point out that I have never been to Georgia Regional Hospital in Atlanta, the facility in which L.C. and her co-plaintiff, E.W., were housed. To the best of my knowledge, it has never been the subject of litigation over patients' conditions of confinement. But see Parham v. J.R., 442 U.S. 584 (1979) (discussing the constitutionality of Georgia's juvenile commitment statutes). My intuition, however, from reading a range of cases about Georgia Regional Hospital in which other issues (malpractice, see, e.g., Davis v. State, 439 S.E.2d 40 (Ga. Ct. App. 1993), reconsideration denied (1993), cert. denied (1994); Swofford v. Cooper, 360 S.E.2d 624 (Ga. Ct. App. 1987), rev'd, cert. granted, 368 S.E.2d 518 (Ga. 1988), reconsideration denied (1988); release of insanity acquittees, see, e.g., Ledbetter v. Cannon, 384 S.E.2d 875 (Ga. Ct. App. 1989), reh'g denied (1989); and DuBose v. State, 251 S.E.2d 15 (Ga. Ct. App. 1978), reh'g denied (1978); racial discrimination involving employees, see, e.g., Collier v. Dep't. of Human Resources, 397 S.E.2d 632 (Ga. Ct. App. 1990)) have been litigated, is that there is no reason to expect that the conditions there are significantly different than the conditions at many other American state hospitals-often dreary, dull, depressing, and dispiriting. See generally Rebecca Perl, Suit Says Children Illegally Confined: Mental Hospitals Misused?, Atlanta Const., Dec. 4, 1991, at A1 (discussing a class action suit brought against Georgia state hospitals, including Georgia Regional Hospital, alleging that hundreds of non-mentally ill children were being unlawfully detained).

[FN21]. Bob Dylan, Lyrics 1962-1985 166 (1985).

[FN22]. See id.

[FN23]. 457 U.S. 307 (1982). See generally 2 Perlin, supra note 9, § 3A-9, at 87-90 (2d ed. 1999).

[FN24]. See infra notes 31-79 and accompanying text.

[FN25]. See infra notes 80-101 and accompanying text.

[FN26]. L.C. v. Olmstead, 138 F.3d 893 (11th Cir. 1998), aff'd and remanded, 119 S. Ct. 2176 (1999).

[FN27]. See infra notes 157-214 and accompanying text.

[FN28]. See infra notes 122-56 and accompanying text.

[FN29]. See infra notes 215-57 and accompanying text; see also Perlin, supra note 1.

[FN30]. See infra notes 258-64 and accompanying text.

[FN31]. This section of the article and the accompanying footnotes were developed from Michael L. Perlin, The ADA and Persons With Mental Disabilities: Can Sanist Attitudes Be Undone?, 8 J.L. & Health 15, 15-27 (1993-94); and Michael L. Perlin, "Make Promises by the Hour:" Sex, Drugs, the ADA, and Psychiatric Hospitalization, 46 DePaul L. Rev. 947, 947-955 (1997) [[hereinafter Promises].

[FN32]. 42 U.S.C.A. § 12101 (West 1995).

[FN33]. Bonnie Milstein et al., The Americans With Disabilities Act: A Breathtaking Promise for People With Mental Disabilities, 24 Clearinghouse Rev. 1240 (1991).

[FN34]. Kent Jenkins Jr., Spotlight Finds Hoyer, Washington Post, May 28, 1990, at D1.

[FN35]. Kimberly Ackourney, Comment, Insuring Americans With Disabilities: How Far Can Congress Go to

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Protect Traditional Practices?, 40 Emory L.J. 1183, 1183 (1991); see also Sandra Law, The Americans With Disabilities Act of 1990: Burden on Business or Dignity for the Disabled?, 30 Duq. L. Rev. 99, 114 (1991) (stating that the ADA is a "solid and positive step toward making this country a better nation").

[FN36]. Perlin, supra note 9, § 6.44A, at 16 (1999 Cum. Supp.).

[FN37]. H.R. Rep. No. 101-485, pt. 3, at 23 (1990).

[FN38]. See generally 42 U.S.C.A. §§ 1971, 1973 (West Supp. 1999).

[FN39]. Compare Bonnie P. Tucker, The Americans With Disabilities Act of 1990: An Overview, 22 N.M.L.Rev. 13 (1992) (discussing enforcement provisions), with Pamela S. Karlan & George Rutherglen, Disabilities, Discrimination, and Reasonable Accommodation, 46 Duke L.J. 1 (1996) (reading the ADA to provide more protections than do other civil rights acts).

[FN40]. See Amy Lowndes, Note, The Americans With Disabilities Act of 1990: A Congressional Mandate for Heightened Judicial Protection of Disabled Persons, 44 Fla. L. Rev. 417, 446 (1992) (discussing the "shocking and eye-opening" nature of these findings).

[FN41]. 42 U.S.C.A. § 1210(a)(7) (West Supp. 1999).

[FN42]. See 2 Perlin, supra note 9, § 7.13, at 617-23 (giving a full commentary on above issues); see also Perlin, Promises, supra note 31, at 955 (discussing the question of whether key sections of the ADA will be seen as little more than hortatory language). Compare Pennhurst State Sch. & Hosp.v. Halderman, 451 U.S. 1, 11 (1981) (stating that 42 U.S.C.A. § 6010 "simply does not create substantive rights" in developmentally disabled individuals with a legally enforceable cause of action), with David Ferleger & Patrice Maguire Scott, Rights and Dignity: Congress, the Supreme Court, and People With Disabilities After Pennhurst, 5 W. New Eng. L. Rev. 327, 350 (criticizing the conclusion as "absurd" and "objectionable" in an article co-authored by plaintiffs' lead counsel in the Pennhurst case).

[FN43]. James B. Miller, The Disabled, the ADA, and Strict Scrutiny, 6 St. Thomas L. Rev. 393, 413 (1994).

[FN44]. 304 U.S. 144, 152 n.4 (1938).

[FN45]. See id; see also Michael L. Perlin, On "Sanism," 46 SMU L. Rev. 373, 380-81 n.51 (1992) (discussing the impact of this footnote on the development of mental disability law); and 1 Perlin, supra note 9, § 1-2.1, at 7 (2d ed. 1998). See, e.g., Susan Lee, Heller v. Doe: Involuntary Civil Commitment and the "Objective" Language of Probability, 20 Am. J.L. & Med. 457, 477 n.90 (1994) (reflecting Congressional intent to identify disabled persons as a group "deserving heightened scrutiny"); Leonard S. Rubenstein, Ending Discrimination Against Mental Health Treatment in Publicly Financed Health Care, 40 St. Louis U. L.J. 315, 339 (1996) (demonstrating the ADA's invocation of the Carolene Products footnote justifies employing "heightened judicial scrutiny" test); and Lisa Montanaro, Comment, The Americans With Disabilities Act: Will the Court Get the Hint? Congress' Attempt to Raise the Status of Persons With Disabilities in Equal Protection Cases, 15 Pace L. Rev. 621, 663 (1995) (stating that by adopting the ADA, Congress attempted to utilize the Carolene Products theory to imply that a "heightened level of scrutiny" should be used in ADA cases).

[FN46]. See Phyllis Coleman & Ronald A. Shellow, Ask About Conduct, Not Mental Illness: A Proposal for Bar Examiners and Medical Boards to Comply With the ADA and the Constitution, 20 J. Legis. 147, 151 n.23

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(1994) (stating that "the ADA treats disabled persons as a suspect class."); Lowndes, supra note 40, at 446 (stating that "Congress clearly intended to create a new protected class-the disabled."); Miller, supra note 43, at 412 (stating that Congress applied "suspect class" test in ADA statutory language); and Montanaro, supra note 45, at 664 (stating that "Congress' intent was to transform the disabled into a suspect class for purposes of constitutional and statutory interpretation").

In a trilogy of employment cases, the Supreme Court recently narrowed the category of persons who are to be treated as "disabled" under the ADA. See also Sutton v. United Air Lines, Inc., 119 S. Ct. 2139 (1999); Murphy v. United Parcel Serv., Inc., 119 S. Ct. 2133 (1999); Albertsons, Inc v. Kirkingburg, 119 S. Ct. 2162 (1999) (sometimes called "the Sutton trilogy"). Nothing in these decisions, however, goes to the question of how the Court would construe discrimination cases involving individuals found to be "disabled" within the ADA's meaning.

[FN47]. On the relationship between this language and the heightened scrutiny requirement, see Crowder v. Kitagawa, 842 F. Supp. 1257, 1264 (D. Haw. 1994) (assuming application of strict scrutiny level in ADA cases); William Christian, Note, Normalization as a Goal: The Americans with Disabilities Act and Individuals with Mental Retardation, 73 Tex. L. Rev. 409, 424 (1994) (stating that laws treating persons with disabilities differently should be subject to heightened scrutiny).

In City of Cleburne v. Cleburne Living Ctr., Inc., 473 U.S. 432, 442 (1985), the Supreme Court had ruled that mental retardation was neither a suspect class nor a quasi-suspect class for purposes of equal protection analysis. In supporting its conclusion, it noted that a contrary decision would have made it difficult to distinguish other groups such as persons with mental illness "who have perhaps immutable disabilities setting them off from others, who cannot themselves mandate the desired legislative responses, and who can claim some degree of prejudice from at least part of the public at large." Id. at 445.

[FN48]. 42 U.S.C.A. § 12101(b)(4) (West Supp. 1999).

[FN49]. U.S. Const. amend. XIV, § 1.

[FN50]. See, e.g., Timothy M. Cook, The Americans With Disabilities Act: The Move to Integration, 64 Temp. L. Rev. 393, 434 (1991) (finding "unambiguously that Congress considered disability classifications to be just as serious and just as impermissible as racial categorizations that are given 'strict' or 'heightened' scrutiny, sustainable by the courts only if they are tailored to serve a 'compelling' governmental interest.").

Cook's article is cited approvingly in, inter alia, Muller v. Costello, 187 F.3d 298, 308 (2d Cir. 1999); Kathleen S. v. Department of Pub. Welfare, 10 F. Supp. 2d 460 (E.D. Pa. 1998), stay denied, 10 F. Supp. 2d 476 (E.D. Pa. 1998); Valentine v. American Home Shield Corp., 939 F. Supp, 1276, 1388 (N.D. Iowa 1996); Muller v. Hotsy Corp., 917 F. Supp. 1389, 1402 (N.D. Iowa 1996); Heather K. by Anita K. v. City of Mallard, Iowa, 887 F. Supp. 1249, 1263 (N.D. Iowa 1995); Hutchinson v. United Parcel Serv., Inc., 883 F. Supp. 379, 387 (N.D. Iowa 1995); and Fink v. Kitzman, 881 F. Supp. 1347, 1368 (N.D. Iowa 1995).

[FN51]. See Rubenstein, supra note 45, at 338-39, 350.

[FN52]. See generally 42 U.S.C.A. § 12101 (West 1995).

[FN53]. See City of Cleburne v. Cleburne Living Ctr., Inc., 473 U.S. 432, 454 (1985) (Stevens, J., joined by Burger, C.J., concurring) (Marshall, J., joined by Brennan and Blackmun, JJ., concurring in part and dissenting in part); see generally Cook, supra note 50, at 399-407.

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[FN54]. See Michael L. Perlin, "Where the Winds Hit Heavy on the Borderline:" Mental Disability Law Theory and Practice, "Us" and "Them," 31 Loy. L.A. L. Rev. 775, 779 (1998).

[FN55]. See Perlin, Promises, supra note 31, at 968.

[FN56]. 480 U.S. 273 (1987) (describing an individual with tuberculosis as a "handicapped individual" under the amended § 504 of the Rehabilitation Act of 1973).

[FN57]. Id. at 284.

[FN58]. See 42 U.S.C.A. § 12102(2)(C) (West 1995).

[FN59]. See generally H.R. Rep. No. 101-485, pt. 2 (1990).

[FN60]. See generally id.

[FN61]. Id. at 30. Discrimination against disabled persons "often results from false presumptions, generalizations, misperceptions, patronizing attitudes, ignorance, irrational fears[,] and pernicious mythologies." Id. at 57.

[FN62]. Elizabeth Morin, Note, Americans With Disabilities Act of 1990: Social Integration Through Employment, 40 Cath. U. L. Rev. 189, 189 (1990). On employers' myths in this context, see Peter David Blanck, The Emerging Work Force: Empirical Study of the Americans With Disabilities Act, 16 J. Corp. L. 693 (1991); and Peter David Blanck, Empirical Study of the Employment Provisions of the Americans With Disabilities Act: Methods, Preliminary Findings, and Implications, 22 N.M. L. Rev. 119, 129 (1992). On the significance of "misinformed stereotypes," see generally W. Robert Gray, The Essential-Function Limitation of the Civil Rights of People With Disabilities and John Rawls's Concept of Social Justice, 22 N. M. L. Rev. 295, 317 (1992).

[FN63]. H.R. Rep. No. 101-485, pt. 2, at 57 (stating that "[t]he determination that an individual with a disability will pose a safety threat to others must be made on a case-by-case basis and must not be based on . . . generalizations, misperceptions, . . . ignorance, irrational fears, [or] pernicious mythologies"); see also Renee Cyr, Note, The Americans With Disabilities Act: Implications for Job Reassignment and the Treatment of Hypersusceptible Employees, 57 Bklyn. L. Rev. 1237, 1273 (1992) (stating that "[g]eneralized fear about risks from the employment environment cannot be used by an employer to disqualify a person with a disability").

[FN64]. H.R. Rep. No. 101-485, pt. 3, at 45-46.

[FN65]. Id. at 48.

[FN66]. On the way that these negative stereotypes affect our homelessness policies, see generally Pedro Greer, Medical Problems of the Homeless: Consequences of Lack of Social Policy - A Local Approach, 45 U. Miami L. Rev. 407 (1990-91); Michael L. Perlin, Competency, Deinstitutionalization, and Homelessness: A Story of Marginalization, 28 Hous. L. Rev. 63 (1991).

[FN67]. See generally Michael L. Perlin, "Half-Wracked Prejudice Leaped Forth:" Sanism, Pretextuality, and Why and How Mental Disability Law Developed As It Did, 10 J. Contemp. Legal Issues 3 (1999) (discussing sanism and pretextuality); Perlin, supra note 1.

[FN68]. See generally Gordon W. Allport, The Nature of Prejudice (1955) (discussing the classic treatment);

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Elisabeth Young-Bruehl, The Anatomy of Prejudice (1996) (discussing an important new and different perspective); Perlin, supra note 1, ch. 2 (discussing roots of sanism and the relationship between sanism and other "ismic" behavior, such as racism or sexism or homophobia); Perlin, supra note 45.

[FN69]. See Koe v. Califano, 573 F.2d 761, 764 (2d Cir. 1978). The phrase "sanism" was, to the best of my knowledge, coined by Dr. Morton Brinbaum.

[FN70]. See Perlin, supra note 67, at 92-93 (discussing Dr. Morton Birnbaum's insights).

[FN71]. See generally Michael L. Perlin, The Jurisprudence of the Insanity Defense (1994) (discussing sanism and its origins and causes).

[FN72]. Charles Sevilla, The Exclusionary Rule and Police Perjury, 11 San Diego L. Rev. 839, 840 (1974). See also Michael L. Perlin, Morality and Pretextuality, Psychiatry and Law: Of "Ordinary Common Sense," Heuristic Reasoning, and Cognitive Dissonance, 19 Bull. Am. Acad. Psychiatry & L. 131, 133 (1991).

[FN73]. See Perlin, Promises, supra note 31.

[FN74]. Compare Niece v. Fitzner, 941 F. Supp. 1497 (E.D. Mich. 1996) (refusing to follow Torcasio v. Murray, 57 F.3d 1340 (4th Cir. 1995) (declining to apply the ADA to state prison cases), with Pennsylvania Dep't of Corrections v. Yeskey, 118 S. Ct. 1952 (1998) (finding unanimously that the ADA does apply to state prison cases). This is further discussed in Michael L. Perlin, Hidden Agendas and Ripple Effects: Implications of Three Recent Supreme court Decisions for Forensic Psychiatrists, 2. J. Forensic Psychology Practice - (2000) (in press).

[FN75]. Perlin, Promises, supra note 31 at 955.

[FN76]. See Jane West, The Social Policy Context of the Act, in The Americans With Disabilities Act: From Policy to Practice 3, 9 (Jane West ed. 1991); see also infra text accompanying notes 223-25 (discussing comments of Senator Helms in floor debate on the ADA).

[FN77]. See Tucker, supra note 39, at 16-17 (describing particularly cruel examples); see also Cook, supra note 50, at 399-41, 424.

[FN78]. See, e.g., Perlin, supra note 45, at 393-97 (citing, inter alia, Sander Gilman, Difference and Pathology: Stereotypes of Sexuality, Race and Madness (1985)); Thomas Grisso & Paul Appelbaum, Mentally Ill and Non-Mentally Ill Patients' Abilities to Understand Informed Consent Disclosures for Medication, 15 Law & Hum. Behav. 377, 385-86 (1991); Michael L. Perlin, Unpacking the Myths: The Symbolism Mythology of Insanity Defense Jurisprudence, 40 Case W. Res. L. Rev. 599, 693-96 (1989-90); Steven Schwartz, Damage Actions as a Strategy for Enhancing the Quality of Care of Persons With Mental Disabilities, 17 N.Y.U. Rev. L. & Soc. Change 651, 681 (1989-90); Linda Teplin, The Criminality of the Mentally Ill: A Dangerous Misconception, 142 Am. J. Psychiatry 593, 597-98 (1985).

[FN79]. See generally Wayne Ramage, The Pariah Patient: The Lack of Funding for Mental Health Care, 45 Vand. L. Rev. 951 (1992) (discussing the way that public perceptions of mental illness and the accompanying stigma perpetuate inadequate treatment of the mentally ill).

[FN80]. This section of the article and the accompanying footnotes were developed from Michael L. Perlin, "Make Promises by the Hour:" Sex, Drugs, the ADA, and Psychiatric Hospitalization, 46 DePaul L. Rev. 947,

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960-62 (1997).

[FN81]. See 42 U.S.C.A. § § 12131-165 (West 1995); see also Alsbrook v. City of Maumelle, 184 F.3d 999 (8th Cir. 1999), cert. granted, in part, Alsbrook v. Arkansas, 120 S. Ct. 1003 (2000), cert. dismissed, 120 S. Ct. 1265 (2000).

[FN82]. 42 U.S.C.A. § 12132 (West 1995).

[FN83]. L.C. v. Olmstead, 138 F.3d 893, 901 (11th Cir. 1998). See generally H.R. Rep. No. 101-485, pt. 2 (1989).

[FN84]. See Roe v. Community Comm'n, 926 F. Supp. 74 (N.D. W. Va. 1996).

[FN85]. Charles Q. v. Houstoun, Civ. A., No. 1, CV-95-280 (M.D. Pa. Apr. 22, 1996), reported in Rights in Facilities, 20 Ment. & Phys. Dis. L. Rep. 490, 490 (1996) see also Halderman v. Pennhurst State Sch. & Hosp., 784 F. Supp. 215, 224 (E.D. Pa. 1992), aff'd, 977 F.2d 568 (3d Cir. 1992) (stating that "in enacting the Americans With Disabilities Act of 1990, Congress affirmed that § 504 prohibits unnecessary segregation").

[FN86]. See Perlin, supra note 9, § 6.44AA at, 70 n.473.43d1 (Cum. Supp. 1999).

[FN87]. See Clark v. Virginia Bd. of Bar Exam'rs., 880 F. Supp. 430 (E.D. Va. 1995), and Ellen S. v. Florida Bd. of Bar Exam'rs., 859 F. Supp. 1489 (S.D. Fla. 1994) (enjoining inquiries); McCready v. Illinois Bd. of Admissions, 1995 WL 29609 (N.D. Ill. 1995), and Campbell v. Greisberger, 865 F. Supp. 115 (W.D.N.Y. 1994) (allowing inquiries). See also supra note 46 (discussing the Sutton trilogy, and noting that immediately after the Court handed down its decision, the Supreme Court vacated the Second Circuit's decision in another bar case, Bartlett v. New York State Bd. of Bar Exam'rs., 156 F.3d 321 (2d Cir. 1998), vacated, 119 S. Ct. 2388 (1999)).

[FN88]. See, e.g., Argen v. New York State Bd. of Bar Exam'rs., 860 F. Supp. 84 (W.D.N.Y. 1994); In re Rubenstein, 637 A.2d 1131 (Del. 1994); and In re Underwood, 1993 WL 649283 (Me. 1993).

[FN89]. See Susie v. Apple Tree Preschool & Child Care Ctr., Inc., 866 F. Supp. 390 (N.D. Iowa 1994); Kerno v. Sandoz Pharm. Corp., 1994 WL 511289 (N.D. Ill. 1994); Voytek v. University of Cal., 1994 WL 478805 (N.D. Cal. 1994). See generally Susan Stefan, "You'd Have to Be Crazy to Work Here:" Worker Stress, the Abusive Workplace, and Title I of the ADA, 31 Loy. L.A. L. Rev. 795, 805 (1998) (arguing that "judicial assumptions about the nature of psychiatric disabilities and essential employment functions have resulted in the near-total failure of the ADA to protect individuals with psychiatric disabilities from employment discrimination"); Susan Stefan, Psychiatric Disability and Discrimination Law (2000) (in press).

[FN90]. See Concerned Parents to Save Dreher Park Ctr. v. City of West Palm Beach, 846 F. Supp. 986 (S.D. Fla. 1994), supplemented, 853 F. Supp. 424 (S.D. Fla. 1994).

[FN91]. See T.P. v. DuBois, 843 F. Supp. 775 (D. Mass. 1993).

[FN92]. See Melton v. Community for Creative Non-Violence, 1993 WL 367113 (D.C. Cir. 1993).

[FN93]. 46 F.3d 325 (3d Cir. 1995), cert. denied, 516 U.S. 813 (1995).

[FN94]. See id. at 327.

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[FN95]. See id. at 335.

[FN96]. Id. at 332 (quoting 42 U.S.C.A. § 12101(a)(2) (West 1995)).

[FN97]. Id. (quoting 42 U.S.C.A. § 12101(a)(8) (West 1995)).

[FN98]. Id. at 335.

[FN99]. Id. at 336 (quoting 42 U.S.C.A. § 12101(3) (West 1995)).

[FN100]. See id. at 338.

[FN101]. Id. at 338-39 (citations omitted).

[FN102]. This section of the article and the accompanying footnotes were developed from Michael L. Perlin, "Make Promises by the Hour:" Sex, Drugs, the ADA, and Psychiatric Hospitalization, 46 DePaul L. Rev. 947, 962-64 (1997).

[FN103]. See Cook, supra note 50.

[FN104]. See id. at 429.

[FN105]. Id. at 423.

[FN106]. Id. at 424.

[FN107]. See id. at 427.

[FN108]. Id. at 413.

[FN109]. Id. at 466 (discussing Youngberg v. Romeo 457 U.S. 307 (1982)); see Olmstead v. L.C., 119 S. Ct. 2176, 2181 (1999) (noting that the Court specifically underscored that there was no constitutional issue presented to the Court in this case). On the professional judgment standard, see generally Susan Stefan, Leaving Civil Rights to the Experts: From Deference to Abdication Under the Professional Judgment Standard, 102 Yale L.J. 639 (1992); 2 Perlin, supra note 9, § 3A-9.4 at 95-98 (2d ed. 1999).

[FN110]. See Sutton v. United Air Lines, 119 S. Ct. 2139, 2152 (1999) (Ginsburg, J., concurring) (stating that "Congress's use of the [[discrete and insular minority] phrase . . . is a telling indication of its intent to restrict the ADA's coverage to a confined, and historically disadvantaged, class").

[FN111]. Perlin, ADA, supra note 31, at 38.

[FN112]. In addition to the cases cited infra notes 113-118, see also Helen L. v. DiDario, 46 F.3d 325, 331 (3d Cir. 1995); Easley by Easley v. Snider, 841 F. Supp. 668, 677 (E.D. Pa. 1993), rev'd, 36 F.3d 297 (3d Cir. 1994).

[FN113]. See Heather K. v. City of Mallard, Iowa, 887 F. Supp. 1249, 1251 (N.D. Iowa 1995).

[FN114]. See Muller v. Costello, 187 F.3d 298, 302 (2d Cir. N.Y. 1999); Valentine v. American Home Shield Corp., 939 F. Supp. 1376, 1379 (N.D. Iowa 1996).

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[FN115]. See Hutchinson v. United Parcel Service, Inc., 883 F. Supp. 379, 385 (N.D. Iowa 1995).

[FN116]. See Fink v. Kitzman, 881 F. Supp. 1347, 1356 (N.D. Iowa 1995).

[FN117]. See Muller v. Hotsy Corp., 917 F. Supp. 1389, 1399 (N.D. Iowa 1996).

[FN118]. See Dare v. California, 191 F.3d 1167, 1169 (9th Cir. 1999).

[FN119]. 10 F. Supp. 2d 460 (E.D. Pa. 1998).

[FN120]. See id. at 471, stay denied, 10 F. Supp.2d 476 (E.D. Pa. 1998).

[FN121]. See 2 Perlin, supra note 9, § 3A-12.1, at 120-21 n.965 (2d ed. 1999) (citing cases). Another major potential persuasive scholarly force is Rubenstein, supra note 45, at 319 (urging litigators to focus on the ADA as a source of rights in combating discrimination in health benefits for persons with psychiatric disabilities).

[FN122]. 119 S. Ct. 2176 (1999).

[FN123]. See L.C. v. Olmstead, 138 F.3d 893 (11th Cir. 1998), aff'd and remanded, 119 S. Ct. 2176 (1999).

[FN124]. L.C., 138 F.3d at 897.

[FN125]. Id. at 895. Although both plaintiffs were transferred to community settings prior to the court's decision, the court declined to find the case moot as such cases were "capable of repetition, yet evading review." Id. at n.2.

[FN126]. Id. at 895.

[FN127]. See id.

[FN128]. Id. (quoting 28 C.F.R. § 35.130(b)(7) (1999)).

[FN129]. See id. at 896 (citing 42 U.S.C.A. §§ 12132, 12134 (West 1995)).

[FN130]. See id. at 896-98.

[FN131]. Id. at 897 (quoting 28 C.F.R. § 35.130(d) (1999)).

[FN132]. Id. (summarizing 28 C.F.R. § 35.130(d) (1999)).

[FN133]. Id.

[FN134]. Id.

[FN135]. Id. at 898.

[FN136]. Id.

[FN137]. Id.

[FN138]. Id. at 899 (quoting 42 U.S.C.A. § 12101(a)(8) (West 1995), and citing Willis v. Conopco, Inc., 108

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F.3d 282, 285 (11th Cir. 1997) (finding that the goal of the ADA is to ensure people with disabilities can participate in society)).

[FN139]. Id. at 899.

[FN140]. 46 F.3d 325 (3d Cir. 1995); see also supra text accompanying notes 93-101.

[FN141]. 473 U.S. 432, 455-78 (1985).

[FN142]. L.C., 138 F.3d at 899-900 (quoting Helen L., 46 F.3d at 335, and City of Cleburne, 473 U.S. 432, 461-64).

[FN143]. Id. at 901.

[FN144]. 469 U.S. 287 (1985).

[FN145]. L.C., 138 F.3d at 901 (quoting Alexander, 469 U.S. at 295-96).

[FN146]. See id. at 902.

[FN147]. Id. (quoting 28 C.F.R. § 35.130(b)(7) (1999)).

[FN148]. Id. (quoting H.R. Rep. No. 101-485, pt. 3, at 50). The L.C. court distinguished cases such as S.H. v. Edwards, 886 F.2d 292 (11th Cir. 1989), as those cases did not have occasion to consider the "integration regulation" that was central to the methodology in deciding ADA cases. See id. at 901-02.

[FN149]. Id. at 902.

[FN150]. Id.

[FN151]. Id. at 902-03.

[FN152]. Id. at 903. The court further stressed "because the State's own professionals agreed that E.W. could be placed in a less segregated setting, the State has failed to demonstrate that there is a material issue of fact for trial . . . ." Id.

[FN153]. Id. at 904. "Under Title II, '[a] public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.'" Id. (quoting 28 C.F.R. § 35.130 (b)(7) (1999)).

[FN154]. Id.

[FN155]. Id. at 904-05 (citing United States v. Bd. of Trustees for Univ. of Alabama, 908 F.2d 740 (11th Cir. 1990)).

[FN156]. Id. at 905. In an accompanying footnote, the court added: "We note that this case is not a class action, but a challenge brought on behalf of two individual plaintiffs. Our holding is not meant to resolve the more difficult questions of fundamental alteration that might be present in a class action suit seeking deinstitutionalization

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of a state hospital." Id. at n.10.

[FN157]. See Olmstead v. L.C., 119 S. Ct. 2176, 2176, 2179 (1999). Justices O'Connor, Breyer, Souter, and Stevens (the latter in a separate opinion) joined Justice Ginsburg in most of her opinion. Justice Stevens, who would have preferred to simply affirm the Eleventh Circuit's opinion, joined with these four justices in all of the opinion save that portion that outlined the State's obligations in such cases, see infra text accompanying note 180. Justice Kennedy filed a concurring opinion, joined in part by Justice Breyer, see infra text accompanying notes 181-193. Justice Thomas dissented for himself, the Chief Justice, and Justice Scalia, see infra text accompanying notes 194-198.

[FN158]. See Olmstead, 119 S. Ct. at 2176 (1999).

[FN159]. Id. at 2181 (quoting 42 U.S.C. § 12101 (a)(5)).

[FN160]. Id. at 2183 (referring to 28 C.F.R. pt. 35, app. A (1998)).

[FN161]. See id.

[FN162]. Id. at 2185.

[FN163]. Id.

[FN164]. Id. at 2186.

[FN165]. See id. (discussing 42 U.S.C. § 6010 (2), as construed in Pennhurst State Sch. & Hosp. v. Halderman, 451 U.S. 1, 24 (1984)). See generally 2 Perlin, supra note 9, § 7.13, at 617-23 (2d ed. 1999).

[FN166]. Olmstead, 119 S. Ct. at 2187.

[FN167]. Id.

[FN168]. Id.

[FN169]. Id. at 2188.

[FN170]. Id.

[FN171]. Id.

[FN172]. Id. at n.14.

[FN173]. Although this section of the opinion was co-signed by only four justices (Ginsburg, Souter, Breyer and O'Connor), a reading of it in tandem with Justice Kennedy's concurrence, see infra text accompanying notes 181-193, makes it likely that it will be treated by lower courts as having the weight of a majority opinion.

[FN174]. Olmstead, 119 S. Ct. at 2188.

[FN175]. Id. at 2189.

[FN176]. Id. At one point, Georgia had proposed such a placement for one of the named plaintiffs, and then later

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retracted it. See id.

[FN177]. Id. On this point, the opinion cited, inter alia, Justice Blackmun's concurrence in Youngberg v. Romeo, 457 U.S. 307 (1982): "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." Id. at 327.

[FN178]. Olmstead, 119 S. Ct. at 2189.

[FN179]. Id. at 2190.

[FN180]. See id.

[FN181]. Id. at 2192.

[FN182]. Id. at 2191.

[FN183]. Id.

[FN184]. Id. (quoting E. Fuller Torrey, Out of the Shadows 11 (John Wiley & Sons, Inc. 1997)).

[FN185]. Id. at 2191-92.

[FN186]. Id. at 2191.

[FN187]. Id.

[FN188]. Id. at 2192.

[FN189]. Justice Breyer joined in the prior portion of Justice Kennedy's concurrence, but not in the portion discussed infra text accompanying notes 190-93.

[FN190]. See Olmstead, 119 S. Ct. at 2192. The Court stated:

> If they could show that persons needing psychiatric or other medical services to treat a mental disability are subject to a more onerous condition than are persons eligible for other existing state medical services, and if removal of the condition would not be a fundamental alteration of a program or require the creation of a new one, then the beginnings of a discrimination case would be established.

Id.

[FN191]. Id. at 2193.

[FN192]. Id.

[FN193]. Id.

[FN194]. Id. at 2194.

[FN195]. Id. at 2197.

[FN196]. Id. at 2198.

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[FN197]. Id. at 2199.

[FN198]. Id.

[FN199]. See id. at 2176.

[FN200]. See id. at 2181.

[FN201]. Id. at 2185.

[FN202]. Id. at 2186.

[FN203]. Id. at 2187.

[FN204]. Id.

[FN205]. See supra text accompanying note 109.

[FN206]. See Olmstead, 119 S. Ct. at 2181.

[FN207]. Id. at 2189.

[FN208]. Id.

[FN209]. To my mind, Torrey's critique is a terribly flawed one. See Perlin, supra note 66, at 87. See generally Michael L. Perlin et al., Therapeutic Jurisprudence and the Civil Rights of Institutionalized Mentally Disabled Persons: Hopeless Oxymoron or Path to Redemption?, 1 Psychol. Pub. Pol'y & L. 80, 84-118 (1995).

[FN210]. Olmstead, 119 S. Ct. at 2191. On the impact of "litigaphobia" (fear of litigation) on mental disability law jurisprudence, see, e.g., Michael L. Perlin, Tarasoff and the Dilemma of the Dangerous Patient: New Directions for the 1990s, 16 Law & Psychol. Rev. 29, 61-62 (1992).

[FN211]. See 1 Perlin, supra note 9, § 2C-7.3, at 491-99 (2d ed. 1998).

[FN212]. See Perlin, Promises, supra note 31. Olmstead has been cited sparingly in the months since it was decided; Rodriguez v. City of New York, 197 F.3d 611, 618-19 (2d Cir. 1999) (distinguishing Olmstead in a case holding that state's implementation of certain programs used to determine number of personal-care service hours to which persons with disabilities are entitled did not violate the ADA); Dare v. State of California, 191 F.3d 1167, 1176 n.7 (9th Cir. 1999) (referring to Olmstead's characterization of "unjustified isolation" as "discrimination based on disability," and to it having spoken "approvingly" of the ADA's efforts to end that isolation in a disability parking sticker case); Alsbrook v. City of Maumelle, 184 F.3d 999, 1016 n.24 (8th Cir. 1999), cert. granted, in part, Alsbrook v. Arkansas, 120 S. Ct. 1003 (2000), cert. dismissed, 120 S. Ct. 1265 (2000) (relying on Olmstead's interpretation of the meaning of "reasonable modifications" in an 11th Amendment case).

[FN213]. See 1 Perlin, supra note 9, §§ 3A-12 to 12.3 (2d ed. 1998); see also Michael L. Perlin, "Their Promises of Paradise:" Will Olmstead v. L.C. Resuscitate the Constitutional "Least Restrictive Alternative" Principle in Mental Disability Law? (work in progress, on file with author).

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[FN214]. See Michael L. Perlin, "For the Misdemeanor Outlaw:" The Impact of the ADA on the Institutionalization of Criminal Defendants with Mental Disabilities (unpublished manuscript, on file with the Alabama Law Review).

[FN215]. This section of the article and the accompanying footnotes were developed from Michael L. Perlin, The ADA and Persons with Mental Disabilities: Can Sanist Attitudes Be Undone?, 8 J.L. & Health 15, 29-43 (1993-94); Michael L. Perlin, "Half-Wracked Prejudice Leaped Forth:" Sanism, Pretextuality, and Why and How Mental Disability Law Developed As It Did, 10 J. Contemp. Legal Issues 3, 4-5; Michael L. Perlin, "Make Promises by the Hour:" Sex, Drugs, the ADA, and Psychiatric Hospitalization, 46 DePaul L. Rev. 947, 976-82 (1997).

[FN216]. See supra text accompanying notes 63-64.

[FN217]. See EEOC v. Kinney Shoe Corp., 917 F. Supp. 419, 431-32 (W.D. Va. 1996) (stating that firing an employee due to timing of his epileptic seizures was not "unlawful discrimination" under ADA).

[FN218]. I use this word consciously. It is impossible to assess the ADA's ultimate impact without some consideration of the value of "tolerance." See, e.g., Martha Minow, Putting Up and Putting Down: Tolerance Reconsidered, 28 Osgoode Hall L.J. 409 (1990); Steven D. Smith, The Restoration of Tolerance, 78 Cal. L. Rev. 305 (1990).

[FN219]. Michael L. Perlin & Deborah A. Dorfman, Sanism, Social Science, and the Development of Mental Disability Law Jurisprudence, 11 Behav. Sci. & L. 47, 54 n.47 (1993) (discussing Michael Saks, Expert Witnesses, Nonexpert Witnesses, and Nonwitness Experts, 14 Law & Hum. Behav. 291, 293 (1990)).

[FN220]. See Taylor v. Principal Fin. Group, Inc., 93 F.3d 155, 165 (5th Cir. 1996), reh'g. denied (1996) (discussing disabilities that are not "open, obvious, and apparent"); see also Julie Odegard, The Americans with Disabilities Act: Creating "Family Values" for Physically Disabled Parents, 11 Law & Ineq. J. 533 (1993) (discussing discrimination against parents with physical disabilities by both state support policies and the court system).

[FN221]. See 42 U.S.C.A. § 12201(c)(1) (West 1995); see also Parker v. Metropolitan Life Ins. Co., 121 F.3d 1006 (6th Cir. 1997), cert. denied, 522 U.S. 1084 (1998) (stating that the ADA's prohibition against disability discrimination in public accommodations did not prohibit an employer from providing a long-term disability plan which contained longer benefits for employees who become disabled due to physical illness than for those who become disabled due to mental illness).

[FN222]. See 42 U.S.C.A. § 12201(c). See generally Christopher Jones, Legislative "Subterfuge?:" Failing to Insure Persons with Mental Illness Under the Mental Health Parity Act and the Americans with Disabilities Act, 50 Vand. L. Rev. 753 (1997) (discussing the lack of protection for the mentally ill under the Mental Health Parity Act (MHPA) and the ADA from private insurance limitations for mental health care); and Ramage, supra note 79, at 969-70.

[FN223]. See Perlin, ADA, supra note 31, at 27-28.

[FN224]. See Deborah K. Dallmann, The Lay View of What "Disability" Means Must Give Way to What Congress Says It Means: Infertility as a "Disability" Under The Americans With Disabilities Act, 38 Wm. & Mary

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L. Rev. 371 (1996) (discussing factual backdrop of Pacourek v. Inland Steel Co., 858 F.Supp. 1393 (N.D. Ill. 1994)):

Ms. Pacourek alleged that in 1992, an Inland manager, Thomas Wides, "verbally abused [her] concerning her pregnancy related condition by expressing doubt as to her ability to become pregnant and her ability to combine pregnancy and her career." She claimed that she was "treated like she had an infectious disease" and that one top-level manager told her, "I don't give a damn about the law. I only care about Inland Steel. If God had wanted you to have children, . . . he would have given them to you."

Id. at 394-95 (footnotes omitted).

[FN225]. See 1 Perlin, supra note 9, § 2A-7.1, at 186-88 (2d ed. 1998) (citing and discussing, inter alia, Paul Chodoff, The Case for Involuntary Hospitalization of the Mentally Ill, 133 Am. J. Psychiatry 496, 501 (1976); Paul Chodoff, Involuntary Hospitalization of the Mentally Ill as a Moral Issue, 141 Am. J. Psychiatry 384, 388 (1984); William McCormick, Involuntary Commitment in Ontario: Some Barriers to the Provision of Proper Care, 124 Can. Med. Ass'n J. 715, 717 (1981)).

On efforts to limit the ADA's protections to the "truly disabled," compare Overton v. Tar Heel Farm Credit, 942 F. Supp. 1066, 1068 (E.D. N.C. 1996) (relying on the language of Forrisi v. Bowen, 794 F.2d 931, 934 (4th Cir. 1986), a pre-ADA case), with Robert Hammel, Some Reflections on New York City's Disability Law, 23 Fordham Urb. L.J. 1195, 1216 (1996) (local human rights law should be limited to protect only the "seriously disabled"). Hammel is responded to carefully, thoughtfully, and persuasively in Janet Eriv, Persistent Misconceptions: A Response to Robert Hammel, 23 Fordham Urb. L.J. 1219 (1996). The Supreme Court has recently narrowed the universe of individuals who come within ADA protections. See generally supra note 46 (discussing Sutton v. United Air Lines, Inc. 119 S. Ct. 2139 (1999); Murphy v. United Parcel Service, Inc., 119 S. Ct. 2133 (1999); Albertsons, Inc. v. Kirkingburg, 119 S. Ct. 2162 (1999)).

[FN226]. Compare United States v. Cohen, 733 F.2d 128, 134-35 (D.C. Cir. 1985) (Scalia, J.) (rejecting immutability argument in equal protection challenge to constitutionality of post-insanity acquittal commitment statute), with James Wilson, Constraints of Power: The Constitutional Opinions of Judges Scalia, Bork, Posner, Easterbrook, and Winter, 40 U. Miami L. Rev. 1171, 1198-99 (1986).

[FN227]. For a general discussion on the way that public fears about the purported link between mental illness and dangerousness "drive the formal laws and policies governing mental disability jurisprudence," see John Monahan, Mental Disorder and Violent Behavior: Perceptions and Evidence, 47 Am. Psychol. 511, 511 (1992); see also Allan H. Macurdy, The Americans With Disabilities Act: Time For Celebration, or Time for Caution?, 1 Pub. Int'l. L. J. 21, 32-34 (1991) (discussing the ways that stereotypes pervade our views of persons with disabilities).

[FN228]. 135 Cong. Rec. 19871 (daily ed. Sept. 7, 1989) (statement of Senator Armstrong), available in WESTLAW, at 64.

[FN229]. Id. at 19878 (remarks of Senator Domenici).

[FN230]. For illustrative cases, compare Koehler v. State, 830 S.W.2d 665 (Tex. App. 1992), reh'g denied (1992) (being determined incompetent to manage one's own affairs not a prima facie showing of incompetency to stand trial), with Godinez v. Moran, 509 U.S. 389 (1993) (Blackmun, J., dissenting):

But the majority cannot isolate the term "competent" and apply it in a vacuum, divorced from its specific context. A person who is "competent" to play basketball is not thereby "competent" to play the violin. The majority's monolithic approach to competency is true to neither life nor the law. Competency for one pur-

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pose does not necessarily translate to competency for another purpose.
Id. at 413.On the multiple meanings of competency, see generally Michael L. Perlin, "The Borderline Which Separated You From Me:" The Insanity Defense, the Authoritarian Spirit, the Fear of Faking, and the Culture of Punishment, 82 Iowa L. Rev. 1375, 1378-97 (1997); Bruce J. Winick, Competency to Consent to Voluntary Hospitalization: A Therapeutic Jurisprudence Analysis of Zinermon v. Burch, in Essays in Therapeutic Jurisprudence 83, 102-05 (David B. Wexler & Bruce J. Winick eds. 1991).
[FN231]. See, e.g., Peter Blanck, The Americans with Disabilities Act and the Emerging Workforce: Employment of People with Mental Retardation 59-60 (1998); Peter David Blanck & Mollie Weighner Marti, Attitudes, Behavior and the Employment Provisions of the Americans with Disabilities Act, 42 Vill. L. Rev. 345, 391-92 (1997); Peter David Blanck, Civil Rights, Learning Disability, and Academic Standards, 2 J. Gender, Race & Just. 33, 53-54 (1998); Peter David Blanck, Students with Learning Disabilities, Reasonable Accommodations, and the Rights of Colleges and Universities to Establish and Enforce Academic Standards: Guckenberger v. Boston University, 21 Mental & Physical Disability L. Rep. 679, 684 (1997) (linking sanism to ADA inquiries).

[FN232]. See Olmstead v. L.C., 119 S. Ct. 2176 (1999). It is not at all clear how it is to be determined if the judgment is reflective of "reasonable assessments of [the State's] own professionals . . . ." Id. at 2188.

[FN233]. See, e.g., 2 Perlin, supra note 9, § 3A (2d ed. 1999).

[FN234]. 325 F. Supp. 781 (M.D. Ala. 1971). See generally 2 Perlin, supra note 9, §§ 3A-3.1 (2d ed. 1999).

[FN235]. 446 F. Supp. 1295 (E.D. Pa. 1977). See generally 2 Perlin, supra note 9, §§ 7.10-7.12 (2d ed. 1999).

[FN236]. See generally 2 Perlin, supra note 9, § 3A-3.1, at 24 n.152 (2d ed. 1999) (stating that the defendants were still not in compliance with certain aspects of Wyatt orders after 25 years). E.g., Wyatt v. Rogers, 985 F. Supp. 1356 (M.D. Ala. 1997); Wyatt v. Rogers, 1998 WL 862920 (M.D. Ala. 1998).

[FN237]. See Olmstead, 119 S. Ct. at 2191.

[FN238]. See, e.g., Perlin, supra note 9, § 7.02, at 108 n.26 (1999 Cum. Supp.).

[FN239]. See Michael L. Perlin, "The Executioner's Face Is Always Well-Hidden:" The Role of Counsel and the Courts in Determining Who Dies, 41 N.Y.L. Sch. L. Rev. 201, 231 (1996).

[FN240]. 504 U.S. 127 (1992).

[FN241]. Id. at 139; see also 2 Perlin, supra note 9, § 3B-8.3, at 323-29 (2d ed. 1999).

[FN242]. 119 S. Ct. 2139 (1999).

[FN243]. Id. at 2147.

[FN244]. See Michael L. Perlin, Fatal Assumption: A Critical Evaluation of the Role of Counsel in Mental Disability Cases, 16 Law & Hum. Behav. 39 (1992).

[FN245]. See Michael L. Perlin, Out of Bedlam: The Truth About Deinstitutionalization, 8 N.Y. L. Sch. J. Hum. Rts. 557 (1990-91) (book review) .

[N]urtured by radical psychiatrists (such as Thomas Szasz and R.D. Laing), spurred on by politic-

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ally-activist organizations pushing egalitarian social agendas (such as the ACLU), a cadre of brilliant but diabolical patients' rights lawyers dazzled sympathetic and out-of-touch judges with their legal legerdemain - abetted by wooly-headed social theories, inapposite constitutional arguments, some oh-my-god worst-case anecdotes about institutional conditions, and a smattering of "heartwarming successful [[deinstitutionalization] cases"-as a result of which courts entered orders "emptying out the mental institutions" so that patients could "die with their rights on." When cynical bureaucrats read the judicial handwriting on the hospital walls, they then joined the stampede, and the hospitals were thus emptied. Ergo deinstitutionalization. Ergo homelessness. Endgame.
Id. at 559-60.
[FN246]. See Olmstead v. L.C., 119 S. Ct. 2176 (1999).

[FN247]. See id. at 2185.

[FN248]. See id. at 2187.

[FN249]. Id.

[FN250]. Id. (emphasis added).

[FN251]. See generally Perlin, supra note 1; Perlin, supra note 67 (explaining such topics as sanism and pretextuality and the role they play in mental disability law).

[FN252]. See supra note 53 (discussing City of Cleburne v. Cleburne Living Center, 473 U.S. 432 and explaining the various stances taken by the Justices).

[FN253]. Olmstead, 119 S. Ct. at 2191.

[FN254]. See Perlin, supra note 230, at 1397.

[FN255]. See Michael L. Perlin, Power Imbalances in Therapeutic and Forensic Relationships, 9 Behav. Sci. & L. 111, 125 n.112 (1991).

[FN256]. Michael L. Perlin, Pretexts and Mental Disability Law: The Case of Competency, 47 U. Miami L. Rev. 625, 662 (1993).

[FN257]. David Bazelon, Institutionalization, Deinstitutionalization, and the Adversary Process, 75 Colum. L. Rev. 897, 909 (1975).

[FN258]. State hospital populations are far less now than they were ten, twenty, or thirty years ago. See Linda S. Dakin, Homelessness: The Role of the Legal Profession in Finding Solutions Through Litigation, 21 Fam. L.Q. 93, 104 (1987) (discussing a 70 percent decline in New York from 1965 to 1982). Researchers have pointed out that, in some jurisdictions, when involuntary civil commitment laws are loosened, the number of newly admitted patients increases significantly.

[FN259]. 10 F. Supp.2d 460 (E.D. Pa. 1998), stay denied, 10 F. Supp.2d 476 (E.D. Pa. 1998).

[FN260]. There were three classes in the Kathleen S. case: residents who would be placed in the community following closure, those who were suitable for community treatment but for whom inadequate facilities existed, and those not appropriate for community placement.

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[FN261]. See, e.g., Bruce Winick, Therapeutic Jurisprudence Applied: Essays on Mental Health Law (1997); Essays in Therapeutic Jurisprudence (David Wexler & Bruce Winick eds. 1991); Law in a Therapeutic Key: Recent Developments in Therapeutic Jurisprudence (David Wexler & Bruce Winick eds. 1996); Therapeutic Jurisprudence: The Law as a Therapeutic Agent (David Wexler ed. 1990); Essays, supra note 230; David B. Wexler, Applying the Law Therapeutically, 5 App'l. & Preven. Psychol. 179 (1996); David B. Wexler, Putting Mental Health Into Mental Health Law: Therapeutic Jurisprudence, 16 Law & Hum. Behav. 27 (1992); David B. Wexler, Reflections on the Scope of Therapeutic Jurisprudence, 1 Psychol., Pub. Pol'y & L. 220 (1995); Bibliography of Therapeutic Jurisprudence, 10 N.Y.L. Sch. J. Hum. Rts. 915 (1993); 1 Perlin, supra note 9, § 2D-3, at 534-41(2d ed. 1998).

[FN262]. See, e.g., Michael L. Perlin, Therapeutic Jurisprudence: Understanding the Sanist and Pretextual Bases of Mental Disability Law, 20 New Eng. J. on Crim. & Civ. Confinement 369 (1994); Michael L. Perlin, A Law of Healing (unpublished manuscript, on file with the University of Cincinnati Law Review).

[FN263]. Riley, supra note 4, at 104.

[FN264]. Muir, supra note 11.
17 T.M. Cooley L. Rev. 53

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Fiduciary Appointments in New York

A Report to Chief Judge Judith S. Kaye and
Chief Administrative Judge Jonathan Lippman

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Executive Summary

Fiduciaries perform a wide range of functions in the New York courts. Courts, for example, appoint fiduciaries as guardians for incapacitated persons, as receivers for properties involved in foreclosure proceedings and as guardians ad litem for children involved in litigation. Fiduciary appointees are usually private attorneys, who are paid for their services from the assets of the litigants.

The fiduciary appointment process has been the target of extensive public criticism over the years, with charges that judges have selected fiduciaries based on factors other than merit and complaints that fiduciary appointees have mishandled cases or received excessive fees from their assignments. Following widely publicized allegations regarding the connection between political party service and receipt of fiduciary appointments in Brooklyn Supreme Court, Chief Judge Judith S. Kaye last year announced a broad program to reform the State's fiduciary appointment process. She created a high-level Commission on Fiduciary Appointments to examine existing rules and practices and make recommendations for improvement. She also established an Office of the Special Inspector General for Fiduciary Appointments, with jurisdiction to monitor and enforce existing rules governing the appointments.

This report is based on a comprehensive investigation, involving hundreds of interviews and examination of thousands of court files, by the Office of the Special Inspector General and the court system's Internal Auditing Unit. Most of the individuals involved in the cases discussed in the report were interviewed. The findings have been shared with the Commission on Fiduciary Appointments, which will be releasing its own report and recommendations shortly. The findings are being released now so that the public can more fully understand the basis upon which many of the Commission's recommendations are being made and better evaluate its proposed reforms of fiduciary appointment rules and practice.

Brief Synopsis of the Rules

The cornerstone of regulatory oversight of the fiduciary appointment process is Part 36 of the Rules of the Chief Judge. Under Part 36, individuals seeking appointment as a fiduciary must submit an application to the Office of Court Administration (OCA). OCA compiles lists of the applicants, which are made available to the judges. Anyone is eligible for inclusion on the lists, except a relative within the sixth degree of relationship of a Unified Court System judge. The rules contemplate that judges will make fiduciary appointments from the lists, although a judge may deviate from the lists in certain circumstances.

Part 36 also requires appointees, prior to accepting an appointment, to file with the court a written certification that: (1) the appointee is not related to a judge within the sixth degree of relationship; and (2) the appointment will not result in the appointee receiving within a 12-month period more than one appointment in which the anticipated compensation will exceed $5,000 (the "$5,000 rule"). Within ten days of appointment, appointees must file a notice of appointment with OCA. Additionally, when a judge approves payment greater than $500 to a fiduciary, the judge must file with OCA a statement of approval of compensation specifying the amount. Under the rules, judges are not authorized to approve payment unless the fiduciary appointee has filed the written certification and the notice of appointment.

OCA enters information from these filings in the court system's fiduciary database, which is electronically available to judges (along with the applications submitted by fiduciaries and the lists of the applicants). This information is also available to the public.

Findings

Given the thousands upon thousands of fiduciary appointments made in the New York courts each year, it was not possible to review all cases in which appointments were made. Rather, the investigation focused on a representative number of cases in a representative group of jurisdictions throughout the State. The review concentrated on guardianship cases and receivership cases in Supreme Court and guardian ad litem appointments in Surrogate's Court.

Guardianship Cases

When a petition for a guardianship is brought, the court must appoint a court evaluator or counsel for the alleged incapacitated person to assist the court in its determination of whether a guardian should be appointed. A guardian will be appointed if the court determines that the individual is incapacitated because he or she is unable to provide for personal needs or property management (or both) and cannot adequately appreciate the nature and consequences of the inability.

Our examination revealed a series of problems and concerns in these cases. Compliance with the Part 36 filing requirements was mixed:

- In some counties, notices of appointments, certifications of compliance and statements of approval of compensation were filed in a minimal number of cases
- Even in the counties with the best rate of filing compliance, forms were filed in less than half of the cases.

The law gives judges discretion to determine the method of the guardian's compensation, and guardians were compensated in a variety of ways. Some received statutory commissions based on a percentage of the assets of the incapacitated person (the "IP") or based on the amounts that the guardian received and disbursed. Other appointees, usually guardians who were lawyers, received hourly fees for their guardian services, in some cases as much as $400 per hour. Still others received both statutory commissions and additional, separate legal fees. And guardians who were not attorneys often retained attorneys to assist them. In many of those cases judges regularly approved separate legal fees for services that appeared to be the statutory responsibilities of the guardian. For example, judges approved legal fees for services such as:

- preparing the guardian's reports and accountings;
- preparing the OCA filings;
- obtaining a bond; and
- gathering the IP's assets.

Additionally, when approving fees the courts frequently did not distinguish between legal services and services not legal in nature that should have been billed at a considerably lower rate. For example:

- A guardian and an employee of the guardian's law firm billed $850 to celebrate the IP's birthday when they brought her flowers and a cake and visited with her at the nursing home. On another occasion, when the guardian and one of his employees visited the IP at the nursing home, they took her out for a walk and bought her an ice cream cone. The guardian billed $1,275 for this visit.
- Another guardian received over $65,000 in compensation based on the guardian's billing rate for legal services for tasks that included visiting an eyeglass store, attending a holiday party, inventorying the IP's wardrobe and sewing and ironing labels on the IP's clothing.
- Another guardian received over $12,000 for services that included shopping for clothes, handling routine banking matters and attending medical appointments with the IP.

A closer examination of several selected guardianship cases revealed that the guardians apparently did not always act in the best interests of their wards. Serious lapses were found in the quality of care that guardians provided in meeting the personal needs of the IPs. Moreover, guardians apparently did not always strive to promote and preserve the IPs' financial interests, as they were obligated to do as fiduciaries.

The investigation further established that many of the recipients of multiple and lucrative appointments in guardianship cases had connections to judges, political parties or court system personnel, raising concerns that they were selected based on factors other than merit. These included:

- An attorney who received over 10 appointments and approximately $250,000 in compensation from a judge for whom the attorney regularly served as a non-paying special master. The attorney, who appeared to lack the qualifications for these appointments, had twice declared bankruptcy.
- Several individuals who received appointments from judges for whom they had provided free legal and other professional services.
- Two attorneys with high-level positions in a local political party who received approximately 110 appointments between them in guardianship and receivership matters and were awarded compensation of approximately $400,000.

Our review also uncovered a significant number of individuals who received more than one appointment within a 12-month period for which they ultimately were paid more than $5,000, an apparent violation of the Part 36 rules.

Receivership Cases

Compliance with the Part 36 filing requirements was extremely poor in receivership cases: · In a number of jurisdictions there was minimal filing, particularly with regard to statements of approval of compensation.

- Even in counties with a better showing, there was barely compliance in a third of the cases.

In at least one county, a disproportionate number of the appointments and a disproportionate percentage of the fees went to a group of individuals with connections to the local political party establishment. For example:

- An official of the local political party organization received 46 receivership appointments during a five-year period (about 10% of all the receivership appointments), and about one-third of all receiver fees during that period.
- A law firm, one of whose two members was a high-ranking local political party official, received 34 appointments during the same five-year period.

In general, and contrary to the requirements of the Part 36 rules, receivers, and not judges, appointed their counsel

or property managers. Indeed, the general practice across the State was not to apply the fiduciary rules to these "secondary" appointees.

- One extreme result of this practice was that, in one jurisdiction, a single, small law firm obtained approximately 75% of all counsel to receiver assignments over a five- year period, amounting to over $700,000 in fees. If the rules had been followed, two of the three lawyers in that firm would not have been eligible for even a single assignment because they were the sons of a current Supreme Court Justice.
- Another result of this practice was that, over a five-year period in one county, two management companies received 76% of all property manager appointments and 84% of all fees awarded from such appointments.

Although counsel were routinely retained in receivership cases, our investigation revealed that the work they performed often was not of a legal nature, involving tasks that the receiver should have been performing such as preparing accountings, preparing billings and meeting with tenants and property managers. Because receivers are compensated at the statutory rate of a maximum of five percent of the amounts they receive and disburse, and the counsel are compensated at their hourly legal rates, the result was that in the smaller receivership cases (which made up the great number of the cases) usually the counsel were awarded higher fees than the receivers. Moreover, in many cases the counsel were compensated for the full amounts they requested even though they failed to detail the work they performed. Similarly, receivers frequently failed to specify expenditures they made, and in some cases they were paid fees that exceeded the five percent statutory maximum.

Guardian Ad Litem Appointments

In general, compliance with the Part 36 filing requirements in cases in which guardians ad litem were appointed was much better than compliance in guardianship or receivership cases:

- In some counties, 80% or more of the required forms were filed.
- In a few counties, however, forms were filed in only half of the cases.

In some of the jurisdictions we examined, a disproportionate number of the higher-paying appointments went to a relatively small group of attorneys, who often had some close connection to the court. For example:

- In one county, where roughly 100 attorneys received guardian ad litem appointments in the year we examined, a group of 11 attorneys received 40% of the appointments and nearly half of the total compensation awarded.
- In one case that we carefully examined, involving an unusually large estate, the court appointed a retired County Court Judge as guardian ad litem and a retired Surrogate as special referee. The retired County Court Judge hired as his assistants two attorneys--his daughter and the county's deputy public administrator (a close friend of the Surrogate). All told, the combined fees paid to the appointees and the assistants were nearly $1.5 million.

Additionally, a significant number of attorneys received guardian ad litem appointments in apparent violation of the $5,000 rule.

Conclusion

Despite the extensive problems found, we are confident that significant reform of the fiduciary appointment process is underway. First, the Commission on Fiduciary Appointments is about to release its report and recommendations, which will directly address concerns we have raised. Second, to correct the widespread flaws in the fiduciary filing process, the court system has already implemented a new oversight system involving designation of special fiduciary clerks and close monitoring of all aspects of this process. This will better ensure that forms are properly - filed and that fiduciaries are not paid unless the required filings are made. Third, clear violations of the fiduciary rules and ethical standards that we have identified have resulted in referrals to appropriate disciplinary authorities. This is sending strong message to the bar and bench that violations of these important rules will not be tolerated. Finally, the Office of the Special Inspector General has been established as a permanent entity within the court system, and we are continuing our efforts to promote compliance with the fiduciary rules and facilitate greater public confidence in the fiduciary appointment process.

Preface

Courts have long relied on fiduciaries to perform a range of functions in our justice system. For example, courts appoint fiduciaries as guardians for incapacitated persons, as guardians ad litem for children involved in litigation and as receivers for properties involved in foreclosure proceedings. Fiduciary appointees are usually private attorneys, but unlike private attorneys who are assigned to represent indigent persons in criminal, family and other proceedings, fiduciaries are not compensated with public funds. Rather, they are usually paid from the assets of the litigants.

Allegations that judges have selected fiduciaries based on factors other than merit have undermined public confidence in our courts, as have charges that fiduciary appointees have mishandled cases or received excessive fees from their assignments. Criticism of the fiduciary appointment process soared recently with the public disclosure of an extraordinary letter written by two attorneys who had been retained but then dismissed as counsel to a court-appointed receiver in a Brooklyn Supreme Court proceeding. The letter laid bare the long-suspected influence that political connections can have on the fiduciary appointment process. This time, however, the allegations of political influence came from an unlikely source--disgruntled attorneys seeking to perpetuate their receipt of fiduciary appointments, which they considered their entitlement based on their service and loyalty to the county political organization.

In the wake of these developments, Chief Judge Judith S. Kaye announced a comprehensive program to reform the fiduciary appointment process in New York. She directed the establishment of an Office of the Special Inspector General for Fiduciary Appointments, with Statewide jurisdiction to monitor and enforce the existing rules governing judicial appointments. She also created a high-level Commission on Fiduciary Appointments to examine existing fiduciary rules and make recommendations for improvement.

This report is based on a far-reaching investigation conducted by the Office of the Special Inspector General for Fiduciary Appointments and the Unified Court System's Internal Audit Unit. As part of this investigation, we have examined thousands of court files and conducted hundreds of interviews with individuals directly involved in or knowledgeable about the process of appointing fiduciaries. Most of the individuals involved in the cases discussed in the report were interviewed. We have also reviewed extensive information in the Unified Court System's fiduciary appointment database. Comprehensive investigation of the fiduciary appointment process is a huge undertaking--in any given year, thousands upon thousands of fiduciary appointments are made in the New York courts. We have not examined all of these appointments, nor would it be possible to do so. What we have done in this report is present our findings with regard to a representative group of cases and jurisdictions. In doing so, we have identified a series of problems and concerns that require the attention of court administrators, policy makers and, perhaps most importantly, the Commission on Fiduciary Appointments, which will be issuing its report and recommendations in the next several days. The Commission's report will include recommendations for rule changes that will be considered by the Administrative Board of the Courts and ultimately by the State's highest court, the Court of Appeals.

Throughout our investigation, we have shared our findings with the Commission. This report is being released now so that the public will understand the basis upon which many of the Commission's recommendations are being made and thus can better evaluate the forthcoming proposed changes in fiduciary appointment rules and practice.

Finally, except when discussing certain matters that already have received extensive attention in the media, we have not identified individuals whose actions are described in the report. As noted, the purpose of this public report is to provide a factual context for recommendations to improve the process, not to make accusations against people who may have committed misconduct. This would be an inappropriate forum in which to do so. Rather, under the State Constitution (N.Y. Const., Art. 6, § 28) and statutory law (Jud. Law §§ 212(1)(h), (m), (s) and (t)), and pursuant to the authority and direction of the Chief Administrative Judge of the Courts, our investigation has resulted in referrals to appropriate disciplinary authorities, with additional

referrals currently under consideration. The law provides that these are confidential processes in which the subjects are not revealed unless they waive their statutory right to confidentiality or unless a finding of misconduct is made. Although many have long urged that disciplinary charges against judges and lawyers be made public at an earlier point, as of yet there has been no legislative action in that regard.

REGULATORY BACKGROUND

Part 36

The cornerstone of regulatory oversight of the fiduciary appointment process in New York is Part 36 of the Rules of the Chief Judge (see 22 NYCRR Part 36). Promulgated in 1986, the Part 36 rules apply to the appointment of guardians, guardians ad litem, court evaluators, attorneys for alleged incapacitated persons, receivers, persons designated to perform services for a receiver and referees. Under the rules, individuals interested in being considered for appointment must submit an application to the Office of Court Administration. OCA compiles lists of

the applicants, which are made available to judges who must make the appointments (§ 36.2(a)). Anyone is eligible for inclusion on the lists, except a person who is a relative of, or related by marriage to, a judge of the Unified Court System within the sixth degree of relationship (§ 36.1(b)(1)).[1] Thus, although the application that a prospective fiduciary appointee submits to OCA contains extensive information about the applicant, such as prior experience, education, employment history, area of expertise and criminal record, the only factor that renders an applicant ineligible for inclusion on the list is relation to a judge within the sixth degree.

The rules contemplate that judges will make fiduciary appointments from the list. A judge may deviate from the list, however, if the appointee "is better qualified for appointment in a particular matter, either because of prior experience with the ward or estate, or because of particular expertise necessary to the case." When deviating from the list, the judge must place the reasons for doing so as well as the appointee's qualifications on the court record (§ 36.1(a)). The rules provide generally that the appointing judge is "solely responsible" for determining the qualifications of a fiduciary appointee.

Part 36 sets forth strict filing requirements for fiduciaries. Before accepting an appointment, a prospective appointee must file with the court a written certification that the appointment will not violate the Part 36 rules (UCS Form 830.3; see § 36.1(d)). In essence, this is a certification of two facts. First, as noted, it is a certification that the prospective appointee is not related to a judge within the sixth degree. Second, it is a certification that the appointment will not result in the appointee receiving within a 12-month period more than one appointment, calculated from the date of appointment, in which the anticipated compensation will exceed $5,000. The prospective appointee's certification must also include a list of any fiduciary appointments received within the preceding 12 months.

If the appointee is unable to make this certification, the judge is not authorized to make the appointment, with one limited exception. The judge may waive the $5,000 rule upon determining, in writing, that "unusual circumstances of continuity of representation or familiarity with a case require" the appointment (§ 36.1(c)).

Within ten days of receiving an appointment, the fiduciary must file with OCA a "notice of appointment" form (UCS Form 830.1; see § 36.3(a)). The filing provisions, however, do not apply to every fiduciary appointee. Section 36.1 (e)(3) provides that the provisions do not apply to the Mental Hygiene Legal Service, a nonprofit institution performing social services or an appointment of a relative or a person having a legally recognized duty or interest with respect to the affairs of the infant, ward, incapacitated person, decedent or beneficiary of an estate.

When the judge approves payment in excess of $500 to any fiduciary, including family members and social service agencies, the judge must file with OCA a "statement of approval of compensation" specifying, among other things, the amount of compensation authorized (UCS Form 830; see Jud. Law § 35-a, 22 NYCRR Part 26).[2] The statement of approval of compensation also includes a certification by the fiduciary that he or she submitted a notice of appointment form to OCA, and a certification by the judge that the fee authorized is fixed by statute or is a "reasonable award" for the services rendered (§ 26.4). The rules further provide that no fee shall be awarded unless the fiduciary has filed the notice of appointment form and the certification of compliance (§ 36.4(c)).

OCA enters information from these filings in the Unified Court System's fiduciary database, which, along with the applications submitted by prospective fiduciaries and the lists of the applicants, is now available to judges on the Judiciary's internal computer network. This information is also available to the public.

Secondary Appointments

Since its promulgation in 1986, Part 36 has included within its ambit "persons performing services for a receiver." Section 36.1(a) provides that their appointments, like those of receivers, guardians and the other fiduciaries enumerated in that section, "shall be made by the judge authorized by law to make the appointment." All of the disqualifying factors, filing requirements and other provisions of Part 36, therefore, apply with equal force to such persons. Thus, receivers cannot appoint their own counsel or property managers, judges may not appoint relatives of judges to those positions and the appointees must make all the filings required by Part 36.

Despite the clear mandate of Part 36, a practice evolved in the courts in which the receivers, and not the judges, selected their own counsel and property managers in cases in which the receivers determined it was advantageous to retain these professionals. To correct this widespread noncompliance with the rules, Chief Administrative Judge Jonathan Lippman in March 2000 issued a memorandum reiterating for judges across the State that appointments of persons designated to perform services for a receiver must be made by the judge, and that such appointments were subject to all the requirements of Part 36 (see Attachment A).

Rules of Judicial Conduct

The Rules of Judicial Conduct also address fiduciary appointments. The rules provide that a judge "shall not make unnecessary appointments . . . . shall avoid nepotism and favoritism . . . . [and] shall not approve compensation of appointees beyond the fair value of services rendered" (22 NYCRR § 100.3(C)(3)). The rules also provide generally that a judge "shall act at all times in a manner that promotes public confidence in the integrity and impartiality of the judiciary," and "shall not allow family, social, political or other relationships to influence the judge's judicial conduct or judgment" (22 NYCRR §100.2(A) & (B)).

A. APPOINTMENTS IN GUARDIANSHIP CASES

In General

A court may appoint a guardian only after determining that the appointment is necessary to provide for the personal needs of that person and/or to manage the property and financial affairs of that person, and that the person has agreed to the appointment or is incapacitated (MHL § 81.02(a) (1) & (2)). The standard in determining incapacity is whether the person is likely to suffer harm because he or she: (1) is unable to provide for personal needs or property management or both, and (2) cannot adequately understand and appreciate the nature and consequences of the inability. A determination that a person is incapacitated must be based on clear and convincing evidence, and requires a hearing, even in cases where the alleged incapacitated person (the "AIP") consents to the appointment of a guardian (MHL § 81.11(a)). The court also must assess the functional abilities of the AIP in order to properly tailor the guardianship order so that it meets the needs of the individual (MHL § 81.02(c)).

A guardianship proceeding (often referred to as an Article 81 proceeding) begins with the filing of an order to show cause and supporting petition. The majority of guardianship petitions are filed by local social services agencies, hospitals and healthcare facilities, with most of the remainder brought by relatives or friends of the AIPs.

At the time of issuance of the order to show cause, the court must appoint a court evaluator (unless counsel for the AIP is appointed) (MHL § 81.10 (g)). Court evaluators must be selected from the OCA fiduciary list. In addition, all court evaluators must complete a training program approved by OCA. Although the court may waive this training, that is rarely done (MHL § 81.40(c)).

In selecting a court evaluator, the court may choose from a broad spectrum of professions, including attorneys, physicians, psychologists, accountants, social workers, nurses or any other persons the court determines possess the knowledge and skill to perform the task (MHL §, 81.09(b)(1)). Additionally, in cases in which the AIP resides in a state facility, hospital, nursing home or adult home, the court has the option of appointing Mental Hygiene Legal Service ("MHLS") as the court evaluator (MHL § 81.09(b)(2)).

The court evaluator acts as an independent investigator and gathers information to aid the court in its determination of the AIP's capacity, the availability and reliability of alternative resources, the proper powers to be assigned to the guardian and selection of the guardian (MHL § 81.09). The court evaluator's specific responsibilities include meeting with and interviewing the AIP to explain the proceedings, the rights to which the AIP is entitled, and the general powers and duties of a guardian. The court evaluator also must interview the petitioner, assess whether legal counsel should be appointed for the AIP and submit a written report providing extensive information with recommendations to the court (MHL § 81.09(c)(5)). All of these tasks must be performed on an expedited basis, because the court must conduct a hearing within 28 days of the filing of the petition (MHL § 81.07(a)(1)).

An AIP for whom a guardianship is being sought has the right to be represented by legal counsel of that person's choosing (MHL § 81.10). Although the court also may appoint counsel for the AIP, this is not always required. Appointment of counsel is mandatory, however, if: (1) the AIP requests counsel; (2) the AIP contests the petition; (3) the AIP does not consent to a request in the petition for removal to a nursing home or other residential facility; (4) the AIP does not consent to necessary medical or dental treatment; (5) the petition seeks temporary powers; (6) the court determines that a conflict exists between the court evaluator's role and the advocacy needs of the AIP; or (7) counsel would be helpful to the resolution of the case (MHL § 81.10(c)).

Following a hearing, the court may appoint a guardian to attend to the personal needs of an incapacitated person (the "IP") and/or to manage the IP's property and financial matters. In general, courts give preference to a family member or to a person nominated by the IP. If no family members or nominated persons are qualified to serve, however, the court may select an appropriate person to serve as guardian. If the petition is brought by a social service agency and the IP resides or plans to return to the community, a community guardianship program may be appointed as guardian (MHL § 81.19(a)(2)).[3]

A guardian may exercise only those powers authorized in the appointment order, which must be tailored to the specific needs of the IP. In general, a guardian usually is required to oversee the IP's assets, make health care and medical decisions, pay bills, supervise home health care or select a health care facility, and periodically visit the IP.

In addition to providing personal care and managing the IP's finances, the guardian must file periodic reports with the court. These reports should document the IP's financial status, including income, assets, expenditures and unpaid claims, as well as medical condition and health care. The reports are reviewed by court examiners who have been appointed by the Appellate Division (MHL § 81.32). Upon the termination of a guardianship, the guardian must file with the court a final report providing a financial accounting of the entire period during which the guardian served.

Compensation of Article 81 Fiduciaries

Article 81 prescribes how the court evaluator, counsel for the AIP and guardian are to be compensated (MHL §§ 81.09(f), 81.10(f) and 81.28). Under the statute, the cost of the guardianship proceeding is to be paid by the IP, unless he or she has minimal or no assets. However, if the proceeding is dismissed or discontinued and the court determines that appointment of a guardian is not warranted, the petitioner is usually responsible for his or her own attorney's fees and possibly even the fees of the court evaluator and counsel to the AIP. If an AIP is indigent, the Court of Appeals has held that the cost of attorney fees should be borne by the county pursuant to Article 18-B of the County Law.[4] And in cases commenced by local social service agencies in which there are minimal or no assets, the court evaluator receives a stipend of $600, to be paid by the petitioner.

Typically, if the AIP has some or substantial assets, the court evaluator and the counsel for the AIP are paid a fee from those assets based on the fair and reasonable value of the services rendered. When determining reasonable compensation for a court appointee, the court generally must consider the following factors: time spent, difficulty involved, nature of the services, amount of assets involved, professional standing of the counsel and results obtained.[5] In making this determination, the court should rely on detailed time records submitted by the court appointees. Compensation for the guardian is addressed in MHL § 81.28, which provides that the court shall establish a plan for reasonable compensation of the guardian. While the statute suggests that the court may use Surrogate's Court Procedure Act (SCPA) § 2309 in setting compensation, that provision is merely a guideline and is not binding, particularly when the primary responsibilities of the guardian involve personal care. In some counties, the courts rely on a variety of methods when determining guardian compensation. Some judges determine a guardian's compensation based on a percentage of the amounts received and disbursed, or on a percentage of the principal, coupled with additional hourly compensation for any legal services rendered in connection with the appointee's official duties as a guardian (SCPA §§ 2307, 2309). In the alternative, some judges authorize compensation for guardians based entirely on an hourly rate.

If a community guardianship program is appointed guardian, its compensation is determined pursuant to section 473-d(3)(d) of the Social Services Law and the Mental Hygiene Law.[6]

New York County

We examined all guardianship cases commenced in New York County Supreme Court between January 1, 1999 and December 31, 1999--a total of 338 cases. We reviewed 335 of these cases (three of the court files were not available). In about one-third of these cases the NYC Department of Social Services was the petitioner; in the remaining cases the petitioners were a health care facility, a hospital, or a friend or relative of the AIP. In addition to examining the court files, we reviewed information relating to these cases contained in the Office of Court Administration's fiduciary database, and we interviewed judges, court personnel and many of the fiduciary appointees in these cases.

Our investigation of these cases revealed the following:

- Compliance with the filing requirements was mixed.
- Although judges appointed a range of individuals as fiduciaries, a smaller, select group of individuals received the majority of the lucrative appointments.
- Judges rarely reduced the fee requests of the court appointees in cases in which the IP had assets.
- In the majority of cases, attorneys were paid hourly rates for legal services even when the services provided were not legal in nature.

Court Evaluators

Of the 285 court evaluators required to file the Part 36 forms, 196 (69%) filed a notice of appointment, and 206 (72%) filed a certification of compliance. In total, 250 court evaluators awarded compensation by the court were required to file their statement of approval of compensation forms. In 146 (58%) of these cases, a statement of approval of compensation form was filed with OCA. In a number of the cases in which forms were not filed with

OCA, a form was in the court file, although many were incomplete.

As noted, the court evaluator's fee is determined by the judge based on reasonable compensation for services rendered. In many of the cases we reviewed, judges awarded to court evaluators who were attorneys compensation at their hourly rate for legal services even though the work performed was not legal in nature. Generally, hourly rates ranged from $150 to $275 per hour. Additionally, in some cases, court evaluators charged over $300 an hour for performing basic administrative tasks usually done by support staff. In some cases, they spent numerous hours working on routine matters. In the cases we examined in which the IP had assets, the court rarely reduced the fee requested by the court evaluator. The following are some examples:

- In one case, the court evaluator was awarded compensation of $36,753, at an hourly rate of $400. An examination of the supporting affidavit made reference to over 80 telephone calls with no explanation provided as to the nature of these calls, each billed at $100. Further, the court evaluator billed almost five hours for preparing the fee application, and billed (at $400 an hour) for picking up a court transcript, calling the court clerk and preparing the OCA forms. The court awarded the entire fee requested, and also appointed the individual co-guardian for the IP at a rate of $400 per hour.
- In another case, a court evaluator who was an attorney was awarded compensation at an hourly rate of $250 for non-legal tasks such as faxing documents, telephoning directory assistance to obtain telephone numbers, renting a car, selecting clothing for and bringing food to the AIP.
- In another case, the court evaluator and associate each billed six hours for interviewing the AIP, medical personnel, and family members at a rate of $425 and $240 an hour, respectively. Further, the associate billed nearly two hours for arranging appointments and preparing the OCA forms.

Although the court evaluator appointments were divided among 199 individuals, a much smaller group of individuals--23 (12%)--received over 50% of the total compensation awarded. Many of these individuals had connections either to each other or the political establishment. For example, two of the appointees were associates at the same small law firm, two were counsel to and one was an officer of a county political party committee, and one employed a county political party leader.

Counsel to AIP

As discussed, not every guardianship proceeding requires the appointment of a counsel for the AIP. The court appointed an attorney for the AIP in only 130 of the cases reviewed (in three of those cases a successor attorney was appointed). In over half of these cases, the court appointed Mental Hygiene Legal Service as the attorney. The other 64 appointments were divided among 47 attorneys. While most of the attorneys only received one appointment, a few were appointed in two or more of the cases.

In total, only 56 of those appointed were required to file the Part 36 forms. Of these, 33 (59%) filed a notice of appointment and 32 (57%) filed a certification of compliance. In the 46 cases in which the attorney was awarded compensation, only 25 (54%) statements of approval of compensation were filed. While 35 attorneys were awarded compensation, a much smaller group of attorneys received most of the money. Six attorneys received more than 70% of the total fees awarded. Two of these attorneys, one a former judge and the other a high-level local bar association officer, were each awarded fees in excess of $50,000 in two cases. By comparison, none of the other 29 attorneys was awarded a fee over $6,000 in any one case.

Guardians

In 129 (46%) of the cases reviewed in which a guardian was appointed, the court selected as the guardian a friend or family member of the IP. In over 20% of those cases, the court appointed a private attorney to act as the co-guardian. Usually, a friend or family member was appointed as co- guardian to handle the IP's personal needs, and the attorney co-guardian managed the IP's property and financial matters.

In 29% of the proceedings, a community guardianship program was appointed guardian. In a few cases, a successor guardian was appointed either to replace a community guardianship program when the IP was placed in a health care facility or when a guardian was discharged or resigned. In 53 (16%) of the proceedings, a guardian was not appointed. In some of those cases, the petition was withdrawn prior to the hearing, and in others the court determined after the hearing that a guardian was not necessary.

Of the 111 guardians required to file the Part 36 forms, only 60 (54%) filed a notice of appointment, and only 65 (59%) filed a certification of compliance. In total, 41 guardians were awarded compensation. Of these cases, the

court filed the approval of compensation form in 31 (76%) of the cases.

As discussed, the courts use a variety of methods in determining a guardian's compensation. Generally, the fee arrangement is determined at the time of appointment. Some judges, however, delay choosing a method of compensation until completion of the guardianship or when payment of the guardian is warranted, such as after the review of the annual report by a court examiner. An examination of the cases revealed that the majority of judges calculated the guardian's compensation based on the statutory commissions while a few judges set a fixed hourly rate for the guardian. Other judges did not commit to a method of compensation, and noted in the appointing order that the guardian's commission was to be based on either SCPA § 2307 or SCPA § 2309, "whichever was higher." In cases where a family member or friend was appointed guardian, compensation was frequently waived.

For 104 (29%) guardians compensation was based on a statutory commission. For 66 (19%) guardians, compensation was based on an hourly billing rate ranging from $10 to $450 per hour. For 59 (17%) guardians, no method of compensation was specified in the court file, and 49 (14%) appointees waived compensation. For 68 (19%) guardians, commission was determined pursuant to section 473-d(3)(d) of the Social Service Law. The remaining eight (2%) guardian's compensation was paid by the local social service agency.

Some judges have expressed dissatisfaction with the compensation provided for guardians under SCPA §§ 2307 and 2309, particularly when the guardian's responsibilities include both personal and property management.[7] In response, judges have awarded additional compensation to guardians when they had extensive responsibilities or appointed co-guardians. In setting the guardian's fee, courts have applied factors such as the type and nature of assistance provided to the IP, the amount of time the guardian expended in providing both personal needs assistance and property management and the allocation of time between the personal needs assistance and property management.

In some cases, judges approved payment of legal fees in addition to statutory commissions to guardians who were attorneys, even for services that appeared to be responsibilities of a guardian as delineated in the statute. When setting hourly fees, the courts often did not differentiate between legal services rendered and guardianship services such as shopping for clothes and toiletries, paying bills and visiting the IP.

The following are some examples:

- In one matter, the IP's relative and an attorney were appointed co-guardians. The court set compensation amounts of $250 per hour for the attorney and $50 per hour for the relative. The IP resided in a health care facility and many of her personal needs were taken care of by the relative co-guardian. The attorney's role in the care of the IP, therefore, should have been limited. However, within a year, the attorney received over $65,000 in compensation, based on billing at the attorney's legal rate for tasks such as visiting an eyeglass store, attending a holiday party, exchanging clothing, inventorying the IP's wardrobe and sewing and ironing labels on the IP's clothing. Administrative duties such as drafting fee applications, calling financial institutions and returning apartment keys were also billed at the attorney's legal billing rate. Recently, a second judge assigned a special referee to examine the compensation awarded and the nature and type of guardian services provided in this case.
- In another matter, the court appointed as guardian of the property an individual who had never before served as a guardian and was not on OCA's fiduciary list at the time of appointment. The IP had limited assets and the case did not present complex legal issues. After about eighteen months, the guardian sought over $12,000 in compensation for services such as: 12 hours shopping for clothes, 12 hours handling banking matters, nearly 45 hours attending medical appointments with the IP, and attending the mandatory eight-hour guardianship training course. In addition, the guardian hired two attorneys to prepare and file the guardian's two affirmations of services, at a total cost of $1,275. Both MHLS and the court examiner opposed the guardian's fee requests, arguing that many of the services the guardian billed for could have been provided by the health care facility or were unnecessary. The court approved the guardian's full fees. If the guardian's compensation had been based on the statutory commission, it would have been less than $6,000.
- In another matter, a guardian who received compensation based on a fixed hourly rate billed over 100 hours for many tasks that appeared to be unnecessary. The guardian repeatedly spent over four hours traveling to a bank in another borough to deposit a $50 monthly social security check; each trip to the bank cost the IP $300. Additionally, the guardian billed at least seven hours for each court appearance. In total, the guardian received a fee over $8,700. If the guardian had received the statutory commission, the fee would have been less than $3,000.

The investigation revealed that many of the recipients of multiple and lucrative appointments had relationships with judges, court system personnel, politics or in some cases each other. For example:

- One attorney received 10 appointments and approximately $250,000 in compensation from a judge for whom the attorney regularly served as a special master.[8] In an affirmation, the attorney listed as qualifications being "raised in a medical family" and having a "personal history of multiple surgical hospitalizations." The attorney also claimed to have been practicing elder law for 15 years, but later, when interviewed and asked to elaborate, admitted the reference was to personal experience with elderly relatives. Moreover, the attorney had declared bankruptcy twice.
- Two attorneys informed us that they received appointments from judges for whom they had provided free legal services. One of the attorneys represented a judge in a civil matter and had a social relationship that included lunches, dinners and visits to each other's home. Another attorney handled a real estate matter for the spouse of a judge from whom he had received fiduciary appointments; the attorney did not recall whether a fee was charged for handling the matter.
- One individual, who was both a law graduate and a registered nurse, received guardianship appointments from a judge with whom the nurse was a close friend. The nurse had been appointed to manage the assets of IPs, despite the fact that the nurse had declared personal bankruptcy. The judge also recommended to one fiduciary appointee that he hire the individual to provide nursing care for his ward.
  - A tax accountant received appointments from a judge for whom the tax accountant had provided free accounting services over a multi-year period. The judge also suggested to other court appointees that they hire the accountant to provide financial services for their wards.

  - The spouse of a law clerk has received numerous appointments, including three from the judge in the court part to whom the law clerk is assigned.
  - Two attorneys, both counsel to a county political leader, received over 110 appointments in guardianship and receivership matters and were awarded compensation of approximately $400,000.
  - One attorney, the spouse of a high-level managerial employee of the court system, received over 120 appointments in guardianship and receivership matters, resulting in over $360,000 in compensation.

Two Selected New York County Guardianship Cases

Two guardianship cases illustrate the problems discovered in many of the cases reviewed. In the first case, a guardianship proceeding was commenced by the hospital where the AIP, a retired college professor who had suffered a stroke, was a patient. The AIP was seriously ill and the hospital was seeking his discharge so he could spend his final days at home. The court appointed two guardians: an attorney who had regularly served as the judge's special master was appointed to handled the IP's personal needs, and a friend of the IP was appointed to handle the IP's property and financial matters. The IP's friend resigned shortly thereafter and was replaced as co-guardian by a tax and financial manager.

A few months after the IP returned home from the hospital, he unexpectedly began to recover from his illness, and soon required much less assistance from the 24-hour home health aides. As he continued to recover, the IP attempted to take a more active role in his financial affairs, and he repeatedly complained about the harsh treatment he was receiving from one of the home health aides. Despite the IP's many requests and complaints, there was no change in his 24-hour health care, the hostile home health aide was not replaced and the guardians provided him with no information about his finances.

The IP eventually retained his own attorney, and the attorney filed a motion to terminate the guardianship. In response, the court appointed a court evaluator to investigate and determine whether the IP still needed a guardianship. Following an extensive investigation and a trial period, the court evaluator concluded that the IP was capable of managing his own affairs. In her report, the court evaluator harshly criticized both guardians, and questioned whether the personal needs guardian had fulfilled his fiduciary obligations. Thereafter, the court discharged the home health aides and made arrangements for the IP to resume control of his finances. Although the guardians' day-to-day responsibilities now were no longer required, they continued to bill for another 70 hours, which included time spent researching the placement of the IP in an assisted living facility and the creation of a burial trust.

Although he provided no legal services, the personal needs guardian was compensated at his legal billing rate of

$215 per hour. The guardian of the property was compensated at a rate of $200 per hour. In all, the guardians spent over $481,000 of the IP's money, with nearly half paid to court appointees. The guardians received over $160,000 combined, nearly $100,000 more than they would have received had they been paid statutory commissions. The judge handling this case subsequently appointed the guardians again in another proceeding.

In the second case, a guardianship petition was brought by a niece of the AIP who was concerned about the handling of the AIP's substantial assets by his newly retained attorney. At the time of the petition, the AIP was a wealthy retired doctor who was living at home with his wife of 50 years.

The judge appointed a high-ranking local bar association official with whom the judge was friendly as counsel to the AIP, and a friend of the bar association official as court evaluator. Subsequently, the judge appointed the court evaluator as temporary guardian of the IP's property and financial matters and also as temporary personal needs co-guardian with the IP's wife. The temporary guardian then hired the original counsel for the IP (who was no longer needed in that capacity once a guardian was appointed) as his counsel and hired two other attorneys to advise him on other issues. At the same time, the court appointed another attorney, also a close friend of the bar association official, as court evaluator. After the guardians were in place, the court kept the court evaluator in the case to advise the court on financial issues.[9] Later, without holding a hearing, the temporary guardians were made the permanent guardians.

Over time, tension between the guardian and the IP's family developed. When the guardian questioned the capacity of the IP's wife to serve as co-guardian of the IP's personal needs, the judge temporarily suspended the wife as the co-guardian. The family eventually hired an attorney who, arguing that the animosity between the IP's wife and the guardian was having a detrimental effect on the IP and his family, requested that the court appoint the IP's niece as the sole guardian of the IP's personal needs. The judge declined to remove the guardian, but appointed the judge's personal physician to serve as personal needs co-guardian for the IP.

After the family's attorney renewed the request for removal of the guardian, the judge appointed a new counsel for the IP to determine whether the IP wished to withdraw his original consent to appointment of guardian. The family also requested that all fees previously awarded to the guardian and his attorneys be disallowed.[10] Shortly thereafter, the guardian resigned. The judge withdrew approval of some of the fees previously awarded and directed the guardian and his attorneys to return a portion of the fees pending further review by the court. The judge then appointed the IP's wife and niece as co-guardians of the IP's property and person and directed the prior guardian to file a final accounting of the proceeding. The judge also withdrew from the case. The new judge then released the court evaluator and the counsel to the IP, and ordered a hearing to determine whether the guardianship was necessary.

By the conclusion of the guardian's tenure over $750,000 in fees had been requested by the guardian, his attorneys, accountants and investigative and investment services. The guardian and the second court evaluator each billed at a rate of $300 per hour. The guardian's three attorneys billed at rates ranging from $325 to $400 per hour, often for the same services. For example, the guardian's billing records reveal that a great deal of his time was spent updating each attorney on the work the other attorneys were doing. Additionally, there were numerous meetings and conference calls involving all of the attorneys and the guardian, with each billing for the time spent. In all, the guardian has requested over $277,000 in compensation for services he provided as guardian and as the first court evaluator. The second court evaluator has received almost $60,000 in compensation. The guardian's three attorneys have requested nearly $290,000 in compensation.[11] Approximately $200,000 was requested for accountants, investment consultants and investigative services.

Findings From Other Jurisdictions

In Queens County, we reviewed a random sample of 25 cases in which guardians were appointed. The court appointed Mental Hygiene Legal Service as court evaluator in one case and a family member as guardian or co-guardian in 10 cases.

Compliance with the filing requirements was mixed. Although 21 of 24 court evaluators (88%) filed a certification of compliance and 23 of 24 (96%) filed a notice of appointment, only eight of 14 guardians (57%) filed a certification of compliance and nine of 14 (64%) filed a notice of appointment. In addition, only 12 approval of compensation forms were filed for the 23 fiduciaries for which they were required (52%).

Guardians were compensated in accordance with SCPA § 2307, SCPA § 2309 or through hourly fees (generally at lawyers' rates). In at least five of the cases in which guardians were paid pursuant to the SCPA, additional hourly fees awarded to guardians appeared to be for duties that the guardian is statutorily required to perform. Some of these routine tasks included:

- preparing the OCA forms;
- obtaining the bond;
- gathering the assets of the ward;
- meeting with the court examiner;
- preparing the annual accounting;
- reviewing the final accounting of the previous guardian; and
- preparing the final accounting and order.

Moreover, some of the guardians who were attorneys billed hourly rates for all of the guardianship work they performed, which often included time spent visiting the IPs and performing personal chores for them such as shopping for clothing and toiletries. In one case, the following occurred:

- The guardian requested fees of $300 per hour for himself, $155 per hour for an associate and $125 per hour for an employee of the firm. On many occasions the guardian and one of his employees visited the IP together and both billed for their time
- One shopping trip cost the IP over $1,000 in fees--$750 for the partner and $387 for the associate.
- The guardian and an employee billed $850 to celebrate the IP's birthday when they bought her flowers and a birthday cake and visited with her at the nursing home. Another visit to the nursing home by the guardian's employee included "shopping for Thanksgiving pies and ice cream," for which the IP was billed $375 in fees.
- On another occasion, when the guardian and the guardian's employee visited the IP at the nursing home, they took her out for a walk and bought her an ice cream cone. The guardian billed $1,275 for this visit.

Several attorneys received multiple appointments that appear to have violated the $5,000 rule. For example:

- One attorney received five appointments in a 12- month period in which the compensation ultimately received was $31,894, $18,600, $8,000, $11,902 and $15,405, respectively. That attorney received nine separate appointments in a period of just over two years for which the compensation exceeded $5,000. In all, the attorney appears to have violated the $5,000 rule eight times in that time span. All of the attorney's appointments were made by the same judge, and none of the files indicate that the attorney received the appointment pursuant to an exception to the $5,000 rule.
- Another attorney received four appointments in a three-month period where the ultimate compensation exceeded $5,000, including two appointments where the compensation was $37,174 and $24,230.

A review of the OCA fiduciary database for the period 1995 through 1999 reveals that about a dozen attorneys received many lucrative appointments in Queens County. Some of these attorneys also received lucrative appointments from judges in other jurisdictions, including New York, Kings, Nassau and Suffolk counties. One of the attorneys received approximately 130 appointments totaling over $525,000. Another attorney received 46 appointments in Queens County, of varying amounts, totaling over $130,000. One attorney received 73 smaller cases totaling over $100,000 and another received 46 fiduciary appointments resulting in over $130,000 in fees. A former judge received over 110 fiduciary appointments in a variety of jurisdictions, including Queens, with compensation over $400,000.

In Kings County, we reviewed a random sample of 50 guardianship cases. The court appointed a family member as the guardian or co-guardian in 30 of the cases and a non- profit organization as guardian in six of the cases reviewed. The court appointed a total of 24 guardians or co-guardians who were not relatives of the IP or a non-profit organization. Court evaluators filed a notice of appointment form in 38 (76%) of the cases, and a certification of compliance in 42 (84%) of the cases. Only six (25%) of the 24 guardians filed a notice of appointment, and only 10 (42%) filed a certification of compliance. Approval of compensation forms were filed for court evaluators in 32 (76%) of the 42 cases where they were required and in 9 (53%) of the 17 cases where they were required for guardians.

As in Queens County, the court awarded compensation to guardians that included both statutory commissions and legal fees. Additionally, the court awarded legal fees for work that is part of a guardian's routine responsibilities. As just one example, the following occurred in a case we reviewed:

- The guardian was paid $9,000 in legal fees (at an hourly rate of $250), in addition to over $6,000 in guardian commissions. The

items identified as legal work in the guardian's affidavit of services included such routine tasks as a review of the IP's assets, preparation of an initial and annual accounting, and conversations with personnel at the IP's nursing home.

- Despite the award to a guardian of $9,000 in legal fees, the guardian performed no legal work. The sole legal matter that arose was a lawsuit that had been filed against the IP, for which the guardian hired an attorney.
- The approval of compensation form stated that the guardian was awarded $2,785 in compensation, but our review of the court file revealed that the guardian received over $15,000 in fees. During an interview, the guardian claimed that all records pertaining to the case had been misplaced.
- Although an attorney himself, the guardian hired another attorney for assistance, at a rate of $250 per hour. The OCA fiduciary database reveals that the other attorney has received over 120 fiduciary appointments and over $350,000 in fees. In this case, the attorney was awarded $1,400 in fees for assisting the guardian in preparing his annual accounting, which is part of the guardian's routine duties. When the guardian withdrew from the case nine days prior to the IP's death, his attorney was appointed as successor guardian. Although guardian for only nine days, the successor guardian was awarded $10,000 in commissions and $5,000 in legal fees.

We concluded that at least two guardians received appointments in apparent violation of the $5,000 rule. One attorney received three guardianship appointments within a 12-month period that ultimately paid $31,006, $21,286 and $15,000, respectively. Another received two appointments where the compensation was $10,000 and $7,500, respectively. The court files in these cases contained no documentation that the appointing judges waived the rule based on the narrow exception.

In Nassau County, we reviewed a random sample of 25 cases in which guardians were appointed. Mental Hygiene Legal Service was appointed as court evaluator in three cases and a family member was appointed as guardian or co- guardian in six cases. Of the 19 court evaluators required to file forms, 17 (89%) filed a certification of compliance and 16 (84%) filed a notice of appointment. Seven of the 11 guardians (64%) required to file forms filed a certification of compliance and six (55%) filed a notice of appointment. Approval of compensation forms were filed on behalf of 17 of the 19 court evaluators (89%) and two of the five guardians (40%) for whom filing was necessary.

Our review of these cases revealed the following:

- In two matters it appears that the guardians, who were attorneys, were awarded separate fees for guardianship services and legal services. The "legal services," however, included preparing and filing the final accounting, which is part of the guardian's responsibilities.
- In another matter, the guardian, who was an attorney, hired another attorney to perform legal work. The guardian's attorney's affirmation included time spent meeting with the guardian to discuss procedures, preparation and review of the guardian's affirmation of services and preparation and review of the final report and account. Thus, the attorney was compensated for services for which the guardian was also compensated by the payment of commissions.
- One IP had been deceased for over three years before the guardian submitted his final accounting.

It also appears that several appointees in Nassau County may have violated the $5,000 rule. In these cases, there was no documentation in the court files suggesting that the court found that these appointees met the narrow exception to the rule.

In Erie County, we reviewed a random sample of 50 cases in which guardians were appointed. Mental Hygiene Legal Service was appointed attorney for the AIP in one case, court evaluator in five cases and guardian in one case, a nonprofit organization was appointed as guardian in eight cases and a family member was appointed guardian or co-guardian in 28 cases. Three of the 12 counsel for the AIP (25%) filed a certification of compliance and five (42%) filed a notice of appointment; 11 of 46 court evaluators (24%) filed a certification of compliance and 19 (41%) filed a notice of appointment; and four of 19 guardians (21%) filed a certification of compliance and two (11%) filed a notice of appointment. Where approval of compensation forms were required to be filed, three of 7 were filed for counsel for the AIP (43%), 14 of 46 for court evaluators (30%) and three of 14 for guardians (21%).

The audit revealed that in many of the cases, guardians were awarded both commissions and legal fees. Some of the fees appear to have been excessive or unsubstantiated. For example:

- Some of the appointees were awarded compensation even though they failed to submit an affidavit.
- One judge approved a fee based on illegible handwritten time sheets.
- In one case the guardian recommended that the court evaluator receive a fee that was higher than the requested fee, on the ground that the guardian had seen how hard the court evaluator had worked. The court awarded the higher fee based on the guardian's oral recommendation.
- In another matter, the court evaluator was appointed as guardian, and was awarded both a commission and an hourly fee. The legal fees, however, included billing for routine guardianship responsibilities that are covered by the statutory commission, such as visiting the IP, corresponding with the court examiner and preparing the annual accounting.

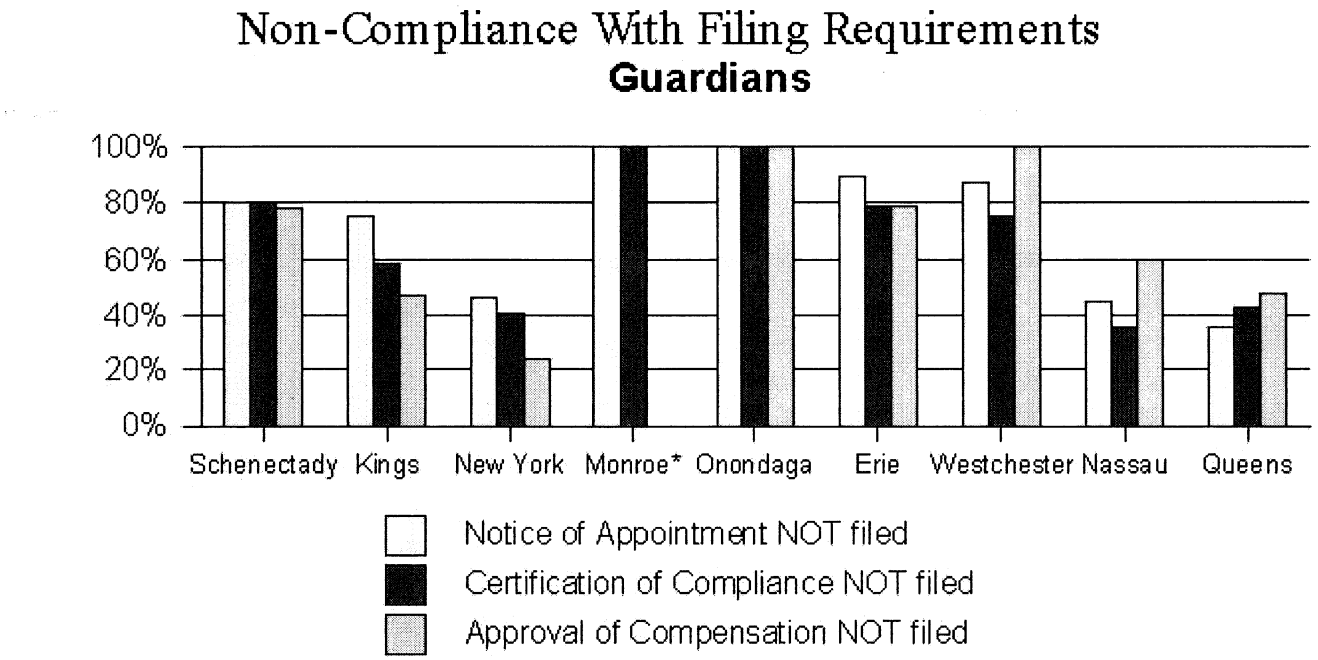
In Westchester County, we reviewed a random sample of 25 cases. The court appointed Mental Hygiene Legal Service as court evaluator in two cases. Family members were appointed as guardians or co-guardians in 11 of the 25 cases. Of the 16 court evaluators appointed, 12 (75%) filed a certification of compliance and 14 (88%) filed a notice of appointment. But of the eight guardians required to file, only two (25%) filed a certification of compliance and only one (13%) filed a notice of appointment. An approval of compensation form was filed on behalf of 11 court evaluators (79%), but none were filed on behalf of six guardians.

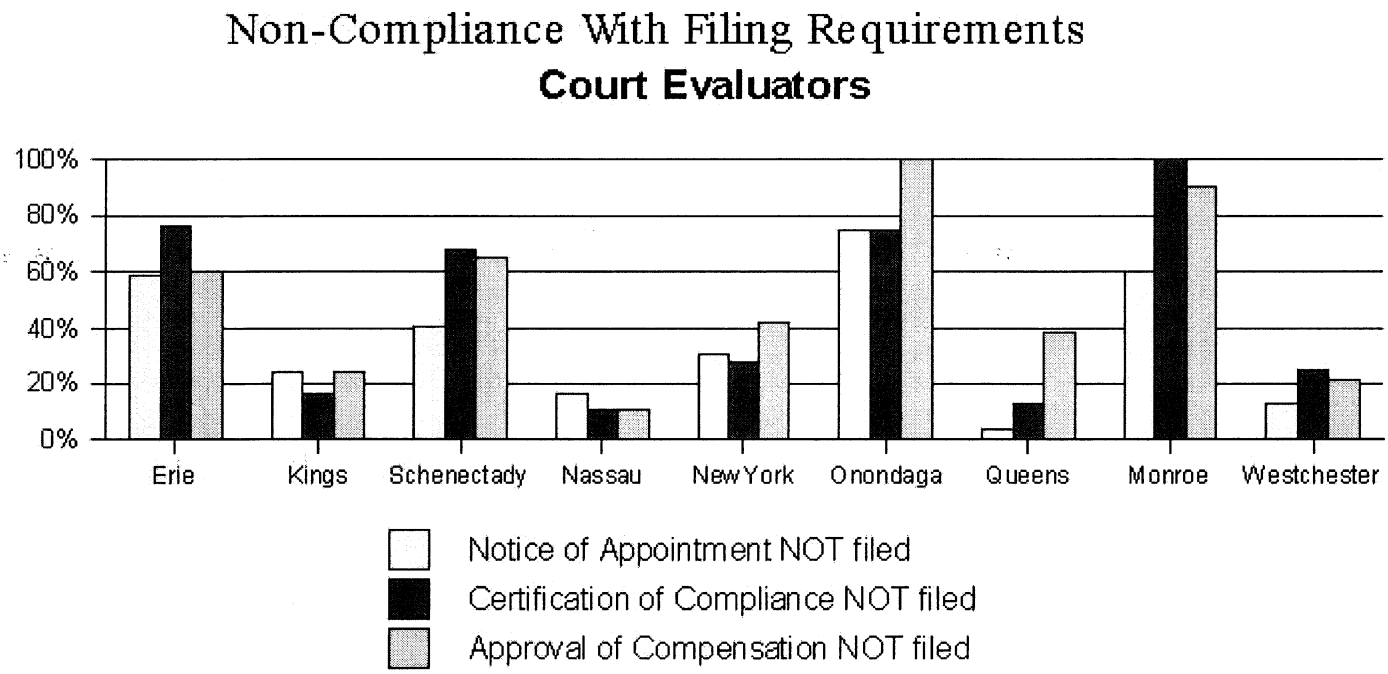
In some of the cases we reviewed, appointees received compensation in excess of the statutory fee originally authorized by the court. In one matter, the appointing order specified that the guardian was to be compensated pursuant to SCPA § 2309. Thereafter, the successor guardian received guardianship commissions and legal fees for filing the final accounting. Despite the original court order, the guardian was compensated based on a calculation using SCPA § 2307, rather than SCPA § 2309, resulting in an increase in fees of over $1,000. The guardian also received legal fees for preparation of the final accounting, a task that a guardian should be expected to perform as part of the guardianship commission.

In Monroe County, we reviewed a random sample of 25 cases. Mental Hygiene Legal Service was appointed court evaluator in two cases, a nonprofit agency was appointed guardian in 10 cases and family members were appointed guardian or co-guardian in 12 cases. Compliance with the filing requirements was poor. None of the appointees filed the certification of compliance form. Only one of five (20%) counsel for the AIP filed a notice of appointment, while only eight of 20 (40%) court evaluators filed and none of the four guardians filed. Fees were awarded to 20 court evaluators but only two approval of compensation forms (10%) were filed, and five counsel for the AIP were compensated but no forms were filed. No guardians received compensation.

It appears from the OCA database that one attorney received appointments that violated the $5,000 rule. The attorney was initially appointed as the court evaluator in one case and awarded over $5,000 and then appointed guardian in that same case for which the attorney earned $17,000; subsequently, the attorney was appointed guardian in another case for which the attorney eventually earned over $13,000.

We also reviewed a random sample of 25 cases in Schenectady County. Mental Hygiene Legal Service was appointed counsel to the AIP or court evaluator in five cases, and 14 family members were appointed guardian or co- guardian. Of those required to file the forms, one (25%) counsel for an AIP filed a certification of compliance and two (50%) filed a notice of appointment; seven of the 22 (32%) court evaluators filed a certification of compliance and 13 (59%) filed a notice of appointment; and two (20%) of the ten guardians filed a certification of compliance and two (20%) filed a notice of appointment. Of those appointees for whom an approval of compensation form was required, none were filed for the counsel for the AIP, seven (35%) were filed for the court evaluators and two (22%) were filed for the nine guardians.





B. APPOINTMENTS IN RECEIVERSHIP CASES

In General

Under New York law, when there is a risk that a business or property that is the subject of a civil action in a superior court may be "removed from the state, or lost, materially injured or destroyed," a person with interest in the business or property may move for appointment of a receiver to manage the business or property while the action is pending (CPLR § 6401(a)). Generally, the receiver is authorized to take and hold real and personal property and sue for, collect and sell debts or claims (CPLR § 6401(b)). In the most common proceeding in which a receiver is appointed--a mortgage foreclosure proceeding--this means that the receiver is authorized to collect rents and institute or defend lawsuits related to the collection of rent or the eviction of tenants.

In general, a receiver's fee, which is paid from the proceeds of the property or business that is the subject of the receivership, may not exceed five percent of the total sums the receiver collects and disburses (CPLR § 8004(a)). In cases in which the receiver's commission, based on the five percent formula, would not amount to $100, the court may authorize a fee of up to $100 for the services rendered. In addition, in cases in which the receiver collects no sums, or is in possession of no sums at the termination of the receivership, the court may authorize a fee based on

the services rendered (CPLR § 8004(b)). A receiver "shall have no power to employ counsel unless expressly so authorized by order of the court" (CPLR § 6401(b)). As noted, Part 36 provides that "persons designated to perform services for a receiver" shall be appointed by the court (22 NYCRR § 36.1(a)). If a counsel is appointed, the fees for such appointees must be reasonable. A receiver may also be reimbursed for expenses necessarily incurred in the performance of his or her duties, such as clerical, auditing, legal or other services. If the receiver is an attorney, however, routine legal services should be performed without separate compensation.[12] Additionally, if the receiver hires an individual to do work that should properly be performed by the receiver, the receiver's commission should be reduced accordingly.[13] A receiver must provide a full accounting and document in sufficient detail the services provided (see generally CPLR § 6404).

Kings County

The Cypress Hills Case

An illustration of the dynamics of fiduciary appointments in receivership proceedings in Kings County is the case of People of the State of New York v. Cypress Hills Cemetery (Index. No. 38143/93). The Cypress Hills case is not a mortgage foreclosure proceeding, and it is far more complex and protracted than the typical Brooklyn receivership proceeding. Yet the relationships of the fiduciary appointees in this case to the Brooklyn political establishment and to each other are emblematic of the process in many of the more routine receivership cases in Brooklyn.

In 1993, the State Attorney General's Office initiated an action in Brooklyn Supreme Court requesting that Cypress Hills Cemetery be placed in receivership because of mismanagement. It was also revealed that the Cemetery Board had permitted over 1,000 bodies to be buried in a "hill" of construction debris that had been created for cemetery plots.

Since its inception, the matter has been handled by Supreme Court Justice Richard D. Huttner. Justice Huttner appointed the first receiver for the cemetery in 1993. The receiver then hired the Brooklyn law firm of Garry & Ludwig as counsel to the receiver. The firm was composed of two partners, William J. Garry and Arnold J. Ludwig, and associate Thomas J. Garry, William Garry's younger brother. Arnold Ludwig, a former law secretary to two Brooklyn Supreme Court Justices, is an officer in the Brooklyn Democratic organization and was a member of the County party's law committee. Thomas Garry is also an officer of the Brooklyn Democratic organization and was a member of the party's law committee. William Garry and Thomas Garry, who joined the firm in 1995, are the sons of a Brooklyn Supreme Court Justice. The receiver also hired a property manager to manage the cemetery.

Although the first receiver was replaced in 1996, Garry & Ludwig were continued as counsel. Then, in 1998, Justice Huttner replaced the second receiver with Manhattan attorney Ravi Batra. Beginning in 1995, Mr. Batra has employed the Brooklyn Democratic County Leader in an "Of Counsel" capacity. Since then, the number of Mr. Batra's fiduciary appointments has substantially increased.

Following his appointment as receiver, Mr. Batra continued to employ the services of Garry & Ludwig and the property manager. On December 6, 1999, however, he wrote to Garry & Ludwig advising that he was replacing them as counsel to the receiver with his own law firm, not only in the Cypress Hills case but also in three other pending cases in which Mr. Batra was serving as the receiver. Conflicting reasons have been offered for the replacement of Garry & Ludwig as counsel. Mr. Batra claims that the firm was incompetent and was attempting to "churn" legal fees. Garry & Ludwig claim that Mr. Batra was motivated by greed.

Cypress Hills was a lucrative appointment for all concerned. Since the inception of the case, well over $1.5 million has been awarded to the various receivers, counsel and property manager. From April 1994 through May 1998, the two initial receivers were awarded $128,000 in commissions. Mr. Batra initially sought $117,000 in compensation for the period of June 1998 through November 1998, but his commission was reduced to $31,400. As counsel to the receivers, Garry & Ludwig received approximately $250,000 in fees. Based on a series of one-year contracts approved by the Cemetery Board providing for monthly management fees ranging from $14,500 to $17,100, the property manager has received over $1.2 million in fees for its management of the cemetery.

Interviews disclosed that shortly after their termination, Garry & Ludwig sought the assistance of the Brooklyn Democratic County Leader and the Chair of the Brooklyn Democratic Law Committee as intermediaries. When their attempts at resolving the dispute failed, Thomas Garry and Arnold Ludwig sent a letter, dated December 20, 1999, to the Law Committee Chair resigning their positions as members of the Committee.[14]

As the letter explains:

It has become apparent that our diligent work and unquestioned loyalty to the Organization over the many years are clearly not as important as the desires of Mr. Ravi Batra. Although Mr. Batra holds no party or elected position in our

County, he has nevertheless imposed himself on the political workings of our Organization for the sole purpose of his own personal financial gain. * * * * [W]e will be unable to continue to represent candidates for elected and/or judicial office free of charge as we have done so in the past . . . . while the Organization sits idly by and permits Mr. Batra to maliciously injure our practice and reputation without consequence * * * * To continue on in our capacity as Law Committee members in light of Mr. Batra's inexcusable actions would be far too much to expect, given the fact that the Organization has permitted an individual with no party position or history in this County to dictate how our Organization is run. . . . Mr. Batra has never assisted the Law Committee on any level whether it be collecting signatures, binding petitions or trying an election law case, etc. In fact, it is unknown as to what Mr. Batra has accomplished in any capacity to benefit our Organization.

The letter concludes:

It is unfathomable that such action would be tolerated by any other political organization within this City or State. It is quite evident that permitting Mr. Batra's behavior has severely damaged our credibility and reputation as a political Organization. * * * * We hope that one day in the not so distant future we will be able to work together again when the interests of the Organization are once again paramount to the unfettered demands of one non-contributing individual.

Garry and Ludwig sent copies of the letter to dozens of other party officials. Weeks later, the press obtained the letter, which was also attached as an exhibit to papers filed in the Cypress Hills litigation. Months later, Mr. Batra resigned his appointment as receiver in the case, and he was replaced by the property manager. In September 2000, the cemetery filed a petition in federal Bankruptcy Court seeking reorganization under Chapter 11.

Findings

Our investigation in Brooklyn Supreme Court concentrated on all mortgage foreclosure cases in which a receiver was appointed between January 1, 1995 and October 31, 2001. Although receivers are occasionally appointed in other types of Supreme Court cases, these appointments overwhelmingly arise in mortgage foreclosures.

The investigation identified 468 mortgage foreclosure cases in which a receiver was appointed between January 1, 1995 and December 31, 1999. We reviewed the court files in only 417 of these cases, because the Clerk's Office was unable to locate the remaining 51 files. Of the files we reviewed, many were incomplete, with required forms and information about appointments and compensation either missing or inadequate.[15] Additionally, we reviewed OCA's fiduciary appointment database to determine whether the filings required under Part 36 were made in these cases. We also conducted a wide range of interviews with judges, fiduciary appointees, other attorneys involved in these cases and court personnel.

In sum, our investigation of these cases revealed the following:

- In general, there was extremely poor compliance with the filing requirements of Part 36.
- Although the judges appointed a range of individuals as receivers, and a majority of those appointed received only one or two appointments, a few individuals received numerous appointments
- In general, receivers were authorized to decide themselves whether to retain counsel or a property manager; contrary to the requirements of Part 36, the receivers, not the judges, appointed their counsel and property managers.
- In the vast majority of the cases in which receivers retained counsel, they retained the law firm of Garry & Ludwig, in violation of the requirements of Part 36.
- In the vast majority of the cases in which receivers retained property managers, one of two companies was retained.
- Little documentation was provided to the court substantiating fees charged by receivers and their secondary appointees.

Compliance with Filing and Other Requirements

In the 417 cases reviewed, 439 receivers were appointed (successor receivers were appointed in some cases). Of these 439 receivers, only 125 (28%) filed a notice of appointment, while 89 (20%) filed a certificate of compliance. Although, as discussed, the fiduciary rules provide that a judge shall not authorize payment to a fiduciary appointee unless the fiduciary has filed a notice of appointment and a certificate of compliance, our investigation identified no cases in which a judge refused to authorize compensation to a receiver on the ground that filings had not been made. In addition, we found no approval of compensation statements filed in any of the cases we reviewed.

We identified 418 "secondary" appointments in the 417 cases we reviewed. Of these, 253 were appointments of

counsel and 165 were appointments of property managers. None of these appointees filed a notice of appointment or a certificate of compliance. Moreover, no statements of approval of compensation were filed for any of these appointees.

In contrast to these findings of widespread lack of compliance with the filing requirements, the investigation did not reveal widespread violations of the $5,000 rule. Only one individual apparently obtained receivership appointments in violation of this rule. In addition, by virtue of its numerous appointments as counsel to a receiver, the law firm of Garry & Ludwig obtained appointments in violation of this rule. Two management companies, by virtue of their receipt of most of the property manager appointments in these cases, also apparently obtained appointments in violation of the rule. This is more fully discussed below.

Appointment of Receivers

The 439 receivership appointments made during the period from January 1, 1995 to December 31, 1999 were awarded to 132 people, 109 of whom were on the OCA list of eligible fiduciary appointees for Kings County. Most of the appointees received only one or two appointments. However, a small group of individuals affiliated with the Brooklyn Democratic political organization received a greater number of appointments.[16]

The following highlights our key findings:

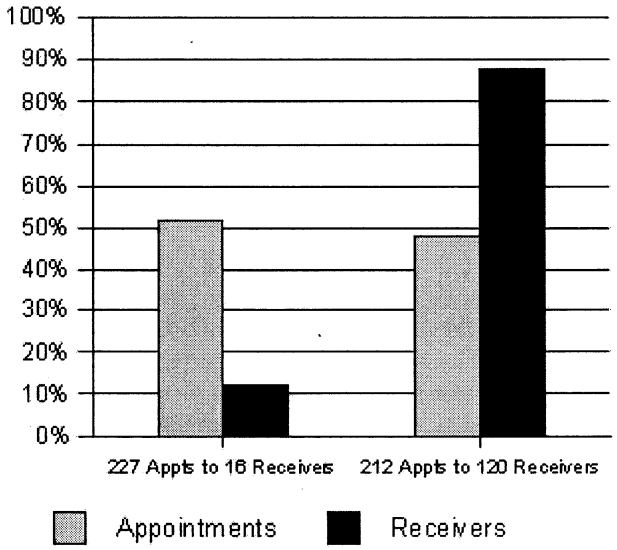
- One individual, who at the time was an official of the Brooklyn Democratic organization, received 46 appointments as receiver, or roughly 10% of all appointments during the period examined. During this period, this person received $137,242 in fees, or 34% of the total fees awarded to receivers in mortgage foreclosure cases.
- In early 1999, the individual described above who received the 46 appointments resigned his appointments. He recommended an attorney with close ties to a top party official as his replacement in those cases that were still outstanding. The individual asserted in motion papers that the attorney was already familiar with the cases and willing to accept the assignments. During our interviews we learned that, in fact, the attorney was not familiar with the specifics of these cases. Judges appointed the attorney as successor receiver in four of these cases. This attorney received a total of 15 appointments.
- The two-member law firm of a high-ranking official of the Brooklyn Democratic organization received 34 receivership appointments.
- One judge made 31 receivership appointments during the period examined, more than twice as many as the judge making the second most appointments. Of the 31 appointments, 21 went to one individual. That appointee contended in motion papers that he needed to hire counsel in those cases because he had no experience in mortgage foreclosures and receiverships.

Overall, a group of 16 individuals (which includes the two-partner law firm noted above) received over half of the receivership appointments during the period examined. Additionally, an even smaller number of appointees--six--received over half of the receivership fees. The appointee with the largest number of appointments received the greatest total amount of compensation--$137,242. The remaining 65 other individual appointees received a total amount of $173,557.

Distribution of Kings County Receivership Appointments

52% of Appointments (227 out of 439) to 16 Receivers

48% of Appointments (212 out of 439) to 120 Receivers



Secondary Appointments

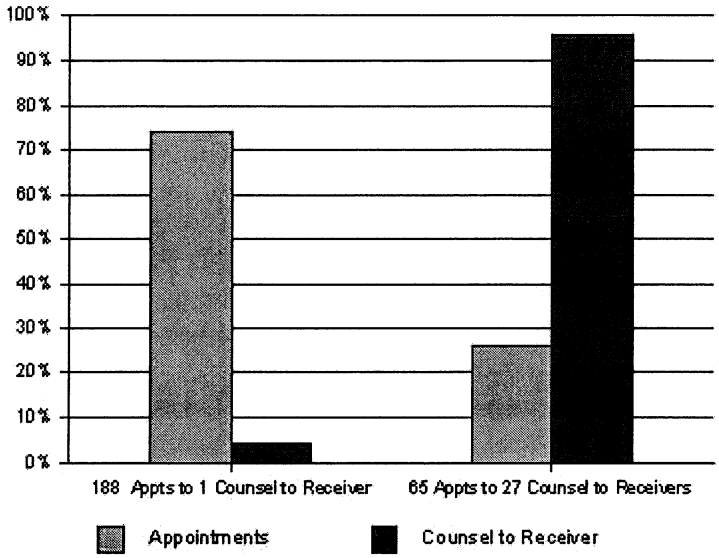
In the 417 cases in which receivers were appointed in Kings County during the 1995-99 period, 253 counsel appointments and 165 property manager appointments were made. As discussed, despite the requirements of Part 36, a practice had evolved in the courts in which the receivers selected their own counsel and property managers. In fact, in all of the cases we reviewed in which counsel or property managers were appointed, the appointments were made by the receiver. The qualifications of those appointed were never reviewed by the court. The only cases in which the court reviewed a receiver's decision to appoint counsel or a management agent were those in which a motion opposing the appointment was filed.

A primary consequence of this practice was that the law firm of Garry & Ludwig, which actually was ineligible for this work because of the prohibition against relatives of judges receiving fiduciary appointments, was appointed as counsel to the receiver in at least 189 cases, or 74% of the cases in which a receiver retained counsel.[17] The firm received $464,554 from these assignments (in addition to the $250,000 it received from the Cypress Hills assignment). By comparison, the other counsel to the receiver appointees received a combined total amount of $130,472.

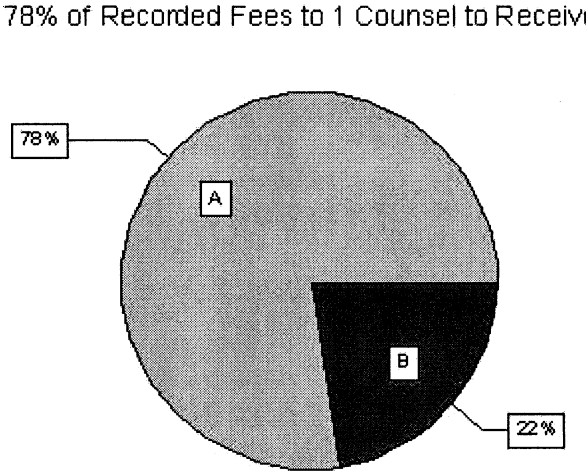
Distribution of Counsel to Receiver Appointments in Kings County

74% of Appointments to 1 Counsel to Receiver

26% of Appointments to 27 Counsel to Receivers



Distribution of Counsel to Receivers' Recorded Total Fees



Two management companies received 63 and 66 appointments respectively, or 76% of the property manager appointments during the period examined. In addition, these two companies received 84% of the fees awarded to property managers (not including the additional money that one received from its Cypress Hills assignment).

In their orders appointing receivers, judges addressed the issue of the receiver's authority to retain counsel in a variety of ways. Some judges permitted the receiver to retain counsel for any matter or purpose. Others specified that the receiver was limited to retaining landlord/tenant counsel if it became necessary to bring an eviction or collection of rent proceeding, but was not permitted to retain counsel for any other purpose. Yet other judges, not intending to limit the receiver's authority at all, crossed out provisions in the order that would have restricted the receiver to retaining counsel only for landlord/tenant matters.

In many cases in which the appointing order did not authorize the receiver to retain counsel or a property manager, the receiver would hire counsel or a property manager anyway. Subsequently, when the time came for payment in these cases, the counsel would prepare a motion to have himself or herself and the property manager appointed *nunc pro tunc* (that is, after the time when it should have been done, with a retroactive effect). In some cases opposition papers were filed, with opposing counsel arguing that the receiver had retained counsel and a property manager without court approval and thus they were not entitled to compensation. These arguments, however, were never successful--in all of the cases we reviewed, the court always authorized payment to such appointees retained without initial court approval.

Regardless of the language in the appointing orders, receivers in Brooklyn routinely retained counsel. This was true even if the receiver was an attorney and had prior experience as a receiver. An attorney who was a recognized expert in receivership law regularly hired counsel whenever he was appointed as receiver. In fact, in several of the cases reviewed, that attorney and another attorney switched roles--when one was appointed receiver he would retain the other attorney as counsel.

The apparent explanation for the great incidence of receivers hiring counsel is a financial one. Our investigation revealed that the nature of the work performed by counsel to the receiver appears to be routine, typically involving review of documents, preparation of accountings and meeting with tenants and property managers.[18] Receivers, however, are compensated at the statutory rate of five percent of receipts and disbursements, whereas counsel for the receiver are compensated at their hourly rate for legal services. Thus, in the average Brooklyn foreclosure receivership case, in which the receipts and disbursements tend to be relatively small, compensation for the counsel is usually more lucrative than for the receiver. Even in cases in which little rent is collected, the counsel to the receiver could still earn over five times the amount earned by the receiver by billing for work that was the receiver's responsibility.

Indeed, in 85% of the cases in which counsel was retained, the counsel's fees exceeded those of the receiver. In 25 of the cases, counsel earned at least twice as much as the receiver, and in one case the counsel actually earned 75 times as much as the receiver. Property managers also typically earned more than the receivers. In 85% of the cases in which property managers were retained, their fees were higher than the receivers' fees. In 17 cases, the property manager earned at least twice as much as the receiver, and in one case the property manager earned 40 times as much as the receiver.

We also reviewed the cases in Kings County in which a receiver was appointed after Chief Administrative Judge

Lippman's March 9, 2000 memorandum reiterating that appointments of persons designated to perform services for receivers must be made by the judge and that these secondary appointments are subject to the requirements of Part 36. We focused on the period from April 2000 to October 2001. Our review revealed that the memorandum has reduced, but not eliminated, the longstanding practice in which the secondary appointees are selected and retained by the receiver. Of the 25 cases in which a counsel to the receiver was actually retained:

- In 11 cases, the order appointing a receiver directed the receiver to apply to the court for approval before retaining counsel.
- In three cases, the order appointing a receiver specified the name of the counsel the receiver should retain.
- In 11 cases, the order appointing a receiver did not instruct the receiver to apply to the court for approval before retaining counsel.

Of the 24 cases in which a property manager was actually retained:

- In seven cases, the order appointing a receiver directed the receiver to apply to the court for approval before retaining a property manager.
- In seven cases, the order appointing a receiver specified the name of the property manager the receiver should retain.
- In ten cases, the order appointing a receiver did not place any restrictions on the receiver retaining a property manager.

Compensation

As discussed, the CPLR expressly limits a receiver's fee to a maximum of five percent of the amounts received and disbursed (CPLR § 8004(a)). In cases in which this limitation would result in a fee of less than $100, the court may approve a fee of up to $100 for the services rendered (Id.). In many of the Kings County cases we reviewed, judges awarded receivers compensation in excess of these statutory limits. Additionally, in other cases judges reduced the receiver's fee but awarded the counsel to the receiver and the property manager their full fee requests, which were always considerably higher than the receiver's fee. And in some cases in which the receiver collected no rent at all, fees were awarded to the receiver, the counsel to the receiver and the property manager.

The following are some examples:

- In one case, the receiver requested and was awarded ten percent--double the statutory amount--as well as attorney fees for preparation of the attorney's own bill.
- In another case, the receivership was terminated without any rent collected. The court awarded the receiver the entire $725 requested. A portion of the receiver's bill included time spent determining whether or not to accept the appointment, reading the statutes governing receiverships (owing to unfamiliarity with the law) and conversing with a political party official about the identity of the defendant's attorney.
- In a case in which very little rent was collected, the court clerk advised the judge that the receiver was entitled under the statute to a fee of only $79.55, not the $500 requested. The judge awarded the receiver $500.
- In a case in which the receivership lasted only 20 days, the receiver failed to collect any rent. The court awarded the receiver $500, the property manager $500 and the counsel to the receiver $5,817.
- In a case in which the receivership lasted only nine days, it was requested that the receiver take no action because the parties were attempting to settle the matter. Although no rent was collected, the receiver sought $500 for himself, over $2,000 for general counsel, $400 for landlord/tenant counsel and $800 for the property manager. In an effort to settle the case, the petitioner agreed to pay the requested amounts.

In many cases, counsel to the receiver submitted bills to the court in which their work was not itemized. Frequently, counsel merely informed the court of their hourly rate and then stated the amount of time they had spent on the case. In some cases, the bills simply reflected "court appearance" with a multi-hour charge and no further indication of what had occurred. In some of the final accountings, counsel failed to detail expenditures, stating simply that the receipts and bills were available for review; in others, receivers offered to produce receipts and other documentation but only if an objection was filed. In the cases examined, rarely did the court request specification. Even in cases in which opposing counsel objected to the amount of the fees sought and requested further specification, the court did not require further specification and simply awarded the fees requested. Although opposing counsel occasionally did object to the fees requested, we learned that they generally did not challenge questionable fee requests because they believed it would be futile to do so as well as prohibitively expensive.

In many cases, a significant portion of the counsel's bill was for preparation of bills for the receiver and counsel. When required to explain these bills, additional billing resulted.

The following are some examples:

- In one case, an objection to the final accounting was filed because the receiver had failed to specify the disbursements and explain why the amount of rent collected had varied from month to month. The receiver, counsel to the receiver and the property manager were all awarded the entire amounts they had originally sought. The counsel was also paid an additional $2,000 for litigating the receiver's final accounting.
- In another case, an opposition to the receiver's final accounting was filed in which billing for boiler repair was questioned because the building did not have a boiler. The parties ultimately settled the matter.
- In another case, the receiver's first accounting erroneously requested an amount in excess of the statutory limit. Thereafter, the counsel to the receiver (who was the receiver's brother) prepared a second bill, and was awarded $750 for the preparation of each bill.
- In a case in which the receivership lasted for approximately seven months, no rent was collected and the only money received was $1,100 from the mortgagor. The receiver requested a fee of $500, along with $6,266 for his outstanding bills which included $3,200 for counsel and $2,100 for the property manager. The petitioner opposed the payments, arguing that a property manager was not needed because the building was a vacant single family home, the property manager had never even visited the premises and the receiver had no authorization to retain counsel. The court approved the final accounting, and awarded the receiver his full fee but cut the payment for the outstanding bills to $3,500, although it did so without specifying how the receiver should distribute the money.

Moreover, in many of the cases reviewed, the receiver and the secondary appointee had a business relationship or were actually the same person. For example, in a number of cases the owner or an employee of a property management company was appointed as receiver and then hired his or her company as the property manager. In other cases, paralegals were appointed receiver and then hired their employers as counsel to the receiver. And in a few cases, the receivers hired themselves or their own law firms as counsel and then were awarded receivership fees and counsel fees.

Contrary to what transpired in most of the cases, routine mortgage foreclosure proceedings in which a receiver is appointed do not necessarily require the appointment of a counsel and a property manager. Some receivers performed the necessary work themselves and did not hire counsel or property managers. Receivers in these cases told us they realized that funds might not be plentiful and so they took steps to minimize expenditures. Additionally, in some cases, efforts were made to contain expenses by charging lower hourly rates and by not charging for preparing the receiver's final accounting.

Findings From Other Jurisdictions

Our review of receivership cases in other counties uncovered many of the same problems we identified in Kings County. Compliance with the filing requirements was poor, many courts authorized payment to appointees without ensuring that the Part 36 forms were filed, very few courts made the secondary appointments and compensation was often excessive, unsubstantiated or in violation of statutory requirements.

In Nassau County, where we reviewed a random sample of 25 receivership cases, there was little compliance with the filing requirements. Only four out of 26 receivers (15%) filed a certification of compliance and only six (23%) filed a notice of appointment. Filing of the approval of compensation forms was also poor, with only 15% of the forms filed for the receivers and no forms filed for secondary appointees. Moreover, the court failed to make any of the appointments of counsel or property managers. In fact, many of the orders appointing receivers expressly authorized the receiver to retain a counsel and property manager. Additionally, in two cases the receivers were awarded fees that were higher than the five percent statutory commission rate. In one case, the receiver was awarded double his permissible compensation.

In Erie County we reviewed a sample of 24 cases in which 26 receivers were appointed.[19] Compliance with filing requirements was inadequate, with only five (19%) of the receivers filing a certification of compliance form and six (23%) filing the notice of appointment forms. Only three of the ten (30%) required approval of compensation forms were filed. None of the property managers, many of whom were not appointed by the court, filed either a certification of compliance or a notice of appointment.

Additionally, in several cases the receivers were awarded fees higher than the statutory commission rate. The following are two examples:

- In one case, the receiver miscalculated the commission and received nearly double the permissible compensation.
- In another case, the receiver was compensated on an hourly basis, resulting in a payment almost three times higher than it would have been had the receiver been compensated in accordance with the statute. The receiver's bills included five hours per month for apparently routine receivership duties such as site inspections, rental of units and conferring with contractors and vendors about repairs.

In Westchester County, we reviewed a sample of 29 cases in which receivers were appointed. All of the cases were selected randomly from the OCA fiduciary database, because the court maintains no method by which foreclosure cases in which receivers are appointed can be identified. Thus, because cases are entered in the OCA database only when at least one fiduciary form for a case has been filed with OCA, we had no way of precisely measuring the rate at which fiduciary appointees and judges in Westchester receivership cases comply with the filing requirements. We did determine, however, that only 15 (52%) of the receivers filed a certification of compliance (which is filed only in the court file and not with OCA), and that no secondary appointees filed any of the forms. In addition, of the 24 fiduciaries who received compensation--23 receivers and one counsel to a receiver--only three (13%) approval of compensation forms were filed.

The court did not appoint most of the counsel and property managers retained by the receivers; in fact, many of the orders appointing the receivers, including receivers who were themselves attorneys, authorized the receiver to appoint a counsel and a property manager. Further, in eight of the cases, the receivers' fees were higher than the statutory commission rate:

- In four of these cases, the court cited a stipulation between the petitioner and the receiver as justification for the fee.
- Judges in the other four cases provided no explanation for approving compensation exceeding the statutory limit.
- In most of the cases, the fees were at least 50% higher than the statutory rate.
- In a few cases, the fee was nearly 200% higher than the statutory rate.

Moreover, in some cases, in addition to collecting their commission, fiduciaries were awarded hourly fees for routine services they were required to perform. In one matter, a receiver hired his own law firm as his counsel. He also hired an accountant and a property manager. The counsel's affidavit of services included many items that appear to be routine responsibilities of a receiver, including calculating the receiver's commission and preparing the final accounting. The receiver, his law firm, the accountant and the property manager each earned approximately $20,000. The court file, however, contained no documentation supporting the fees for the accountant and property manager.

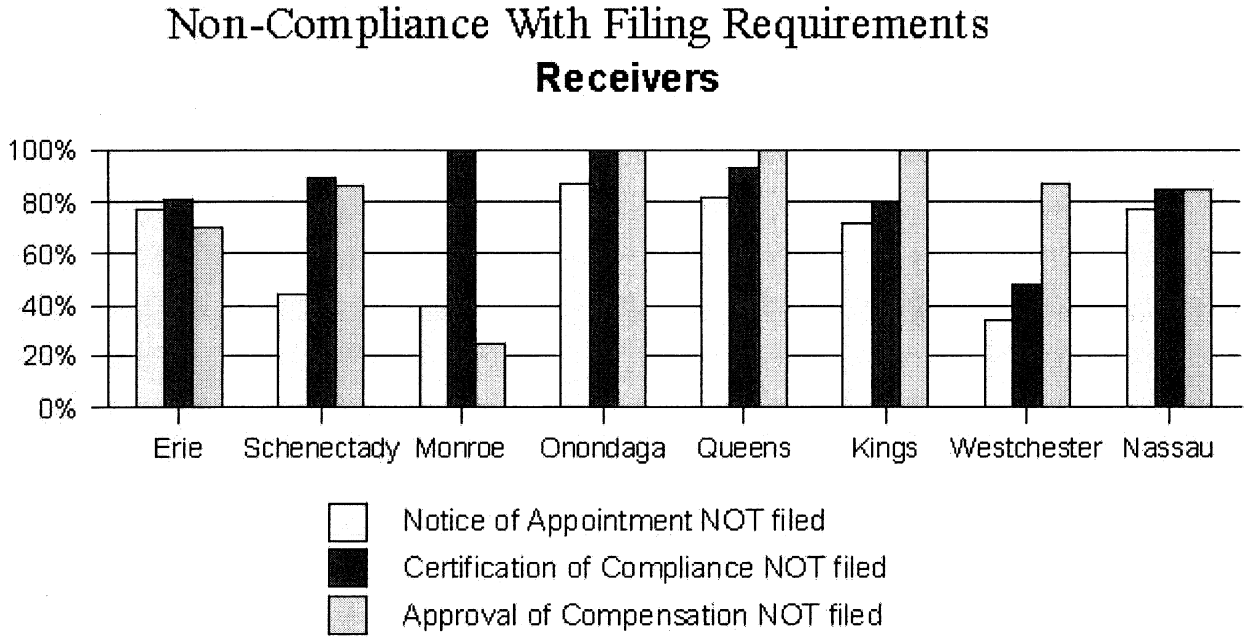
In Schenectady County, we reviewed a sample of 17 cases in which receivers were appointed. Because the court was only able to provide a list of ten cases in which receivers were appointed during the five-year period under examination, the additional seven cases were selected randomly from the OCA fiduciary database. Again, because cases are entered in the OCA database only if at least one of the required forms has been filed, an accurate analysis of compliance with the filing requirements is not possible. In the 17 cases reviewed, there were 18 receivers appointed including a successor receiver. Of these, ten receivers (56%) filed a notice of appointment and only two (11%) filed a certification of compliance. In addition, of the 13 receivers and one property manager who received fees necessitating the filing of an approval of compensation form, only two such forms (14%) were filed.

The court rarely appointed the counsel, property managers or accountants hired by the receivers. Moreover, a number of the orders appointing receivers expressly authorized the receiver to appoint counsel or property managers whenever they thought they were necessary, without any further involvement of the judge:

- In one matter involving a large commercial property, the court appointed the property manager but authorized the receiver to employ such legal counsel as he deemed necessary. The receiver was awarded almost $100,000, or approximately three percent of the receipts, and the property manager was awarded five percent of the receipts. The case file, however, did not contain documentation supporting all of the fees awarded.
- In another matter, the receiver hired an accountant without approval from the court and paid the accountant for his services. When the plaintiff objected, the court awarded the receiver a commission but deducted the amount paid to the accountant.

We reviewed a random sample of 25 receivership cases in Queens County. Only two (7%) of the 28 receivers appointed in these cases filed a certification of compliance form and only five (18%) filed a notice of appointment. No approval of compensation forms were filed for the 12 receivers who received compensation requiring the filing of such forms.

In the cases reviewed, eight secondary appointments were made--four counsel and four property managers. The court did not make these appointments, and none of the required forms were filed. A review of the appointment orders disclosed that the receivers were given broad authority to appoint counsel and property managers as deemed necessary, without any court intervention. In addition, in some of the cases the receivers were paid excessive fees. In one matter, the receiver was paid both the statutory commission and separate legal fees for routine services required of a receiver, such as filing the bond and preparing the accounting.



C. GUARDIAN AD LITEM APPOINTMENTS

In General

A court appoints a guardian ad litem to protect the rights of an individual under a disability who is involved in litigation. The Surrogate's Court Procedure Act (SCPA) defines a person under a disability as: (1) an infant under 18 years of age; (2) a person judicially declared incompetent to manage his or her affairs; (3) an incapacitated person; (4) an unknown person or one whose whereabouts are unknown; or (5) a person confined as a prisoner who failed to appear under circumstances that the court finds are due to confinement in a penal institution (SCPA §§ 103, 402). A guardian ad litem may also be appointed where unborn or unascertained persons may eventually become entitled to an interest in the proceedings (SCPA § 315), or where a possible conflict of interest between a representative of the ward (such as a guardian) and the ward exists (SCPA §§ 315, 402).

A guardian ad litem differs from a guardian of the person or the property under Article 81 in several respects. Most importantly, a guardian ad litem is appointed to act on behalf of the party under disability for the limited purpose of the matter before the court and not for the party's general care and welfare. Moreover, since the guardian ad litem is appointed to protect the person under disability in the context of the litigation before the court, the guardian ad litem must be an attorney admitted to practice in New York (SCPA § 404(1)).

At the time of appointment, the guardian ad litem must file a consent to act and an affidavit affirming that he or she is qualified to protect the ward's rights, does not have a relationship with any of the parties, does not have an interest in the estate and does not have a conflict with the interests of the ward (SCPA §§ 402(1), 404). Once qualified to act, the guardian ad litem must take whatever steps are necessary to protect the interest of the person under disability. The final act of the guardian ad litem is to file with the court a report detailing his or her findings and recommendations (SCPA § 404(3)).

In Surrogate's Court, guardians ad litem are appointed most frequently in will probate proceedings and proceedings to settle the accountings of executors, administrators and trustees. Other proceedings that involve appointment of guardians ad litem include: (1) compromise of wrongful death and personal injury actions; (2) adoptions; (3)

applications for the disposition of real property; (4) construction proceedings under SCPA § 1420; (5) heirship proceedings; and (6) Mental Hygiene Law Article 81 proceedings.

The guardian ad litem's fees are determined in a manner similar to the general process for setting attorney's fees. The statute provides that the guardian ad litem shall receive reasonable compensation for the services rendered (SCPA § 405(1)). Relevant factors in setting the fee include: the nature, extent and necessity of the services provided; actual time spent on the matter; the nature and complexity of the issues involved; the professional standing of the guardian ad litem; the results obtained in the case; the size of the estate; and the size of the interest of the ward in the estate.[20] Typically, the guardian ad litem's compensation is paid from the estate or the interest of the person under disability (SCPA § 405). In determining the value of the guardian ad litem's services, the court reviews the time records supplied by the guardian ad litem.

Nassau County

Our review of guardian ad litem appointments in Nassau County was limited by the recordkeeping procedures of the Surrogate's Court. The Nassau County Surrogate's Court assigns each case a number that stretches back in chronological order to that court's very first case in 1898. The number assigned, however, does not reference the year that the case was filed. As a result, the court was not able to supply us with a list of all matters that began in any particular year. Additionally, we were informed that, until the spring of this year, the court maintained no records of information pertaining to the appointments of guardian ad litem. The court did not keep a list of the guardian ad litem appointments made, the fees awarded to the guardians ad litem or the filings made to OCA. Accordingly, we were compelled to rely on records of guardian ad litem appointments contained in the OCA fiduciary database.

We reviewed the listings in the OCA database of guardian ad litem notices of appointment for each of the last ten years. The number of recorded guardian ad litem appointments made in Nassau County between 1995 and 2000 averaged 255 per year. We selected for review all cases recorded in the OCA database in which a guardian ad litem appointment was made between January 1, 1998 and December 31, 1998, as our goal was to review recent cases but also those in which the guardian ad litem work's would have been concluded.

The OCA database contained filings for 278 guardian ad litem appointments in 272 cases in Nassau County Surrogate's Court for calender year 1998. This included six adoption matters that could not be reviewed because the files had been sealed by the court. In addition, the court clerks were unable to locate eight other court files. Of the 258 cases we were able to review, the court files in two cases contained no information concerning a guardian ad litem. In six cases, the court appointed an additional guardian ad litem, and in one case the court appointed two additional guardians ad litem. Thus, we reviewed a total of 264 appointments.

At the conclusion of our review of these appointments, however, we were informed by the clerk of the court that, in fact, the court had kept some records of guardian ad litem appointments. For the first time, we were informed that the practice of the court, for several years prior to 1999, had been to send a letter notifying all attorneys who had been appointed as guardian ad litem of their appointment. The court began to keep copies of these letters in October 1999. The court had copies of 42 letters sent to guardians ad litem concerning appointments during the period of October 1, 1999 to December 31, 1999. Of these 42 letters, seven were duplicates or pertained to cases the clerks could not find. We reviewed all 35 of the cases where the court had sent a letter to the guardian ad litem and the clerks could locate the file. The court also had 286 copies of letters sent to guardians ad litem in cases that originated in 2000. As we were unable to adequately establish the compliance with the Part 36 filing requirements in our review of appointments made in 1998, we examined the filings made by guardians ad litem in 2000.

In addition to reviewing these cases, we also interviewed judges, court personnel and numerous fiduciary appointees.

Compliance with Filing and Other Requirements (1998)

As noted, we had to rely on the OCA fiduciary database to identify cases in which guardians ad litem had been appointed. Thus, it was impossible to establish the level of compliance for filing the notice of appointment forms. We were, however, able to evaluate the number of certification of compliance forms that were filed (these are filed with the court but not with OCA). Our review of the 264 appointments made in 1998 found that 261 (99%) of the appointees had filed the certification of compliance form with the court. This finding of almost perfect compliance is tempered by the fact that the only appointments we were able to review were of guardians ad litem who had filed their notice of appointment forms, and the certification of compliance typically is filed contemporaneously with the notice of appointment.

We were also able to evaluate compliance with the requirement that the court file a statement of approval of

compensation form at the time the fiduciary is awarded a fee. We found that approval of compensation forms were filed in only 147 of the 264 cases (56%). We reviewed the 117 cases where the approval of compensation was not filed and found that in 34 of those cases, a statement of approval of compensation was in the court file, although only four of those forms were complete and signed by the court while the remaining 30 forms were not signed by the court.

Distribution of Appointments and Compensation (1998)

The 266 guardian ad litem appointments made in 1998 were awarded to 96 people, 95 of whom were on the OCA fiduciary list of eligible appointees. Over two-thirds of the appointees received only one or two appointments and small amounts of compensation. A smaller group of appointees, most of whom had some connection to the court--such as former interns --received almost half of the total appointments, although they also received relatively small fees. A third, even smaller, group received one or two very lucrative appointments. This small group that received lucrative appointments included two retired judges and the former head of the law department of the Surrogate's Court in a neighboring county. With the exception of one attorney, the appointees who received frequent appointments received no cases involving high fees, and the attorneys who received lucrative appointments did not handle the smaller cases. This finding is contrary to the widely-held perception that fiduciaries who take appointments for no fee or for a minimal fee are often rewarded with high-paying appointments.

Throughout these years, the court's system of selecting guardians ad litem was as follows: if the value of the estate was greater than $1 million, the Surrogate would appoint the guardian ad litem without consulting his staff. If the value of the estate was less than $1 million, the chief clerk would recommend to the Surrogate a candidate for appointment and, with rare exception, the Surrogate would then appoint the recommended candidate.

The nature of the case in which the guardian ad litem was appointed dictated the size of the fee the appointee received. In the majority of the cases we reviewed, a petition for probate of a will was filed with no objections. In these cases, the guardian ad litem's role was limited to a review of the validity of the execution of the will, resulting in a report to the court. If the guardian ad litem approved the probate of the will, he or she would not have to make an appearance before the court and the responsibilities generally were completed in ten hours or less. In these straightforward cases, the guardian ad litem's compensation was based on a schedule keyed to the size of the estate, and the guardian ad litem would not file an affidavit of compensation. But if the guardian ad litem sought a fee greater than that allowed by the schedule or greater than $2,500, he or she would file an affidavit of services.

The following highlights our key findings:

- A total of 96 individuals received guardian ad litem appointments in 1998. Of that total, 65 (68%) received only one or two appointments.
- A much smaller group of 11 attorneys received over five appointments each for a total of 105 appointments. Three of these attorneys received over ten appointments each, with the largest number of appointments an individual attorney received being 20. The average compensation awarded was approximately $1,000 per appointment, usually for cases involving simple petitions for the probate of a will.
- We were unable to establish the size of the fees awarded to the guardian ad litem in 42 (16%) of the cases. Of the 222 cases in which the compensation was set forth in the case file, the total compensation awarded was $506,587.
- A group of 11 attorneys received 20 appointments with a total compensation of $237,352. These 11 attorneys received 47% of the total compensation awarded in 1998.
- One individual who was not on the OCA fiduciary list received five appointments in 1998, for which he earned a total of $8,600. None of the case files contained a written record of the reasons why he was appointed despite not being on the OCA list. The OCA database showed that between 1996 and 2000, this attorney reported 24 appointments from Nassau Surrogate's Court and $35,300 in compensation. The attorney stated that he was friendly with the court clerks and had performed legal work for some of the clerk's families. He also told us that, in the early 1990s, he had asked several of the clerks to give his wife guardian ad litem appointments. The OCA database reveals that his wife received 31 guardian ad litem appointments in Nassau Surrogate's Court between 1992 and 2000.
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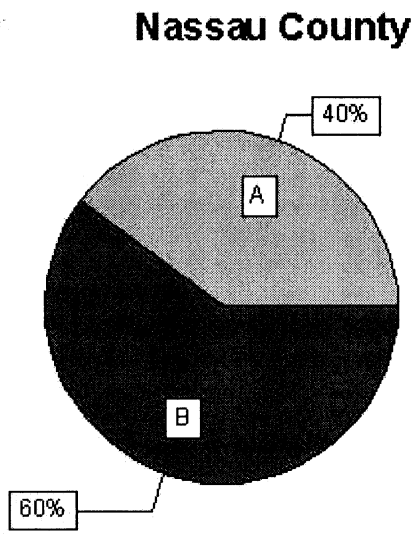
40% of Appointments to 11% of Guardians Ad Litem



A 105 appointments to 11 GALs

B 159 appointments to 85 GALs

Compliance (Fall 1999)

We also reviewed the 35 cases identified in the letters that the court sent to guardian ad litem appointees in October, November and December of 1999. The 35 appointments were given to 24 attorneys, with 16 receiving a single appointment. The remaining eight appointees received a total of 19 appointments. We were able to determine the amount of the fees the guardians ad litem received in 33 of the 35 appointments, and a total of $63,450 in fees was awarded. In two of the cases, the guardians ad litem received no fees. The fees awarded ranged from $150 to $12,000, and the average compensation was approximately $2,000.

Twenty-three (66%) of the appointees filed notice of appointment forms. In the 12 cases in which a notice of appointment had not been filed, a copy of the form was found in half of the court files. The certification of compliance form was present in 30 of the 35 case files (86%). The court filed a statement of approval of compensation in 23 of the 35 cases. Of the 12 cases in which a statement of approval of compensation was not filed, three of the court files contained completed forms; additionally, in two cases, filing was not required because the guardian ad litem was not awarded any fees. Thus, forms were filed in 71% of the cases in which they were required.[21]

One Selected Nassau County Case

Although it was an unusual and complicated proceeding, one case provides an example of how court appointees in Nassau Surrogate's Court frequently have close ties to the court and to each other. The case, which lasted for nearly five years and began as a will probate contest and later continued as an accounting proceeding, involved the appointment of two guardians ad litem, one assistant to the guardian ad litem, two counsel to the guardian ad litem, one special referee and one assistant referee. The total fees for the fiduciaries in the case were more than double the combined fees for all guardian ad litem appointments in all of the cases initiated in the court in 1998.

The estate was valued at over $80 million, and the decedent was survived by a daughter, two granddaughters and several great-grandchildren. The decedent's final will and codicils specifically disinherited one granddaughter and her children. Several law firms were retained and actively litigated the probate of the will.

The Surrogate appointed a retired Nassau County Court Judge as guardian ad litem for the great-grandchildren who were disinherited in the will, a retired Surrogate to act as special referee to oversee the discovery and daily case developments in the matter and an attorney as guardian ad litem for the great-grandchildren who had not been disinherited in the will.

The retired County Court Judge informed us that, shortly after his appointment as guardian ad litem, he anticipated that as a solo practitioner the responsibilities of the case would be greater than he could handle alone, so he hired two attorneys to act as his assistants--his daughter, and the Nassau County Deputy Public Administrator. Because the former County Court Judge was retired from the bench, his hiring of his daughter was not barred by any existing rules or statutes. Nor is there any legal prohibition against a fiduciary appointee hiring a relative to assist in a case. Additionally, there is no bar against a guardian ad litem retaining the Deputy Public Administrator.[22] Nevertheless, since the guardian ad litem needed assistance with the great amount of work he anticipated, his hiring of an attorney with a full-time government position is curious. Additionally, the Deputy Public Administrator had not only been appointed by the Surrogate, but he was the Surrogate's former court officer and a close personal friend.

The former Surrogate, who was the special referee, was paid $250 per hour. The guardian ad litem's billing rate was $300 per hour, and his daughter's and the Deputy Public Administrator's rates were $200 per hour. The total fees awarded in the case were extensive. The guardian ad litem received $424,500. The billing records reveal that, over a two- month period in 1995, the Deputy Public Administrator billed for 167 hours of legal work over 22 days, or an average of almost eight hours per day. In all, the Deputy Public Administrator submitted affidavits of services detailing over 1,000 hours of work, for which he received approximately $215,000. The guardian ad litem's daughter received over $44,000. The retired Surrogate who was the special referee received $192,500, and his assistant received over $10,000. The guardian ad litem for the inheriting great-grandchildren and his counsel received over $500,000 in combined fees. All told, the combined fiduciary fees in the case were nearly $1.5 million.

Findings From Other Jurisdictions

In Erie County, we reviewed a random sample of 50 cases in which 60 guardians ad litem were appointed during the period January 1, 1995 through December 31, 1999. A review of these cases revealed that all of the certificate of compliance forms and 47 (78%) of the notice of appointment forms were filed. In addition, 52 of 55 (95%) statements of approval of compensation were filed. A review of the court files, however, showed that the notice of appointment forms, the court orders appointing fiduciaries and the court's records concerning the appointments often had different appointment dates recorded. This creates confusion regarding the actual date of appointment and makes it more difficult for appointees to comply with the rules. We notified the court about this problem, and the court has now corrected its procedure to ensure that consistent and correct dates are recorded.

Our review of guardian ad litem fees was difficult because in a majority of cases the amount of compensation was determined by the litigants, not the court. The Surrogate told us that his longstanding policy was to approve the fees that the parties agreed upon unless they "shocked the conscience." Typically, if the parties did not prepare an affidavit of services, the court did not request one. The standard hourly fee requested was generally within the range of $125 to $175.

It appears from a review of the OCA database that as many as seven attorneys may have violated the $5,000 rule. In the cases reviewed, there was no documentation in the court file indicating whether the appointees met the narrow exception to the $5,000 rule. Moreover, some of these appointees did not include in their certifications of compliance, as required, a list of appointments they received within the previous 12 months, even though they had received recent prior lucrative appointments. For example:

- One guardian ad litem was awarded $18,000. Later the same month, he received a second appointment for which he was compensated over $61,000, and less than eight months later he received another appointment for which he earned $18,000.
- A guardian ad litem was appointed and received over $16,000. Less then five months later, he received another appointment for which he was paid over $26,000.
- Another guardian ad litem received an appointment for which he earned almost $10,000, and was shortly thereafter appointed in another case in which he earned over $17,000.

In Westchester County, we reviewed a random sample of 25 cases. Of this sample, 23 of 27 guardians ad litem (85%) filed a notice of appointment, and 26 of 27 (96%) filed a certification of compliance. The court filed approval of compensation forms for 19 of 22 (86%) appointees. It appears that one of these attorneys received appointments in violation of the $5,000 rule.

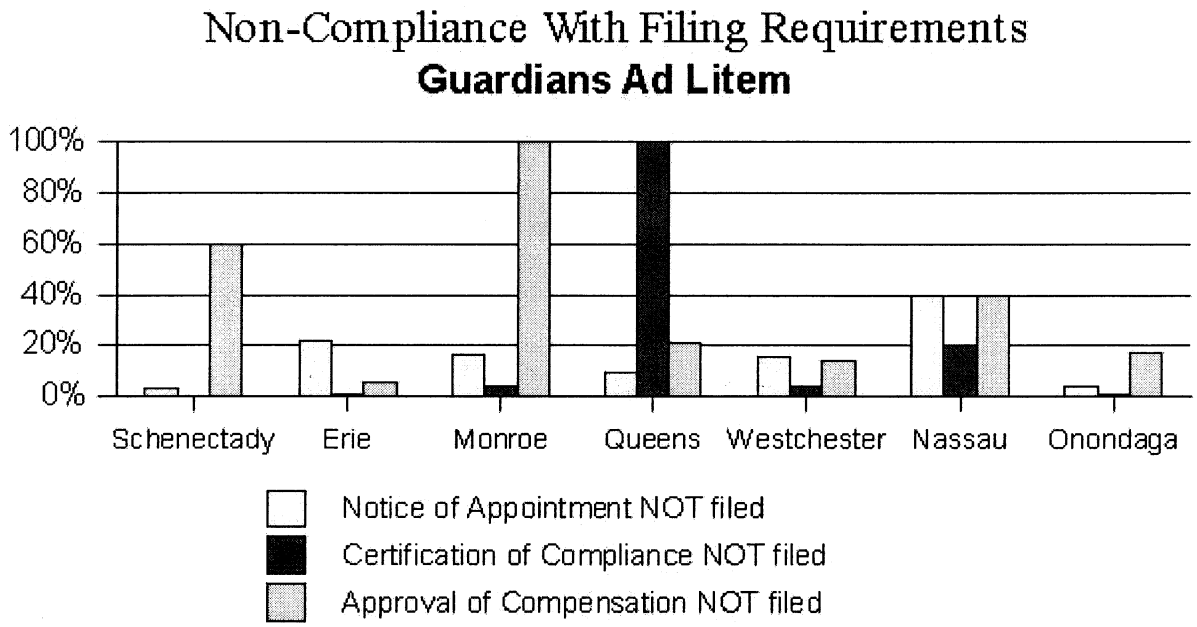
We also reviewed a random sample of 25 cases in Monroe County. Our examination revealed that 21 of 25 guardians ad litem (84%) filed a notice of appointment, and 24 of 25 (96%) filed a certification of compliance. The court, however, had filed no approval of compensation forms since October 1993. The chief clerk explained that this was an oversight possibly related to the court's revamping of its case management system. We also selected a random sample of ten cases in which guardians ad litem had been appointed and determined that five of the appointees were not included on the OCA fiduciary list. The court files, however, contained no indication that the

court had provided a reason for selecting an appointee who was not on the OCA list.

In one case that came to our attention involving a sizeable estate, a guardian ad litem was awarded $4,000 for 3.75 hours of legal work.

Our random sample of 25 cases in Queens County revealed that all of the appointees had filed a certification of compliance, 30 (91%) had filed a notice of appointment and 26 (79%) approval of compensation forms had been filed. It appears that at least three individuals were appointed in violation of the $5,000 rule. One received four guardian ad litem appointments within a 12-month period in which she earned $7,500, $10,500, $7,500 and $31,500, respectively. Another received three appointments within a five-month period in which he earned $11,500, $8,500 and $27,500, respectively.

Our review of 25 cases in Schenectady County revealed that all of the guardians ad litem filed a certification of compliance form and all but one filed a notice of appointment. However, approval of compensation forms were filed for these appointees in only 40% of the cases. Similarly, in Onondaga County, all appointees filed a certification of compliance form and only one failed to file a notice of appointment form. Approval of compensation forms were filed for 83% of these appointees.



CONCLUSION

As this Report makes abundantly clear, the fiduciary appointment process in New York is in need of reform. We have documented a wide range of problems that regularly arise in these cases in courts throughout the State. In doing so, we have confirmed the validity of many of the public criticisms concerning the fiduciary process.

Although our findings are troubling, for the following reasons we are confident that the system is now undergoing significant improvement. First, the Commission on Fiduciary Appointments, which at Chief Judge Kaye's

request has been examining the appointment process, has completed its own review and is about to release its report and recommendations. The recommendations will include, among other things, proposals to strengthen eligibility and qualifications for fiduciary appointment, tighten restrictions on the number of appointments that individual fiduciaries may receive and upgrade oversight of the appointment process. If implemented, these recommendations will lead to significant improvements in the existing system.

Second, court administration already has taken major steps to correct the flaws we found in the fiduciary filing process. Last Spring, a new oversight system was implemented, in which special fiduciary clerks have been appointed in every Judicial District. Reporting directly to the District Administrative Judges, the fiduciary clerks serve as the clearinghouse for all forms appointees and judges are required to file with OCA, and they will be monitoring the OCA fiduciary database to verify that information concerning who is receiving appointments and how much they are paid is entered accurately. The goal is to ensure that all forms are properly filed in every single case in which a fiduciary is appointed and that no fiduciary appointee is paid unless he or she has filed the necessary forms.

Third, in cases in which we have uncovered clear violations of the fiduciary rules or ethical standards, Chief Administrative Judge Lippman has referred individuals to appropriate disciplinary authorities. We have every expectation that these referrals, and any future referrals that may be made, will send an unmistakable message to the bar and bench that violations of the fiduciary rules will not be tolerated.

Finally, our work does not end with this report. In establishing the Office of the Inspector General for Fiduciary Appointments, Chief Judge Kaye made clear that the office will be a permanent entity within the court system. Together with OCA's Internal Audit Unit, our examination of fiduciary appointment practices throughout the State is ongoing. We will continue to identify problems in this process and recommend that individuals be referred to relevant disciplinary authorities, as appropriate. Moreover, in the coming months, we will help to ensure compliance with the rules, monitor the effectiveness of the reforms, and assist the bench and bar in meeting their responsibilities in regard to fiduciary appointments.

Attachment A

M E M O R A N D U M

March 9, 2000

TO: Justices and Judges of the Supreme Court,

County Court and Surrogate's Court

FROM: Jonathan Lippman

RE: Appointment of persons designated to perform services for a receiver

In light of recent disclosures alleging that appointments of persons to perform services for receivers have been made based upon political considerations, we want to ensure, to the extent those practices may exist, that such appointments are made in conformity with court rules that are designed to remove favoritism from this appointment process. It appears that some of you may not be aware of how these court rules apply to appointments of persons to perform services for receivers, and it is important that everyone understands and properly applies our existing rules while the newly appointed Commission studies the entire fiduciary appointment process.

Part 36 of the Rules of the Chief Judge [22 NYCRR], governing certain designated fiduciary and fiduciary-related appointments by judges, sets forth special procedures and restrictions in the making of these appointments -- including selection from lists of applicants, limitations on the number of substantial appoint-ments, prohibition of appointment of relatives of judges, and pre- and post-appointment certification and reporting obligations of the appointee. A copy of Part 36 is attached. Section 36.1(a) expressly applies these requirements to the appointment of persons designated to perform services for a receiver (which include attorneys, agents, appraisers, auctioneers and accountants), and it requires that the court, and not the receiver, make these appointments and do so in accordance with these procedures and restrictions. Your orders appointing receivers should conform to these requirements.

We expect to be issuing shortly additional memoranda addressing in more detail the requirements and logistics of Part 36 to make sure that they are not inadvertently overlooked.

Thank you for your cooperation.

JL/job

Attach.

cc: Hon. Joseph J. Traficanti, Jr.

Hon. Joan B. Carey

Hon. Ann T. Pfau

Administrative Judges

PART 36. APPOINTMENT OF GUARDIANS, GUARDIANS AD LITEM, COURT EVALUATORS, ATTORNEYS FOR INCAPACITATED PERSONS, RECEIVERS, PERSONS DESIGNATED TO PERFORM SERVICES FOR A RECEIVER, AND REFEREES

§ 36.1 Appointments

(a) All appointments of guardians, guardians ad litem, court evaluators, attorneys for alleged incapacitated persons (under Article 81 of the Mental Hygiene Law), receivers, persons designated to perform services for a receiver and referees shall be made by the judge authorized by law to make the appointment upon evaluation by that judge of the qualifications of candidates for appointment. The appointing judge may select the appointee from the list of applicants established by the Chief Administrator of the Courts pursuant to section 36.2(a) of this Part. Except for the appointment of court evaluators, should the appointing judge decide that a person or institution not included on the list of applicants is better qualified for appointment in a particular matter, either because of prior experience with the ward or estate, or because of particular expertise necessary to the case, the judge may appoint that person or institution, and in such instance shall place the reasons for such appointment and the qualifications of such appointee on the record. The appointing judge shall be solely responsible for determining the qualifications of any appointee.

(b)(1) No person shall be appointed who is a relative of, or related by marriage to, a judge or housing judge of the Unified Court System of the State of New York, within the sixth degree of relationship. This provision shall apply only to known relatives of judges and not to the professional associates of those relatives.

(2) No person serving as a judicial hearing officer pursuant to Part 122 of the Rules of the Chief Administrator shall be appointed in actions or proceedings in a court in a county where he or she serves on a judicial hearing officer panel for such court.

(3) No person shall be appointed who is a full-time or part-time employee of the Unified Court System.

(c) No person or institution shall be eligible to receive more than one appointment within a 12-month period, calculated from the date of appointment, for which the compensation anticipated to be awarded to the appointee exceeds the sum of $5,000, except that where the appointing judge determines that unusual circumstances of continuity of representation or familiarity with a case require an appointment for which compensation would exceed that permitted by this subdivision, the judge may make such appointment and must set forth in writing the reason for the exception.

(d) A prospective appointee whose appointment is subject to these rules shall certify in writing to the appointing judge, prior to the acceptance of the appointment, that the appointment will not be in violation of these rules. The certification shall include a statement that the appointment will be in compliance with subdivisions (b) and (c) of section 36.1 of this Part and shall include a list of all previous appointments received within the preceding 12 months. The certification shall be placed in the case file.

(e) The provisions of this Part shall not apply to:

(1) appointments of law guardians pursuant to section 243 of the Family Court Act, guardians ad litem pursuant to section 403-a of the Surrogate's Court Procedure Act, or the Mental Hygiene Legal Service;

(2) an appointment without compensation; and

(3) the appointment of any of the following:

(i) a relative of, or person having legally recognized duty or interest with respect to the affairs of, the infant, ward, incapacitated person, decedent or beneficiary of an estate;

(ii) a guardian ad litem nominated by an infant of 14 years of age or over;

(iii) a nonprofit institution performing social services;

(iv) a bank or trust company as a depository for funds;

(v) a public administrator or a public official vested with the powers of an administrator;

(vi) a person or institution whose appointment is required by law;

(vii) a physician whose appointment as a guardian ad litem is necessary where emergency medical or surgical procedures are required.

(f)The reporting and certification requirements set forth in sections 36.1(d), 36.3(a) and 36.4(c) of this Part shall not apply to the appointment of a referee whose compensation for such appointment is not anticipated to exceed $550.

§ 36.2 Lists of Available Applicants

(a) The Chief Administrator of the Courts shall provide for the application by persons and institutions seeking appointment as guardians, guardians ad litem, court evaluators, attorneys for alleged incapacitated person, receivers, persons designated to perform services for the receiver, and referees. The Chief Administrator shall assemble such applications and shall maintain and make available for use by the appointing judge lists of applicants for appointment.

(b) The lists maintained by the Chief Administrator shall contain such information as will enable the appointing judge to be apprised of the background of the applicants set forth therein. The lists may be maintained by court, county, judicial district, judicial department or combination thereof, and may be differentiated by type of appointment and area of special expertise.

§ 36.3 Reporting of Appointments

(a) Every person and institution receiving an appointment pursuant to this Part shall file a notice of the appointment with the Chief Administrator of the Courts, in a manner to be prescribed by the Chief Administrator, within 10 days of receipt of notice of the appointment. Such notice shall be a public record. The appointee also shall certify in writing to the appointing judge that the notice of appointment has been filed. The Chief Administrator shall arrange for the periodic public publication of the names of all persons and institutions appointed by each appointing judge in appropriate law journals and periodicals.

(b) No later than March 31 of each year, the Chief Administrator shall report in writing to the Chief Judge of the operation of the procedures set forth in this Part, including recommendations for modification. A copy of each report shall be transmitted to the members of the Court of Appeals and the Administrative Board.

§ 36.4 Compensation

(a) Fees to appointees pursuant to this rule shall not exceed the fair value of the services rendered.

(b) Each award of fees of $2,500 or more to appointees pursuant to this section shall be accompanied by an explanation, in writing, of the reasons therefor by the judge making the award.

(c) No fees shall be awarded unless the appointee has filed the notice of appointment and certification of compliance required by section 36.3(a) of this Part.

§ 36.5 Education and Training

The Chief Administrator or the appointing judge may require that applicants for appointment complete designated courses or training curricula prior to receiving an appointment.

APPENDICES

APPENDIX A. NOTICE OF APPOINTMENT FOR GUARDIANS, GUARDIANS AD LITEM, CONSERVATORS, COMMITTEES OF THE INCOMPETENT OR PATIENT, RECEIVERS, PERSONS DESIGNATED TO PERFORM SERVICE FOR A RECEIVER

[See Rules of Chief Judge, § 36]

UCS-830.1

Rev. 12/1/90

NOTICE OF APPOINTMENT

FOR GUARDIANS, GUARDIANS AD LITEM, CONSERVATORS, COMMITTEES

OF THE INCOMPETENT OR PATIENT, RECEIVERS, PERSONS DESIGNATED TO

PERFORM SERVICE FOR A RECEIVER.

PURSUANT TO PART 36 OF THE RULES OF THE CHIEF JUDGE.

22 NYCRR PART 36

(Please print-see instructions on reverse side)

1. _____Court,_____County.

2

2. Appointee

Name_____ Firm Name, if any_____

Address _____ _____

Federal Employment

_____ Identification No. _____

Soc. Sec. No. _____ Phone No. _____

Occupation: _ Attorney _ Other (Specify) _____

3. Date of Appointment / /

MONTH DAY YEAR

4. Court Docket/File/Index Number _____

5. Title of Proceeding _____

(Limit to 25 spaces)

6. Name of Appointing Justice/Judge _____

7. Person or Interest Appointee Represents (Limit to 15 spaces)

_____

8. Nature of appointment (check one):

_Guardian (d) _Receiver (g)

_Guardian ad litem (e) _Service as a for a receiver (z)

_Conservator (j)

_Committee of the Incompetent

Or Patient (b)

_____ _____

Date Signature of Appointee

_____

CERTIFICATION

I HEREBY CERTIFY THAT A COPY OF THIS NOTICE OF APPOINTMENT

WAS FILED WITH THE OFFICE OF COURT ADMINISTRATION.

_____ _____

Date Signature of Appointee

_____

UCS-830.1

Rev. 12/1/90

INSTRUCTIONS FOR COMPLETING NOTICE OF APPOINTMENT

Pursuant to Part 36 of the Rules of the Chief Judge

Item 1 Enter the specific title of the court, e.g., Supreme Court, Surrogate's Court, etc., and enter the name of the county in which the appointing court is located.

Item 2 Name and Address:

Enter name and mailing address of Appointee.

Social Security Number:

Enter social security number of Appointee.

Occupation:

Check appropriate box If "other," please specify, e.g., physician, accountant, etc.

Firm Name:

Appointee's firm name must be entered here regardless of whether a member, partner, associate, counsel or employee and regardless of whether any fee or allowance received is to be retained or is to go to the firm.

Federal Employer Identification No.

Enter firm's Internal Revenue Service Federal Employer's Identification Number. Where no number is available,

enter "None".

Phone No:

Enter appointee's phone number.

Item 3 Enter date of appointment–month, day and year.

Item 4 Enter either the docket, file, index number or any other identification assigned by the court to this matter. If there is no number assigned, enter "None".

Item 5 Enter the title of the action or proceeding in which appointed, e.g., Smith v. Jones, Matter of Adams, etc. Please limit the title to 25 spaces. If it is a multiparty action, name only the first party, e.g., Smith et al. v. Jones et al.

Item 6 Enter the first initial and full last name of the judge or justice who made the appointment. If made by the judges of a multi-judge court, enter "the Court."

Item 7 Enter the name of the person or interest represented. If there are multiple parties, enter the specific name of the client. If appointee represents all plaintiffs or defendants in a mufti-party case, state "all plaintiffs". If appointee represents the court, state "the Court". Please limit entry to 15 spaces.

Item 8 Check the appropriate box for the nature of appointment.

1) SUBMIT NOTICE OF APPOINTMENT TO: REFER INQUIRIES TO:

Office of Court Administration Office of Court Administration

Attn: Fiduciary Attn: Fiduciary

Post Office Box 3171 80 Centre Street–Rm. 500D

Church Street Station New York, N.Y. 10013

New York, N.Y. 10008

2) SUBMIT NOTICE OF APPOINTMENT, WITH COMPLETED CERTIFICATION OF FILING,

TO THE APPOINTING JUDGE.

IMPORTANT: The Notice of Appointment must be filed with the Office of Court Administration at the above address no later than the first business day of the week following appointment. A copy must be file with the appointing judge.

NO COMPENSATION WILL BE AWARDED UNLESS BOTH

FILINGS HAVE BEEN COMPLETED. _____

APPENDIX B. CERTIFICATION OF COMPLIANCE

[SEE Rules of Chief Judge, § 36]

UCS–830.3

12/1/90

CERTIFICATION OF COMPLIANCE

PURSUANT TO PART 36 OF THE RULES OF THE CHIEF JUDGE

1. Court, County.

2. Appointee

Name Firm Name, if any _____

Address _____

Federal Employment

Identification No. _____

Soc. Sec. No. Phone No. _____

Occupation:
_Attorney
Other (Specify) _____

3. Court Docket/File/Index Number _____

4. Title of Proceeding _____

5. Name of Appointing Justice/Judge _____

6. Person or Interest Appointee Represents _____

7. Have you received any other appointments within the previous 12 months? YES_____

NO____

If yes, please attach list of appointments. Include a) court of appointment, b) type of appointment,

c) date of appointment, d) title of proceeding and case index number.

8. Pursuant to 22 NYCRR section 36.1(d) (Rules of the Chief Judge), I hereby certify that:

a) I am not a relative of, or related by marriage to, a judge of the Unified Court System of the State of New York and,

b) Receipt of this appointment will not give me more than one appointment within the prior 12 months for which the compensation was or is anticipated to exceed the sum of $5,000.00.

_____ _____

Date Signature

NOTICE OF APPOINTEE

This certification must be submitted to the appointing judge prior to accepting any appointment.

NOTICE TO APPOINTING JUDGE

This certification is a permanent record and must be placed in the court file.

UCS-830.3

12/1/90

CERTIFICATION OF COMPLIANCE

Pursuant to Part 36 of the rules of the Chief Judge

Item 1 Enter the specific title of the court, e.g., Supreme Court, Surrogate's Court, etc., and enter the name of the county in which the appointing court is located.

Item 2 Name and Address:

Enter name and mailing address of Appointee.

Social Security Number:

Enter social security number of Appointee.

Occupation:

Check appropriate box If "other," please specify, e.g., physician, accountant, etc.

Firm Name:

Appointee's firm name must be entered here regardless of whether a member, partner, associate, counsel or employee and regardless of whether any fee or allowance received is to be retained or is to go to the firm.

Federal Employer Identification No.

Enter firm's Internal Revenue Service Federal Employer's Identification Number.

Where no number is available, enter "None".

Phone No:

Enter appointee's phone number.

Item 3 Enter either the docket, file, index number or any other identification assigned by the court to this matter. If there is no number assigned, enter "None".

Item 4 Enter the title of the action or proceeding in which appointed, e.g., Smith v. Jones, Matter of Adams, etc.If it is a multiparty action, name only the first party, e.g. Smith et al. v. Jones et. Al.

Item 5 Enter the first initial and full last name of the judge or justice who made the appointment. If made by the judges of a multi-judge court, enter "the Court."

Item 6 Enter the name of the person or interest represented. If there are multiple parties, enter the specific name of the client. If appointee represents all plaintiffs or defendants in a multi-party case, state "all plaintiffs". If appointee represents the court, state "the Court".

Item 7 If you have received any other appointments within the previous 12 months, attach a separate page listing appointments. Include a) court of appointment, b) type of appointment, c) date of appointment, d) title of proceeding and case index number.

Item 8 Date, sign and submit to the appointing Judge. If you have a problem completing this certification, contact the appointing Judge immediately.

Attachment B

December 20, 1999

Michael M. Freeman, Esq.

Law Chairman

Kings County Democratic Party

16 Court Street

Brooklyn, New York 11241

Dear Michael,

It is with great unhappiness that we must inform you that we hereby resign our positions as members of the Kings County Democratic Law Committee.

It has became apparent that our diligent work and unquestioned loyalty to the Organization over the many years are clearly not as important as the desires of Mr. Ravi Batra. Although, Mr. Batra holds no party or elected position in our County, he has nevertheless, imposed himself on the political workings of our Organization for the sole purpose of his own personal financial gain.

16 Court Street
Brooklyn, NY 11241
Tel (718) 875-5810
Fax (718) 522-4013

Therefore, we will be unable to continue to represent candidates for elected and/or judicial office free of charge, as we have done so in the past. One cannot reasonably expect our firm to continue to avail to the Orga nization our professional services while the Organization sits idly by and permits Mr. Batra to maliciously injure our practice and reputation without consequence.

As I am sure that the facts surrounding our termination as Mr. Batra's attorneys on his numerous Court appointed Receiverships will be discussed by many members of our Organization, we feel it is now necessary to clarify the issues surrounding our recent termination.

As you have been made aware, on December 7, 1999, Mr. Batra, via facsimile correspondence, terminated our firm as his attorneys on all of his many Receivership matters: including the representation of Mr. Batra with respect to his Receivership of the Cypress Hills Cemetery. **It must be clearly noted that Mr. Batra stated in his termination letter of December 7, 1999, that his own firm will now represent him on all Receivership matters.** Mr. Batra claims that our firing was as a result of our firm's lack of competent legal representation. As you can personally attest, our firm is well recognized as an authority in the area of Receivership law. **I can assure you that any such claims are merely a transparent attempt to deflect attention from Mr. Batra's true motive of obtaining both the legal fees generated from these matters in addition to collecting a Receiver's commission from said cases.**

It is indisputable that our firm has done an excellent job in protecting the interests of our clients, a fact that can be attested to by many members of our own Organization. I must reiterate that Mr. Batra is merely attempting to secure legal fees for his own firm while continuing to collect commissions on these matters as well.

Although, we have the utmost respect and affection for you and the excellent work you have done as the Law Chairman, we are left with no alternative but to resign as members of the Law Committee. To continue on in our capacity as Law Committee members in light of Mr. Batra's inexcusable actions would be far too much to expect, given the fact that the Organization has permitted an individual **with no party position** or history in this County to dictate how our Organization is run. As Law Chairman you are well aware of the fact that Mr. Batra has never assisted the Law Committee on any level whether it be collecting signatures, binding petitions or trying an election law case, etc. In fact, it is unknown as to what Mr. Batra has accomplished in any capacity to benefit our Organization.

I cannot stress to you enough the sense of betrayal we presently are experiencing. Clearly, you recognize the unwavering loyalty and dedication our firm, as well as that of our predecessors, have shown to this Organization over the course of the past twenty five (25) years. It is unprecedented and disheartening how one man's greed and self absorption can go unchecked. Simultaneously, such an act reduces the credibility of the once most powerful political organization in the nation, to an Organization that permits unprovoked attacks by an outsider without consequence.

It is unfathomable that such action would be tolerated by any other political organization within this City or State. It

is quite evident that permitting Mr. Batra's behavior has severely damaged our credibility and reputation as a political Organization.

We hope that one day in the not so distant future we will be able to work together again when the interests of the Organization are once again paramount to the unfettered demands of one non-contributing individual.

Regretfully submitted,

Thomas J. Garry
Treasurer, County Committee

Arnold J. Ludwig
Treasurer, Brooklyn Democrats

cc: Hon. Clarence Norman, Jr.

Hon. Jeffrey C. Feldman

Hon. Joan L. Millman

Hon. Leo A. Barrile

Hon. Herbert E. Berman

Hon. Roberta Sherman

Hon. Diane M. Gordon

Hon. Decosta Headley, Jr.

Hon. Lewis Fidler

Hon. Renee Hauser

Hon. Booker T. Ingram

Hon. Mary L. Hobson

Hon. Heather E. Gayle

Hon. William H. Boone

Hon. Jacob Gold

Hon. Lori Citron Knipel

Hon. Ann Levine

Hon. Michael R. Geller

Hon. Marsha Rapaport

Hon. Paul Podhaizer

Hon. Joan E. Ribaudo

Hon. Charles J. Ragusa

Hon. Pat V. Guadagnino

Hon. Dov Hikind

Hon. Joseph A. Bova

Hon. Maryrose Sattie

Hon. Linda Minucci

Hon. Steven D. Cohn

Hon. Azalia Rivera

Hon. Angel Rodgriguez

Hon. Elizabeth R. Daly

Hon. Ralph J. Perfetto

Hon. Vito J. Lopez

Hon. Narcisa Ruiz

Hon. Martin Malave-Dilan

Hon. Nellie Santiago

Hon. Essie Duggan

Hon. William Boyland, Jr.

Hon. Annette Robinson

Hon. Albert Vann

Hon. Freddie Hamilton

Hon. Kendell Stewart

Hon. Edith Wingfield

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[1] The sixth degree of relationship extends to second cousins.

[2] Last year, the Legislature raised the threshold for filing from $200 to $500.

[3] A community guardianship program is a non-profit organization that has contracted with a social service agency to provide guardianship services to certain eligible incapacitated persons.

[4] See Matter of St. Luke's-Roosevelt Hospital Center (Marie H.), 89 N.Y.2d 889 (1996).

[5] See Matter of Freeman, 34 N.Y.2d 1 (1974); Matter of Potts, 213 A.D. 59, 62 (4th Dept. 1925), *aff'd* 241 N.Y. 593 (1925).

[6] The community guardianship program's compensation is paid from the IP's assets, and is based upon the cost incurred by the program in providing the services or the fee that would otherwise be awarded by the court, whichever is less.

[7] See, e.g., In re Pineda, N.Y.L.J., May 28, 1997, p. 26 (Sup. Ct., New York Co.); In re Schwartz, N.Y.L.J., May 2, 1996, p. 33 col. 2 (Sup. Ct., Nassau Co.).

[8] This was a non-paying, periodic assignment in which the attorney, on behalf of the judge, reviewed motion papers and attempted to expedite matters.

[9] Because a court evaluator is appointed to recommend whether the AIP needs a guardian, once a guardian is appointed the court evaluator's services generally are no longer required.

[10] Among the fee requests that the judge had approved was a bill that the guardian had submitted that included 42 hours of work for in single day. The improper billing was discovered by the family's attorney upon his review of the guardian's affirmation of services. The overpayment of $12,600 was subsequently returned.

[11] This includes the fee received by counsel to the AIP.

[12] See Strober v. Warren Properties Co., 84 A.D. 2d 834 (2d Dept. 1981).

[13] See Lentine v. Fundaro, 56 A.D. 2d 592 (2d Dept. 1977).

[14] A copy of the letter is attached to this Report (see Attachment B). In their letter, the attorneys announced their resignation from their positions as members of the party's Law Committee, but not from their positions as officers in the county Democratic organization.

[15] Given the incompleteness of the court files, the amount of compensation earned by fiduciaries in these cases may well be higher than what we have been able to document in this report.

[16] Several people have informed us that for a number of years the Brooklyn Democratic organization provided judges assigned to the Ex Parte Part (where the overwhelming number of receivership appointments are made) with a list of "recommended" fiduciary appointees. Those on the list were all active in Brooklyn Democratic politics. We were informed that this practice ended several years ago in the wake of rumors of a federal criminal investigation.

[17] Garry & Ludwig apparently was able to learn of the appointment of a receiver before the receiver was notified of the appointment. Acting on behalf of another law firm that represented one of the leading mortgage lending institutions in Brooklyn, Garry & Ludwig frequently would file with the Ex Parte Clerk's Office the bank's applications for the appointment of a receiver. The firm thus would learn from the clerk's office when a receiver was appointed, and then would notify the appointee. This arrangement obviously facilitated the firm's retention as counsel to the receiver in many cases.

[18] Notably, in Lentine v. Fundaro, 56 A.D.2d 592 (2d Dept. 1977), the court found upon its review of the fee request made by the counsel to the receiver that counsel spent time on tasks that the receiver should have performed, such as telephone calls and letter writing. In reducing the fees awar

CHRISTMAS IN PURGATORY

A Photographic Essay on Mental Retardation

BURTON BLATT FRED KAPLAN

Exhibit 7

CHRISTMAS IN PURGATORY

A Photographic Essay on Mental Retardation

BURTON BLATT
Syracuse University
Centennial Professor and
Director, Division of Special
Education and Rehabilitation

FRED KAPLAN
Black Star Corporation

Foreword by

SEYMOUR B. SARASON
Professor of Psychology
Yale University

HUMAN POLICY PRESS / SYRACUSE, NEW YORK / 1974

FOREWORD

The contents, verbal and visual, of this book produced little surprise for me. Initially, it brought back memories of a number of visits I made to various institutions twenty-five years ago when I first began to work in the field of mental retardation. As the years went on, it became increasingly clear to me that the conditions I saw —and which are documented in this book — were not due to evil, incompetent or cruel people but rather to a concept of human potential and an attitude toward innovation which when applied to the mentally defective, result in a self-fulfilling prophecy. That is, if one thinks that defective children are almost beyond help, one acts toward them in ways which then confirm one's assumptions. This is similar to the situation several decades ago when, in many psychiatric hospitals, the diagnosis of schizophrenia contained the prognosis that the sick patients would never improve. That most of these patients did not improve did not reflect the validity of the diagnosis, but the dishearteningly effective way in which state hospitals unwittingly went about confirming their diagnosis. In contrasting one institution (The Seaside), which views the defective child in one way, with other institutions which hold to another viewpoint, the authors have incisively made the point that the basic problem is in the realm of concept of human behavior and its amenability to change under specified conditions.

I would not deny that increased appropriations will make for better physical care. But spending more money is easy compared to the problem of how one gets people to change their concepts and to view innovation and experimentation as necessities rather than as subversive suggestions or the terminal points of the meandering of the academic mind.

Dr. Blatt is an eminent educator, and the reader unfamiliar with his work can be assured that this book reflects the conscientious research of a well-informed man vitally concerned with human welfare in general, and specifically, the problems of mental retardation and institutions. He has been under great pressure from many quarters to reveal the names of the institutions visited, but for reasons made plain on the pages which follow, Dr. Blatt would not go back on promises made to those persons who permitted him to make this study. He wished, also, in not naming names, to avoid creating the impression that this problem is a local rather than a national one.

Seymour B. Sarason
Yale University

PREFACE

The first edition of this book was published in August, 1966, and was distributed without charge under the auspices of a group of parents and friends of the mentally retarded. These thousand copies were sent to prominent legislators, commissioners of mental health, university professors, and leaders in the parent movement in mental retardation. The response to the first volume was overwhelming, leading to the present Allyn and Bacon edition.

The purpose of this book is to present our findings in the hope that they will inspire constructive action among those in responsible positions. For those not in positions to legislate or reform, we hope to strike a chord of awareness, to shatter the shell of complacency born of ignorance that surrounds the problem. From this element of society, we hope for support. The first section of this essay represents conditions existing in too many institutions for the retarded. The second section of the book is devoted to the heartening conditions we found at The Seaside. Our optimism for the betterment of state institutions is based on the evidence of the forward strides that have been made there. To us, The Seaside represents what can be done with funds, intelligent administration and an adequate, sensitive and well-trained staff.

We cannot permit ourselves thoughts of immediate radical reform as a result of our efforts. We can only hope for increased public interest. As Camus once wrote: "Perhaps we cannot stop the world from being one in which children are tortured, but we can reduce the number of children tortured."

When a commercial publisher discontinues, as in this case, publication of a book it is because it is no longer profitable. This does not necessarily mean that people do not want to buy the book. It can mean that the escalating costs of printing and promotion — and, of course, the need to maintain certain profit levels —put the costs of the book out of the reach of most people, e.g., students. (Fairness requires that I acknowledge the fact that the previous publisher was the only one willing to take a chance with so "different" a book.) Some extraordinary good books have sunk into oblivion. It would have been immoral, or at least an adverse commentary on our societal values, if **Christmas In Purgatory** was allowed to be available only in libraries (those which had copies). For one thing, this was an historic document. It was extraordinarily "profitable" in terms of its international influence on thinking, values, practices, and planning (not, ironically, in Dr. Blatt's home state where huge building complexes for the retarded continue to be developed). It was a simple, easily grasped, compelling, upsetting visual document which stood as a reminder of what existed in our society, and as a criterion by which to judge any derivative of our propensity to segregate people who are or look "different." It is noteworthy that in his last book, **Souls in Extremis,** Dr. Blatt concludes that purgatory is inherent in our concept of institutions, and he recommends that we close them and build no more. Precisely because institutional purgatories exist today and will continue to exist for the foreseeable future, **Christmas In Purgatory** should continue to be available. We should be grateful that it will be.

Seymour B. Sarason Yale University

INTRODUCTION

"They cover a dung hill with a piece of tapestry when a procession goes by,"

Miguel de Cervantes

There is a hell on earth, and in America there is a special inferno. We were visitors there during Christmas, 1965.During the early fall of that year, United States Senator Robert Kennedy visited several of his state's institutions for the mentally retarded. His reactions to these visits were widely published in our news media. These disclosures shocked millions of Americans and Infuriated scores of public office holders and professional persons responsible for the care and treatment of the mentally retarded .A segment of the general public was numbed because it is difficult for "uninvolved" people to believe that in our country, today, human beings are being treated less humanely, with less care, and under more deplorable conditions than animals. A number of the "involved" citizenry- i.e. those who legislate and budget for institutions for the mentally retarded and those who administer them — were infuriated because the Senator reacted to only the worst of what he had seen, not to the worthwhile programs that he might have. Further, this latter group was severely critical of the Senator for taking "whirlwind" tours and, in the light of just a few hours of observation, damning entire institutions and philosophies.

During the time of these visits I was a participant in a research project at The Seaside, a State of Connecticut Regional Center for the mentally retarded. The superintendent of The Seaside, Fred Finn, and I spent a considerable amount of time discussing the debate between Senator Kennedy and his Governor, Nelson Rockefeller. We concluded the following. It does not require a scientific background or a great deal of observation to determine that one has entered the "land of the living dead." It does not require too imaginative a mind or too sensitive a proboscis to realize that one has stumbled into a dung hill, regardless of how it is camouflaged. It is quite irrelevant how well the rest of an institution's program is being fulfilled if one is concerned about that part of it which is terrifying. No amount of rationalization can mitigate that which, to many of us, is cruel and inhuman treatment. It is true that a short visit to the back wards of an institution for the mentally retarded will not provide, even for the most astute observer, any clear notion of the antecedents of the problems observed, the complexities of dealing with them, or ways to correct them. We can believe that the Senator did not fully comprehend the subtleties, the tenuous relationships, the grossness of budgetary inequities, the long history of political machinations, the extraordinary difficulty in providing care for severely mentally retarded patients, the unavailability of highly trained professional leaders, and the near-impossibility in recruiting dedicated attendants and ward personnel. But, we know, as well as do thousands of others who have been associated with institutions for the mentally retarded, that what Senator Kennedy claimed to have seen he did see. In fact, we know personally of few institutions for the mentally retarded in the United States completely free of dirt and filth, odors, naked patients groveling in their own feces, children in locked cells, horribly crowded dormitories, and understaffed and wrongly staffed facilities.

After a good deal of thought, I decided to follow through on a seemingly bizarre venture. One of my close friends, Fred Kaplan, is a freelance photographer who has worked for many national publications. The following plan was presented to him. We were to arrange to meet with each of several key administrative persons in a variety of public institutions for the

mentally retarded. If we gained an individual's cooperation, in spite of the obvious great risk he would be assuming with respect to his institutional status and possible job security, we would be taken on a "tour" of the back wards and those parts of the institution that he was most ashamed of. On the "tour" Fred Kaplan would take pictures of what we observed, utilizing a hidden camera attached to his belt. During the month of December, 1965, we visited—at our own expense —five state institutions for the mentally retarded in four eastern states. Through the efforts of courageous and humanitarian colleagues, including two superintendents who put their reputations and professional positions in jeopardy, we were able to visit the darkest corridors and vestibules that humanity provides for its journey to purgatory and, without being detected by ward personnel and professional staff, Fred Kaplan was able to take hundreds of photographs.

The latter point deserves some comment. Our photographs are not always the clearest and, probably, Fred Kaplan is not proud of the technical qualities of every one published in this book. On the other hand, it required a truly creative and skilled photographer to take these pictures, "from the hip" so to speak, unable to use special lighting, not permitted to focus or set shutter speeds, with a small camera concealed in multitudes of clothing and surrounded by innumerable "eyes" of patients as well as of staff. Although our pictures could not even begin to capture the total and overwhelming horror we saw, smelled, and felt, they represent a side of America that has rarely been shown to the general public and is little understood by most of us.

We do not believe it is necessary to disclose the names of the institutions we visited. First, we have a deep debt of gratitude to those who permitted us to photograph that which they are most ashamed of. To reveal the names of the places we visited is, assuredly, an invitation to invite their instant dismissal. However, we have a much more forceful reason for not admitting to where we have been. These pictures are a challenge to all institutions for the mentally retarded in the United States. We are firmly convinced that in many other institutions in America we could have taken the same pictures—some, we are sure, even more frightening.

Our "Christmas in Purgatory" brought us to the depths of despair. We now have a deep sorrow, one that will not abate until the American people are aware of—and do something about—the treatment of the severely mentally retarded in our state institutions. We have again been caused to realize that "Man's inhumanity to man makes countless thousands mourn,"

It is fitting that this book—our purgatory in black and white —was written on the 700th anniversary of the birth of Dante.

B.B.

"Abandon all hope..."

"Abandon all hope, ye who enter here."

Dante

This book is divided into two major sections. The first section covers our visits to four institutions for the mentally retarded, located in three eastern states. The second section describes a fifth institution in another state. The latter is our way of communicating our deep conviction that many of the severe conditions with which you are about to become involved are not necessary consequences of the fact of institutionalization of mentally retarded individuals. These problems are largely the result of inadequate budgets, inferior facilities, untrained personnel, and haphazard planning— in spite of some dedicated and skilled professional workers in each of the institutions we visited. For example, the average per capita daily cost for maintaining a retarded resident in each of the four institutions we are about to describe is less than $7.00 and, in one state school, less than $5.00. In contrast, The Seaside, a regional center for the retarded sponsored by the Connecticut Department of Health, spends $12.00 daily for the care and treatment of each resident.

As was mentioned in the foreword, we are not disclosing the names either of the institutions or the states where they are located with the exception of—for obvious reasons —the contrast institution. As far as the contrast institution, The Seaside, is concerned, we will be speaking about that one Center. We make no claim that The Seaside is representative or not representative of the Connecticut program for the mentally retarded although the State of Connecticut is to be commended for this —at least one— affirmation of the dignity of all mankind.

We repeat something already said, needing emphasis. What was observed in the institutions presented in Part I reflects what we have seen in other state institutions for the mentally retarded in other parts of the country. We know of few state institutions that do not—to a degree — have problems similar to the ones discussed in this book. The Seaside is one of the rare examples where one may see every ward—without becoming revolted or depressed. To be sure, every institution we visited during our Christmas recess had many things of which to be proud and further, each is accomplishing good work in care and treatment. However, with the exception of The Seaside, each had made miniscule progress, especially in those areas concerning the care of severely retarded ambulatory adults and moderately and severely retarded young children. It is in the hope of calling attention to the desperate needs of these institutions and thereby paving the way for upgrading all institutions for the mentally retarded in all dimensions of their responsibilities that this study was undertaken.

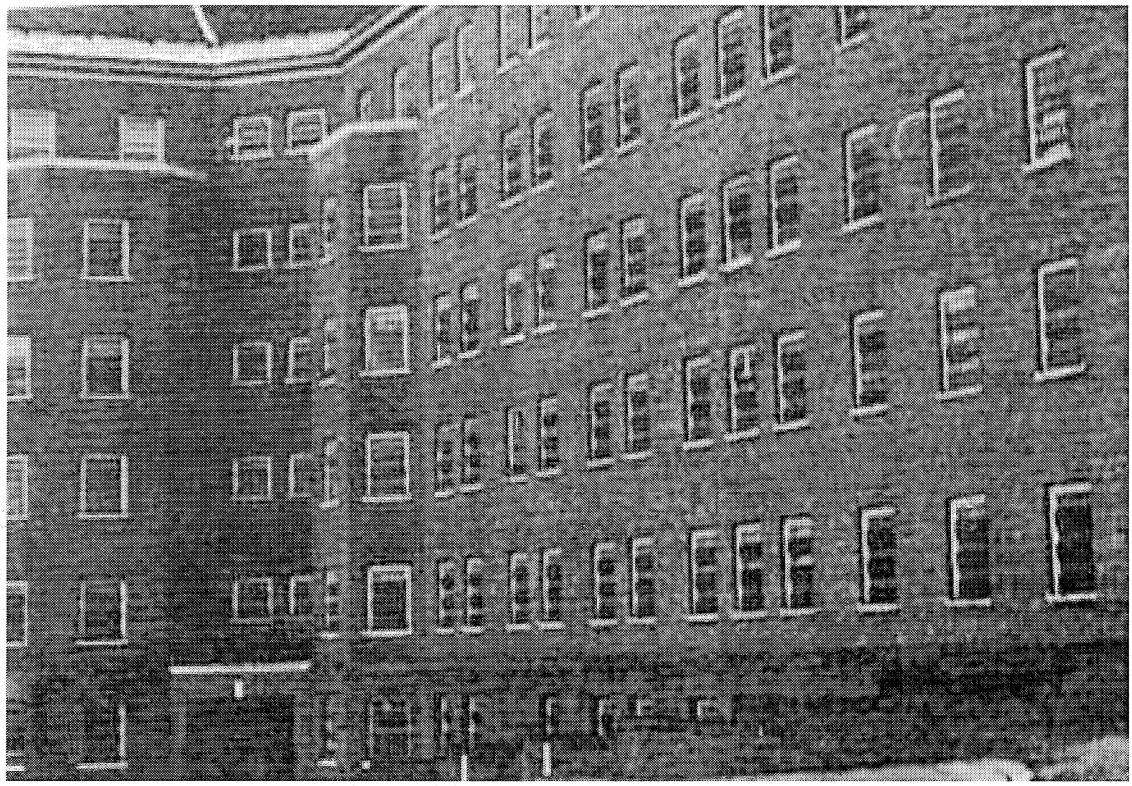
Several things strike the visitor to most institutions for the mentally retarded upon his arrival. Often there are fences. Sometimes with barbed wire. Frequently the buildings impress him with their massiveness and impenetrability. We have observed bars on windows and locks — many locks — on inside as well as outside doors.

As we entered the dormitories and other buildings, we were impressed with the contrast of the functional superiority of the new buildings and the gross neglect of the older buildings. We have observed gaping holes in ceilings of the main kitchen. In toilets, one sees urinals ripped out, sinks broken, and toilets backed up.

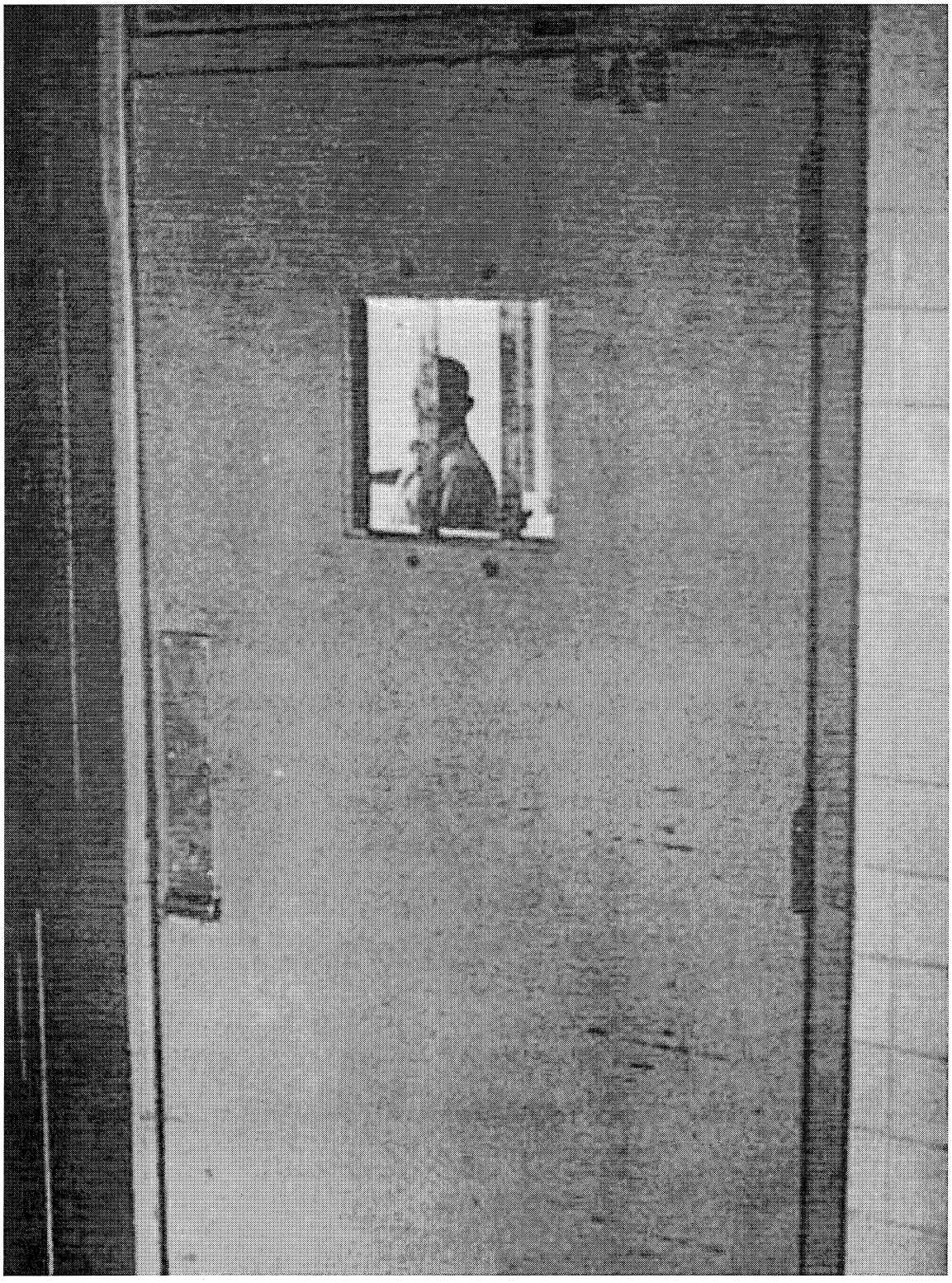
In every institution discussed in this section, we found incredible overcrowding. Beds are so arranged—side by side and head to head—that it is impossible, in some dormitories, to cross parts of the rooms without actually walking over beds. Often the beds are without pillows. We have seen mattresses so sagged by the weight of bodies that they were scraping the floor.

In summary, we were amazed by the over-

crowdedness, by the disrepair of older buildings, by the excessive use of locks and heavy doors, and by the enormity of buildings and numbers of patients assigned to dormitories.



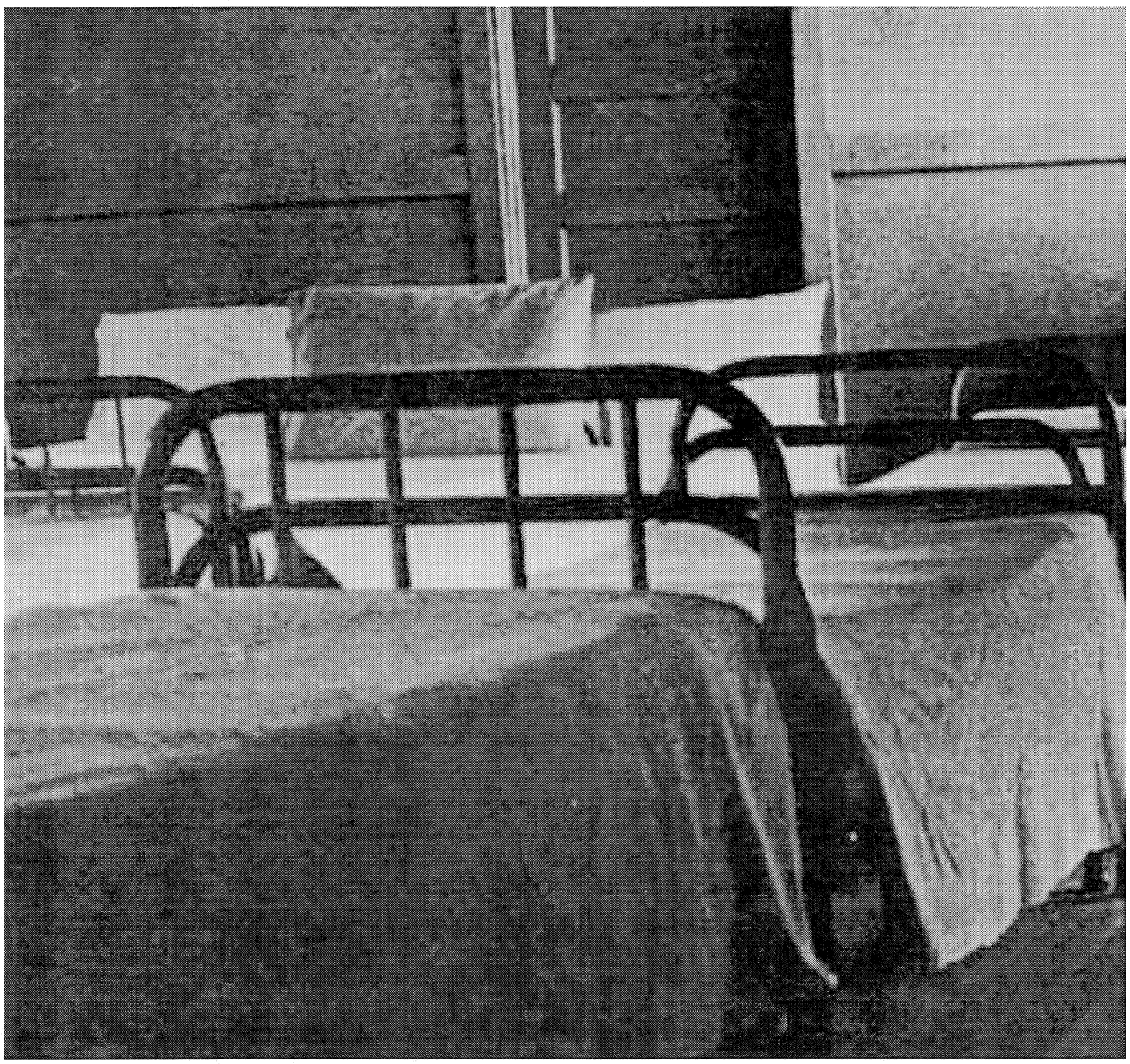
"Abandon all hope..."



"Abandon all hope..."

"There is a wide range among the States in the cost per day spent for the care of the mentally retarded. Six States spent less than $2.50 a day per patient, while only seven States spent over $5.50 per day. Nationally, the average is $4.55 per day, less than one-sixth of the amounts spent for general hospital care."

The President's Panel on
Mental Retardation



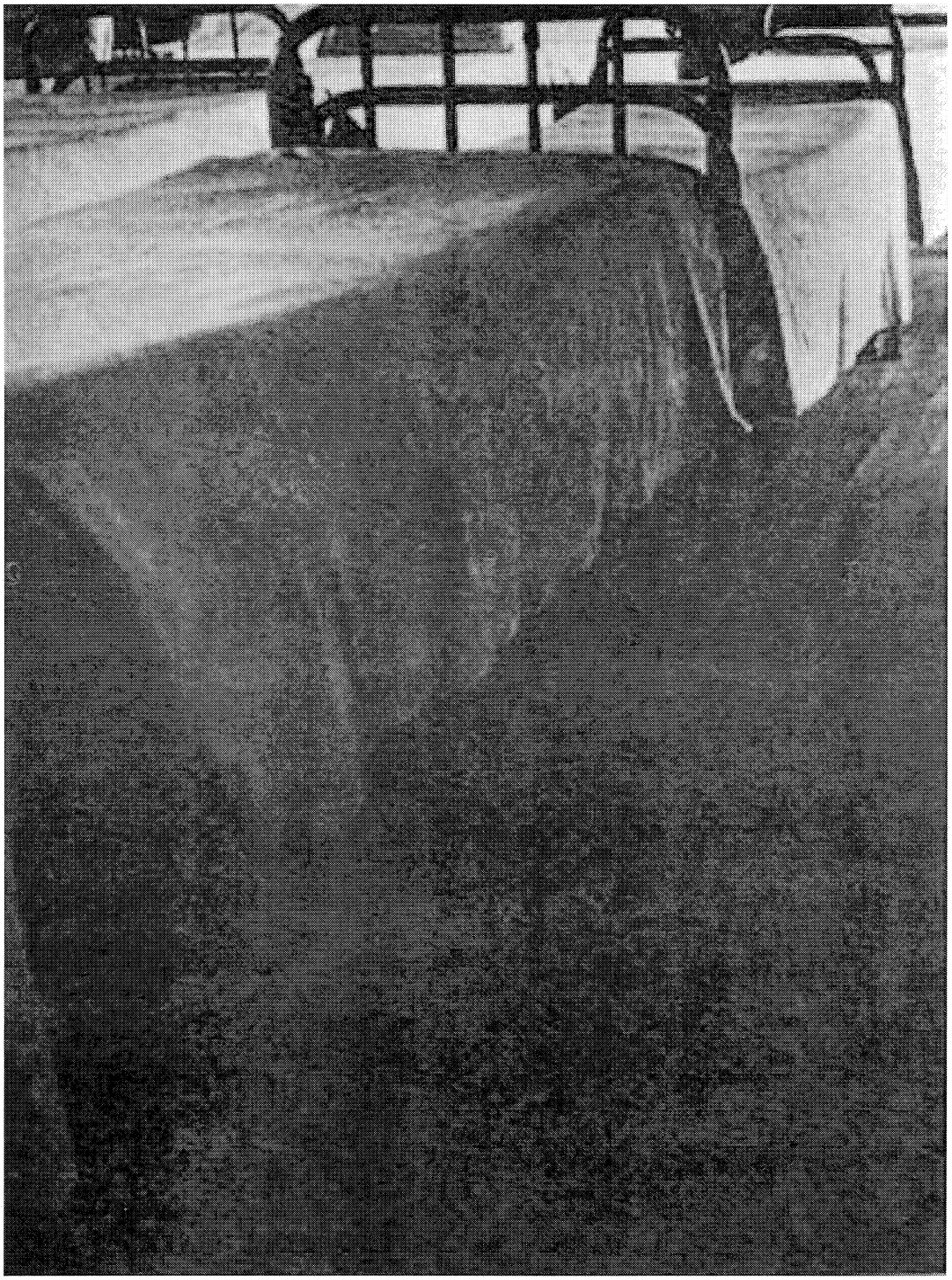
5,000; but on the average, each institution is caring for 350 patients over stated capacity and has a waiting list of better than 300." "The population of State residential facilities runs the gamut from a few hundred to more than

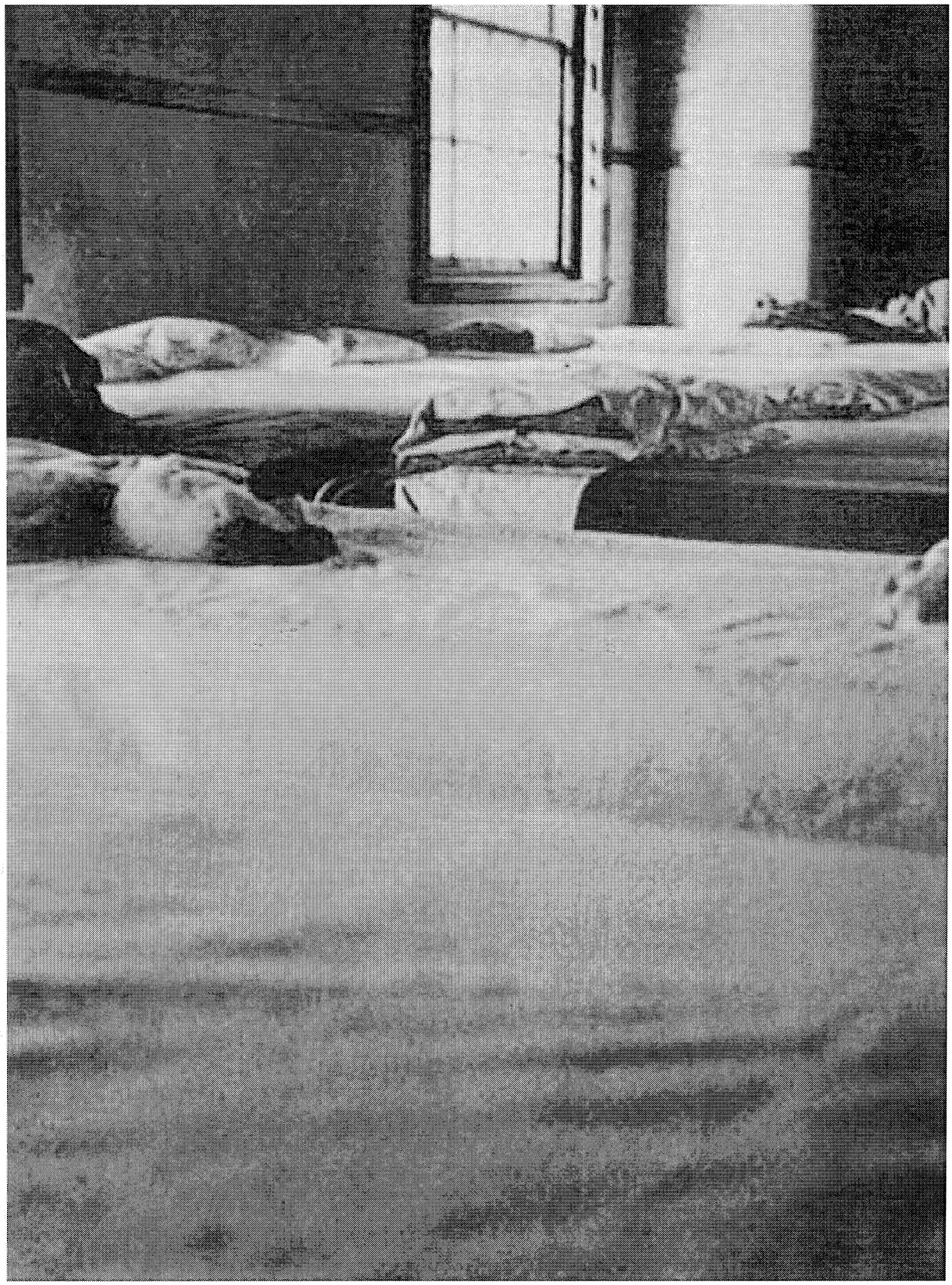
The President's Panel on

Mental Retardation

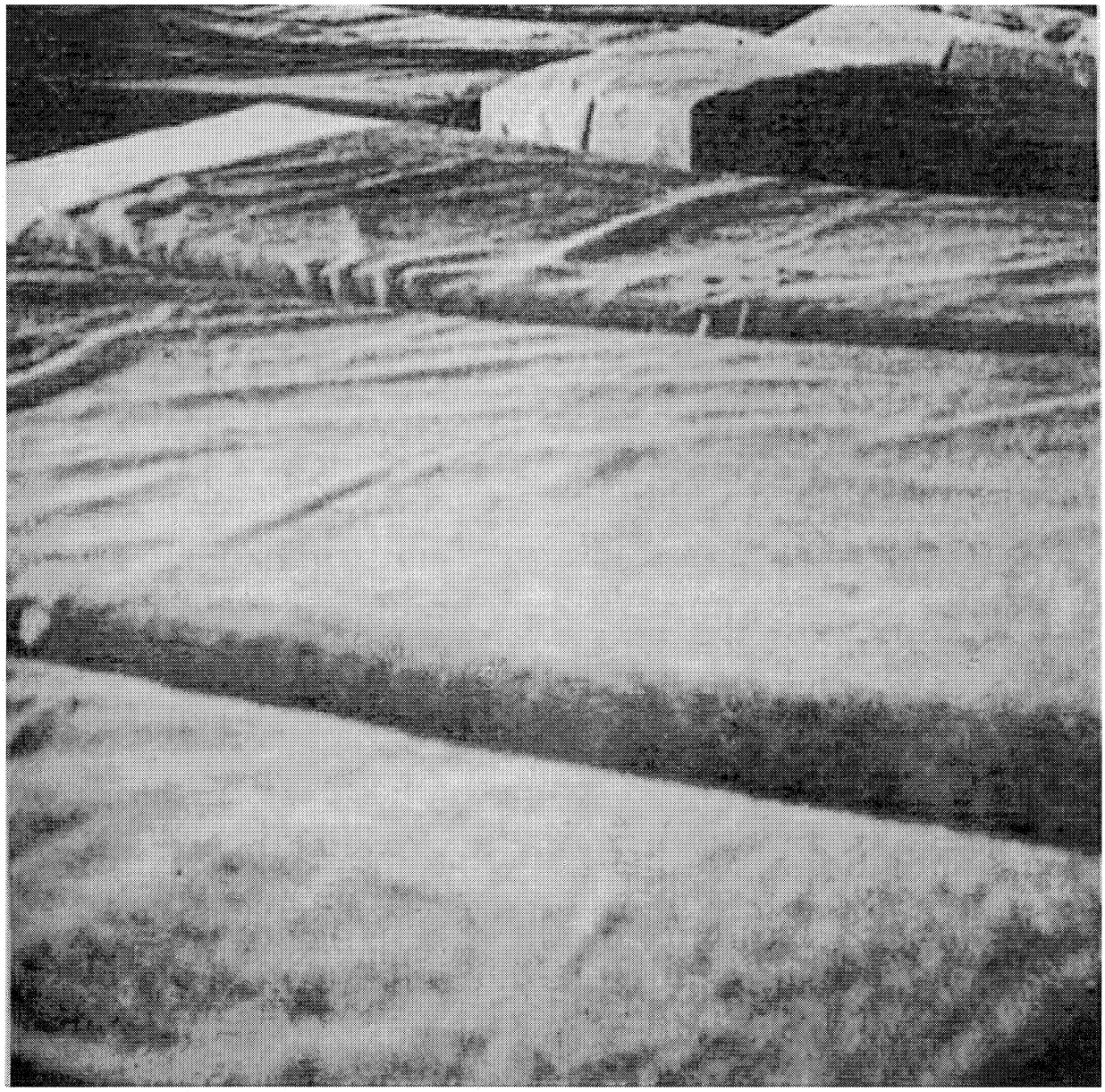
"

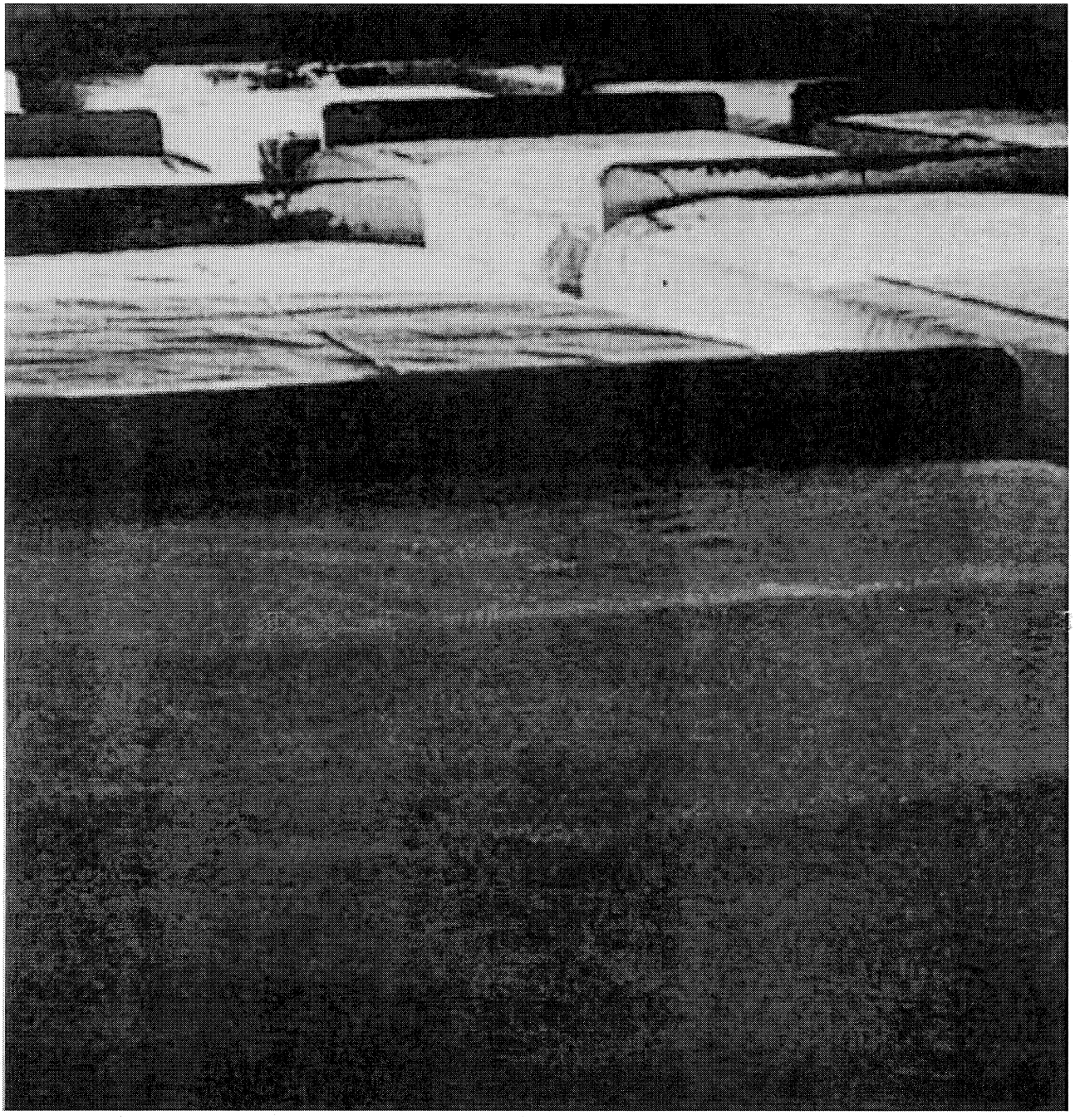
Abandon all hope..."





"Abandon all hope ..."





"The limited resources of the State institutions have been taxed beyond the breaking point."
John Fitzgerald Kennedy

"Abandon all hope..."

"The quality of care furnished by State institutions varies widely, but from the standpoint of well-qualified and adequate personnel and the availability and use of professional services and modern, progressive programs, the general level must be regarded as low. In large State institutions the normal problems of administration and care are compounded by overcrowding, staff shortages, and frequently by inadequate budgets."

The President.s Panel on
Mental Retardation

"Man's inhumanity to man..."

"Man's inhumanity to man
Makes countless thousands mourn,"

Robert Burns

All doors in the living quarters of institutions that we visited had locks, regardless of the age or severity of retardation of the patients immured. These locks are on outside doors as well as inside doors. Boors are made of heavy gauge metal or thick wood. It is routine for attendants to pass from room to room with key chain in hand, unlocking and locking doors en route.

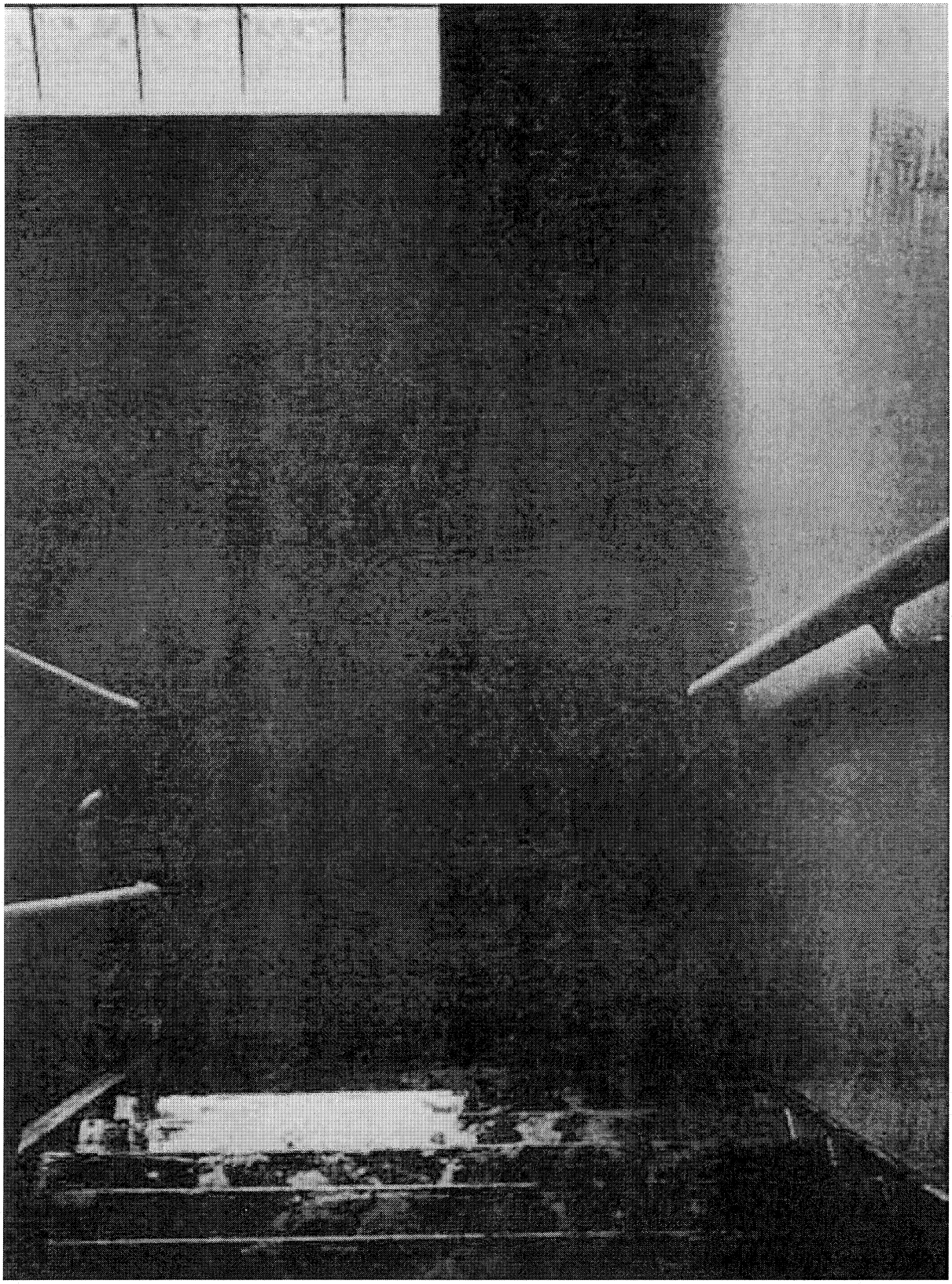
Many dormitories for the severely and moderately retarded ambulatory residents have solitary confinement cells or, what is officially referred to as "therapeutic isolation," "Therapeutic isolation" means solitary confinement -in its most punitive and inhumane form. These cells are usually located in the basements of large dormitory buildings. Sometimes they are located on an upper floor, off to the side and away from the casual or official visitor's scrutiny. They are generally tiny rooms, approximately seven feet by seven feet, shielded from the outside with a very heavy metal door having either a fine strong screen or metal bars for observation of the "prisoner." Some cells have mattresses, others blankets, still others bare floors. None that we had seen (and we found these cells in each institution visited) had either a bed, a wash stand, or a toilet. What we did find in one cell was a thirteen or fourteen year old boy, nude, In a corner of a starkly bare room, lying on his own urine and feces. The boy had been in solitary confinement for several days for committing a minor institutional infraction. Another child, in another institution, had been in solitary confinement for approximately five days for breaking windows. Another had been in isolation through a long holiday weekend because he had struck an attendant. Ironically, in the dormitory where this boy was being incarcerated, we saw another young man who had been "sent to bed early" because he had bitten off the ear of another patient. Apparently, it is infinitely more serious to strike an attendant (and it should not be misunderstood that we condone this) than to bite off the ear of another patient.

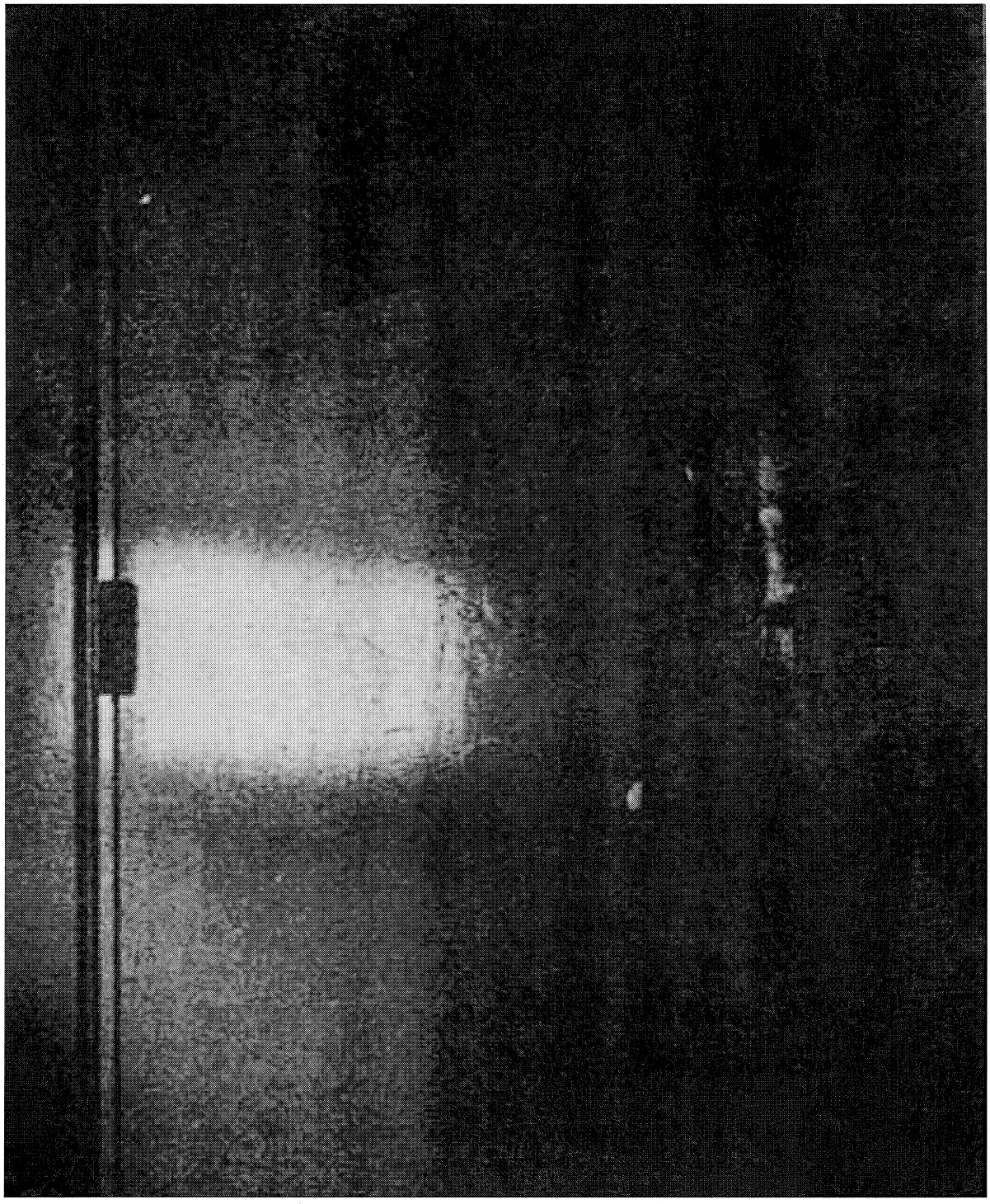
In another institution we saw a young man who was glaring at us through the opening in the door of his solitary cell, feces splattered around this opening. He, too, was being punished for breaking an institutional regulation. In this particular dormitory, we had a good opportunity to interview the attendant in charge. We asked him what he needed most in order to better supervise the residents and provide them with a more adequate program. The attendant's major request was for the addition of two more solitary confinement cells, to be built adjacent to the existing two cells that, we were told, were always occupied, around the clock, day in and day out.

We saw children with hands tied and legs bound. After discussions with attendants and supervisors in the four institutions, we were convinced that one of the major reasons for the heavy use of solitary confinement and physical restraints was the extraordinary shortage of staff in practically all of these dormitories. The attendant who requested the construction of two additional solitary confinement cells was, with one assistant, responsible for the supervision of an old multilevel dormitory, housing over 100 severely retarded ambulatory adults. Almost in desperation he asked us, "What can one do with those patients who do not conform? We must lock them up, or restrain them, or sedate them, or put fear into them."

At that point, we did not feel we had a response that would satisfy either him or us.

Christmas in Purgatory

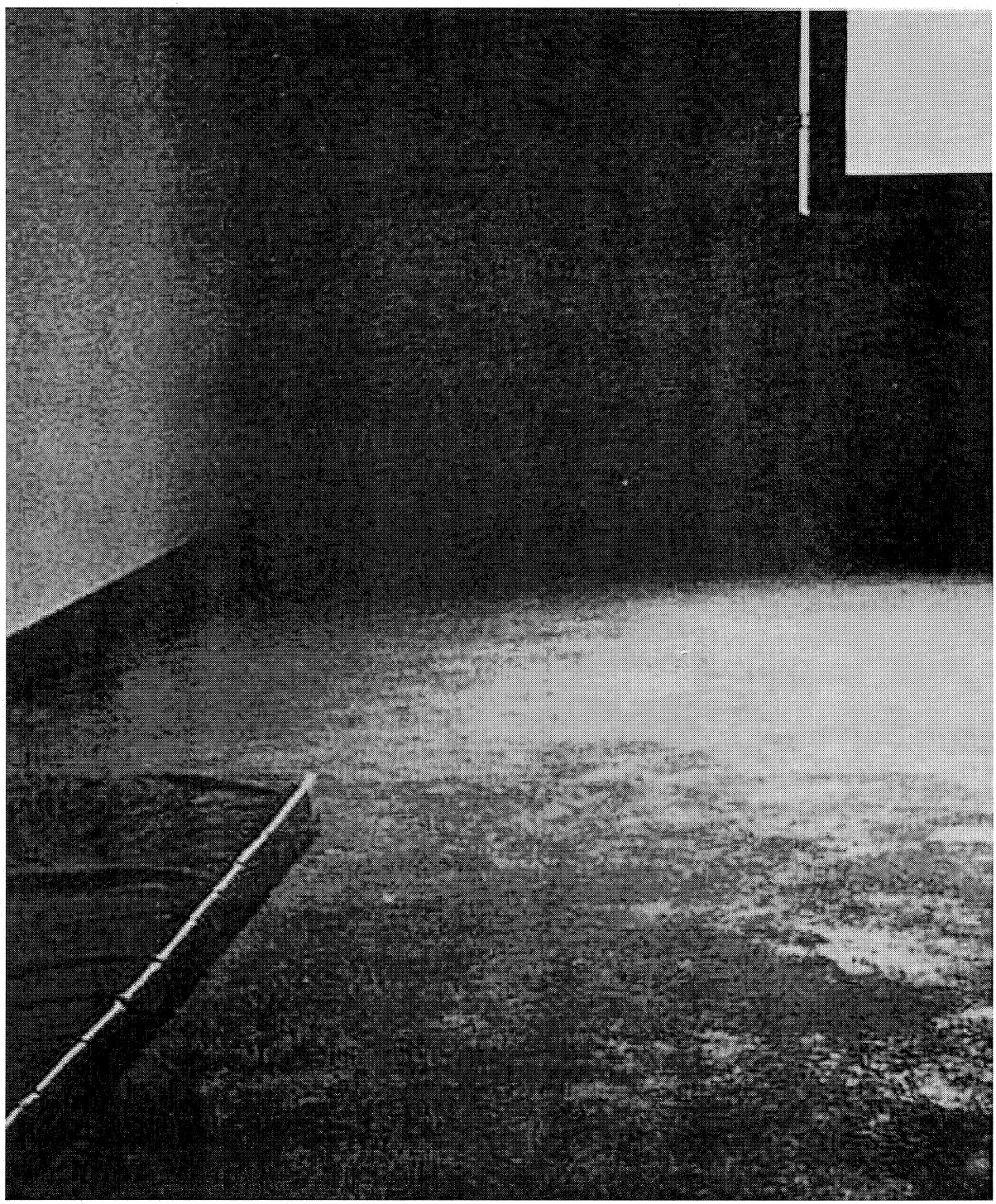




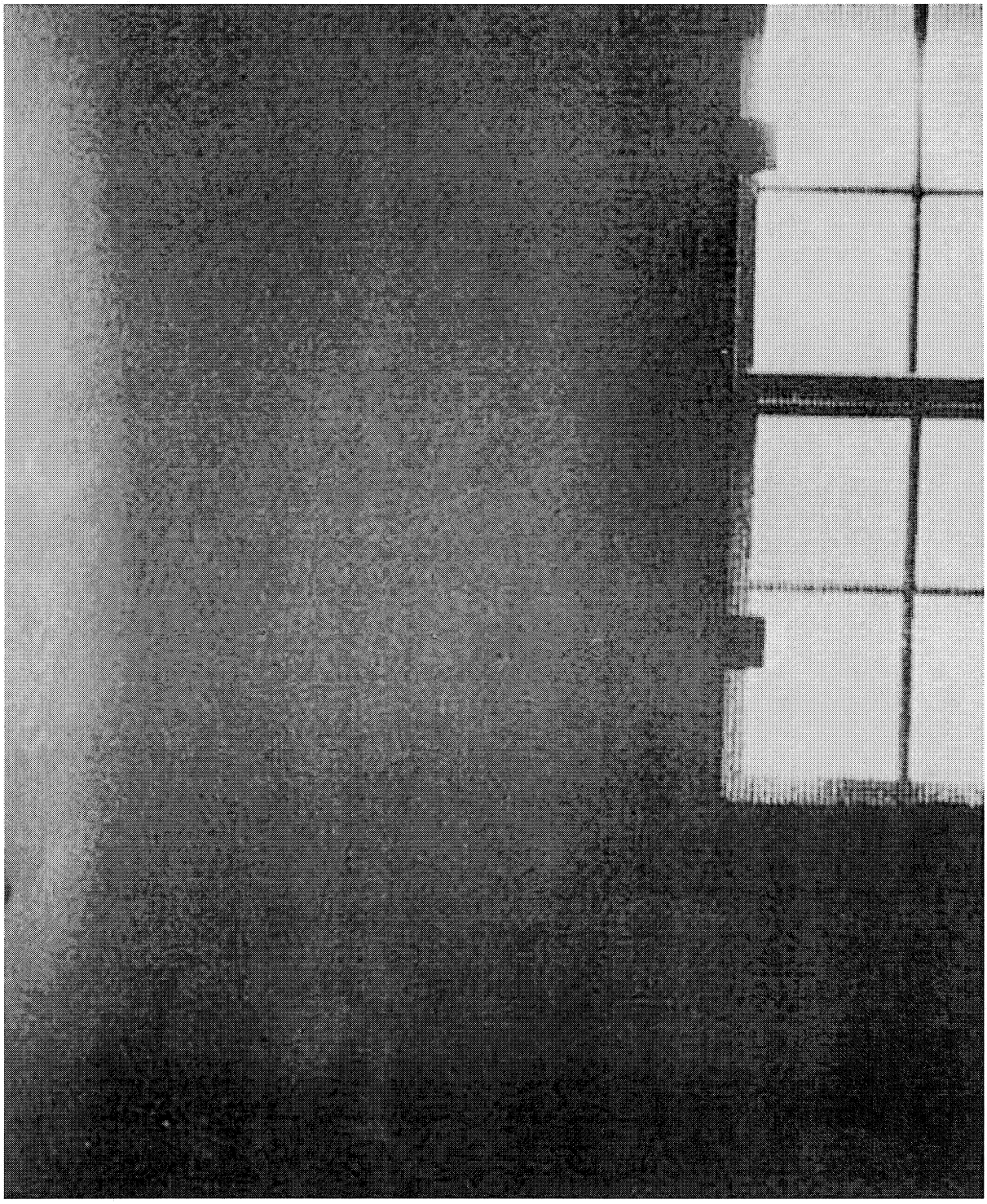
"The door of Death is made of gold That mortal eyes cannot behold."

William Blake

Christmas in Purgatory



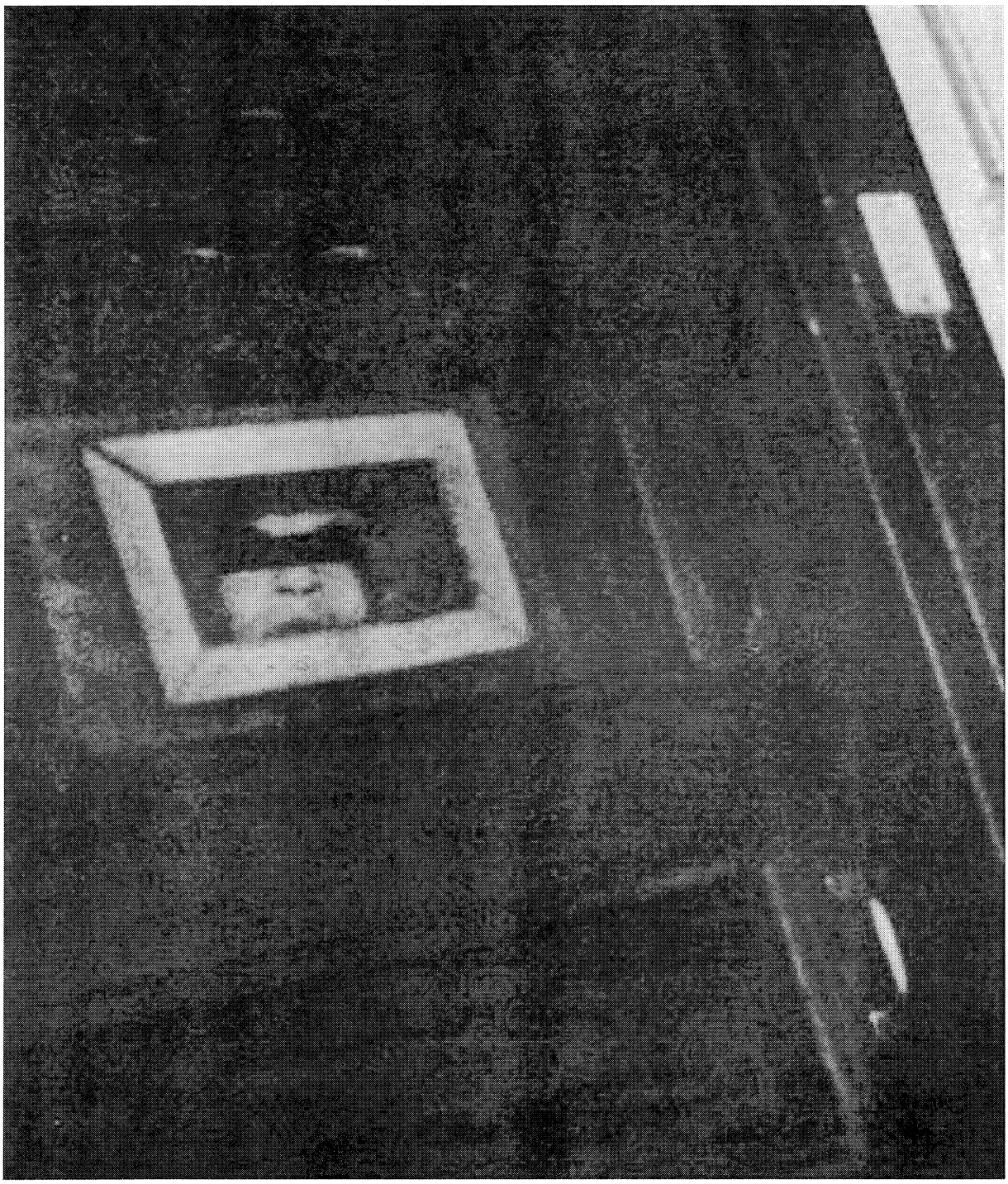
"Man's inhumanity to man..."



"In as much as ye have done it unto one of the least of these my brethren, ye have done it unto me."

Matthew XXV, 40

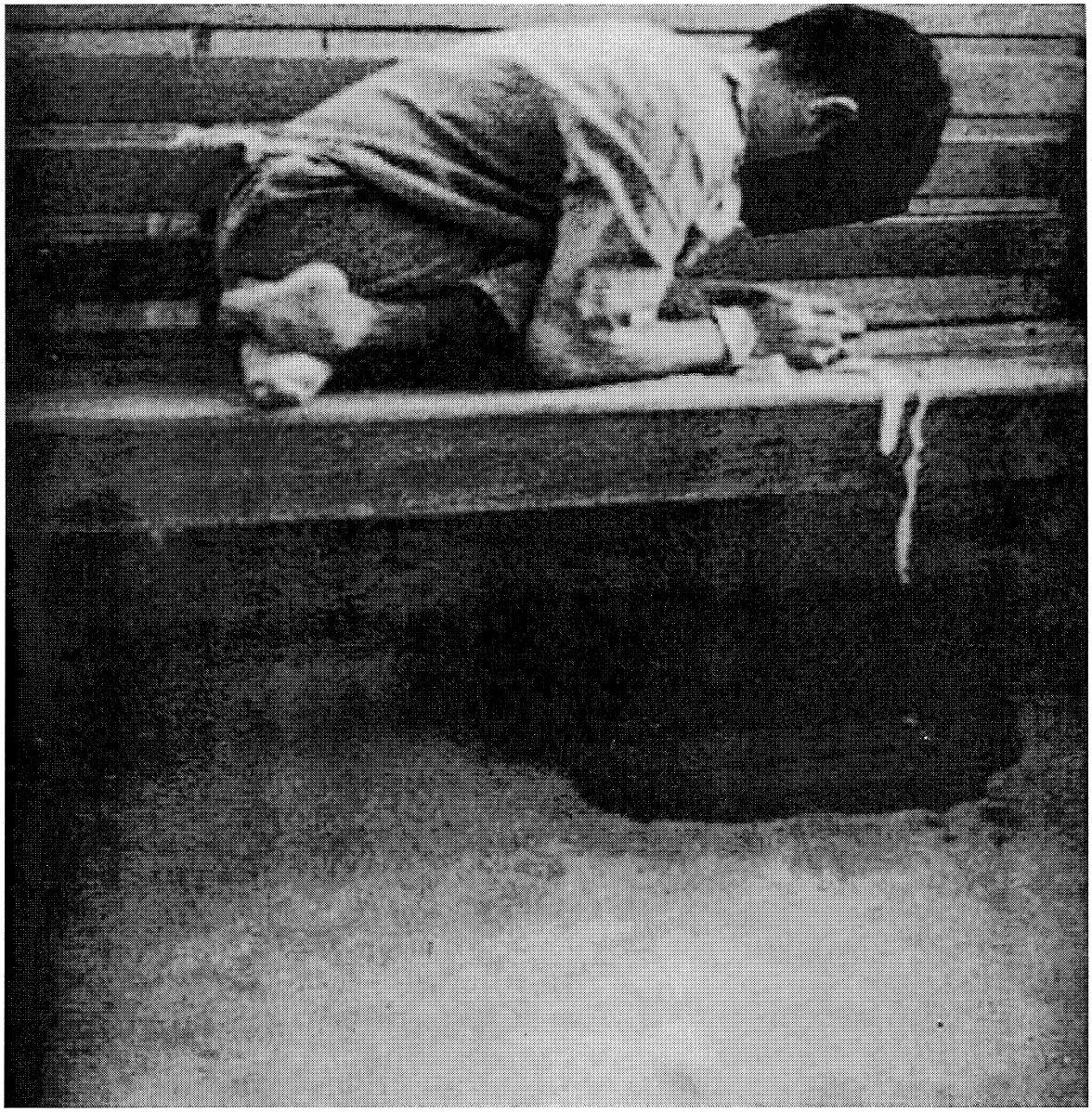
Christmas in Purgatory



"Some of mankind's most terrible misdeeds have been committed under the spell of certain magic words or phrases."

James Bryant Conant

"Man's inhumanity to man. .."

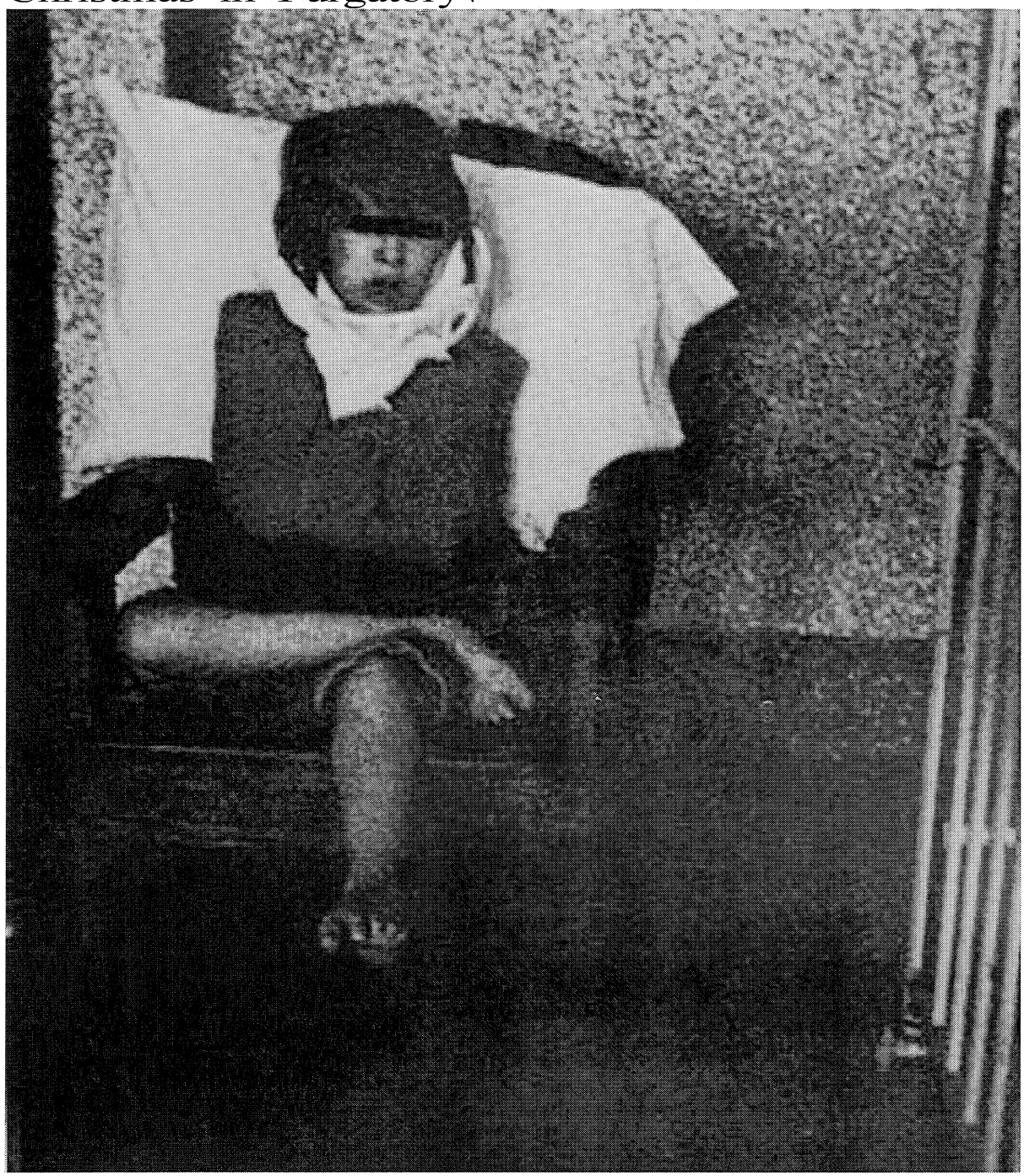


"Oh! why does the wind blow upon me so wild?

Is it because I'm nobody's child?"

Phila Henrietta Case

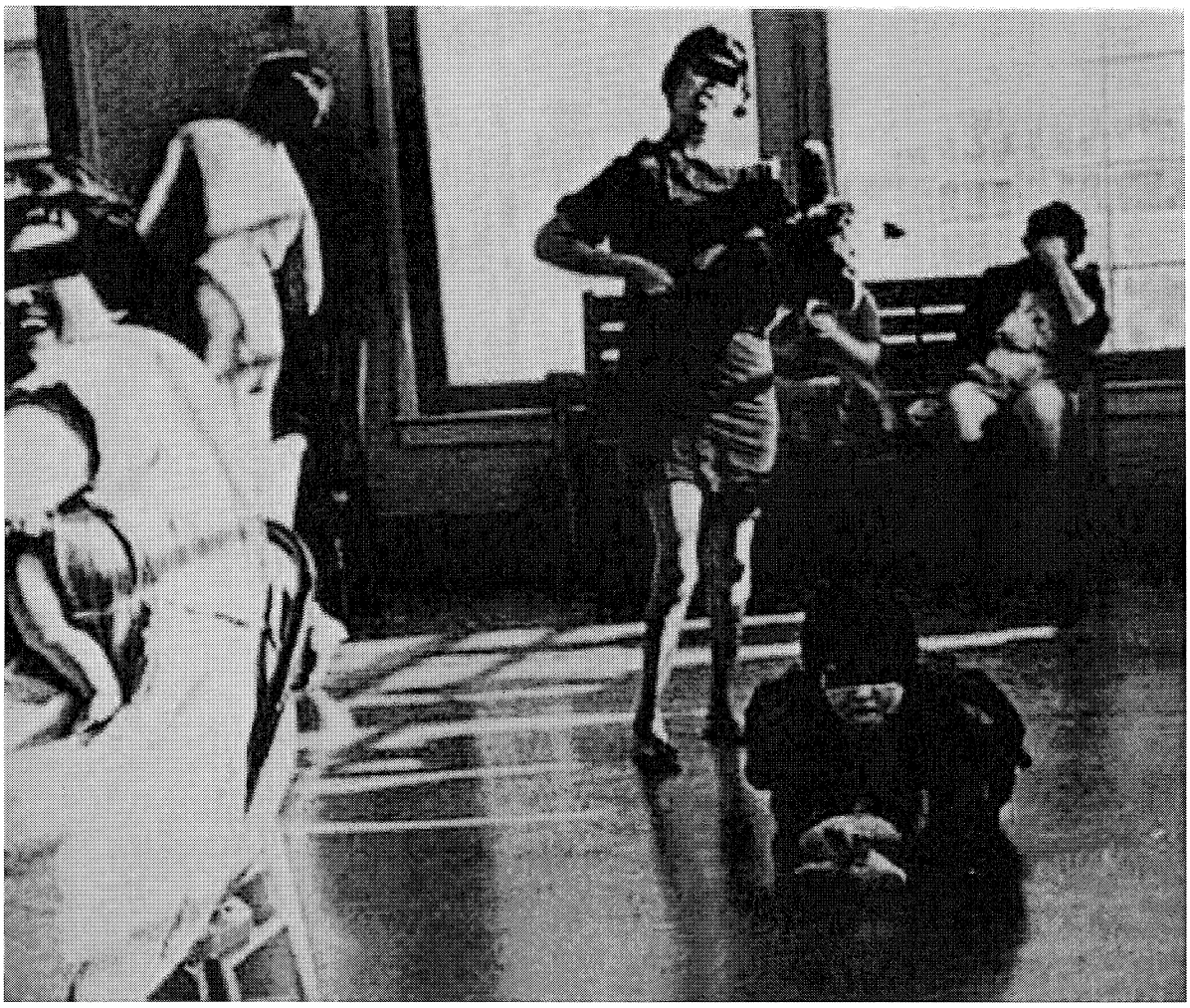
Christmas in Purgatory\



"Perfected and modified according to circumstances, chains gave way (during the early nineteenth century) to a long series of other ingenuous contrivances, all designed to limit the patient's freedom of movement. According to Oegg, restraining devices were generally thought to be as necessary for the preservation of life as eating, drinking, etc."

Emil Kraepelin

"Man's inhumanity to man. . ."



PURGATORY I

"I sometimes wish that God were back..."

"I sometimes wish that God were back
In this dark world and wide; For though
some virtues he might lack, He had his
pleasant side."

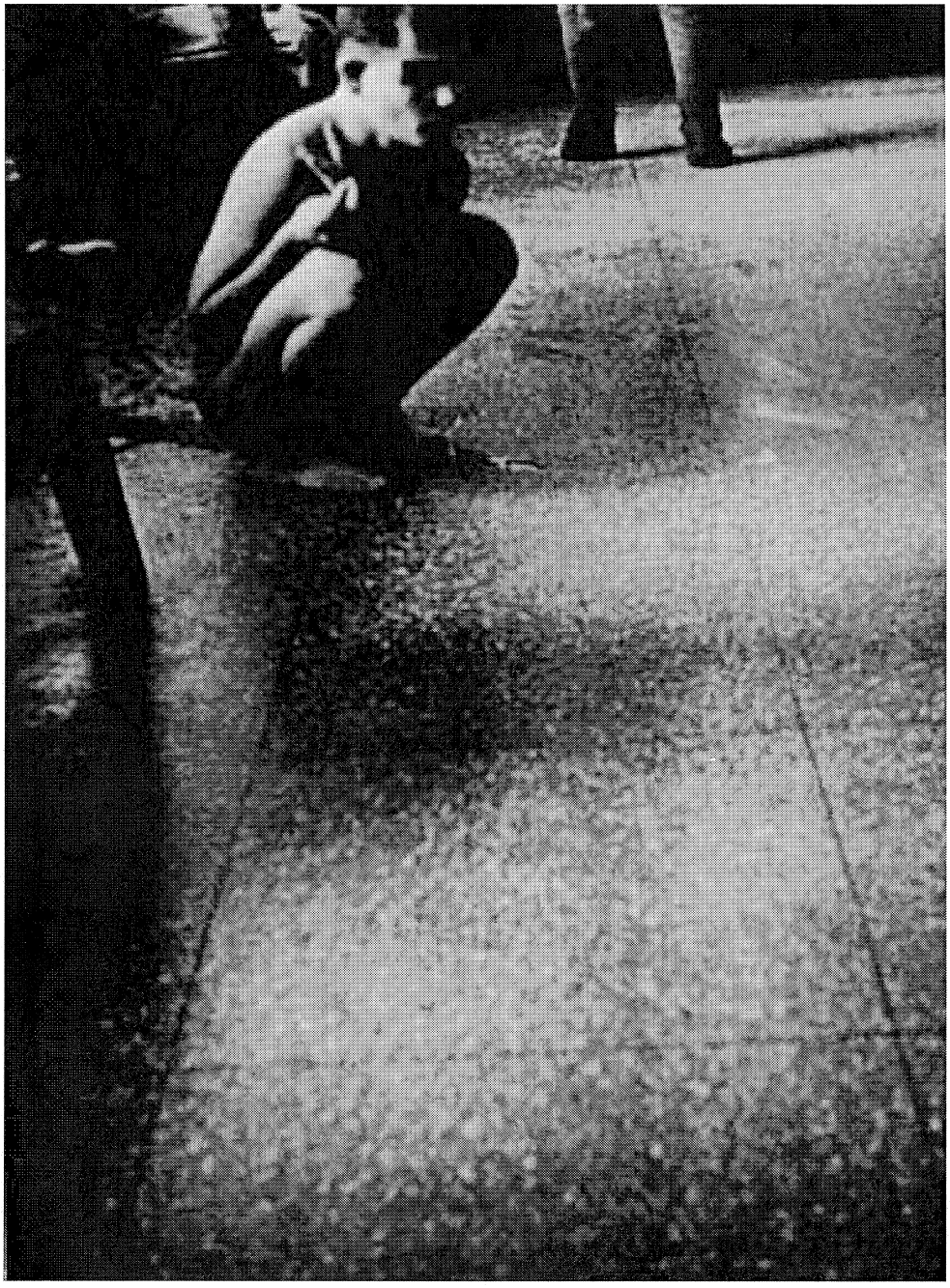
Gamaliel Bradford

In each of the dormitories for severely retarded residents, there is what is euphemistically **called** a day room or recreation room. The odor in each of these rooms is overpowering. After a visit to a day room we had to send our clothes to the dry cleaners to have the stench removed. The facilities often contribute to the horror. Floors are sometimes wooden and excretions are rubbed into the cracks, leaving permanent stench. Most day rooms have a series of bleacher benches, on which sit unclad residents, jammed together, without purposeful activity, communication, or any interaction. In each day room is an attendant or two, whose main function seems to be to "stand around" and, on occasion, hose down the floor "driving" excretions into a sewer conveniently located in the center of the room.

We were invited into female as well as male day rooms, in spite of the supervisor's know ledge that we, male visitors, would be observing naked females. In one such dormitory, with an overwhelming odor, we noticed feces on the wooden ceilings, and on the patients as well as the floors.

The question one might ask is, Is it possible to prevent these conditions? Although we are convinced that to teach severely retarded adults to wear clothes one must invest time and patience, we believe it possible to do so-given adequate staff. There is one more requirement. The staff has to be convinced that residents <u>can</u> be taught to wear clothes, that they <u>can</u> be engaged in purposeful activities, that they <u>can</u> learn to control their bladders. The staff has to believe that their "boys" and "girls" are human beings who can learn. Obviously, the money and the additional staff are vitally important. However, even more important, is the fundamental belief that each of these residents is a human being.

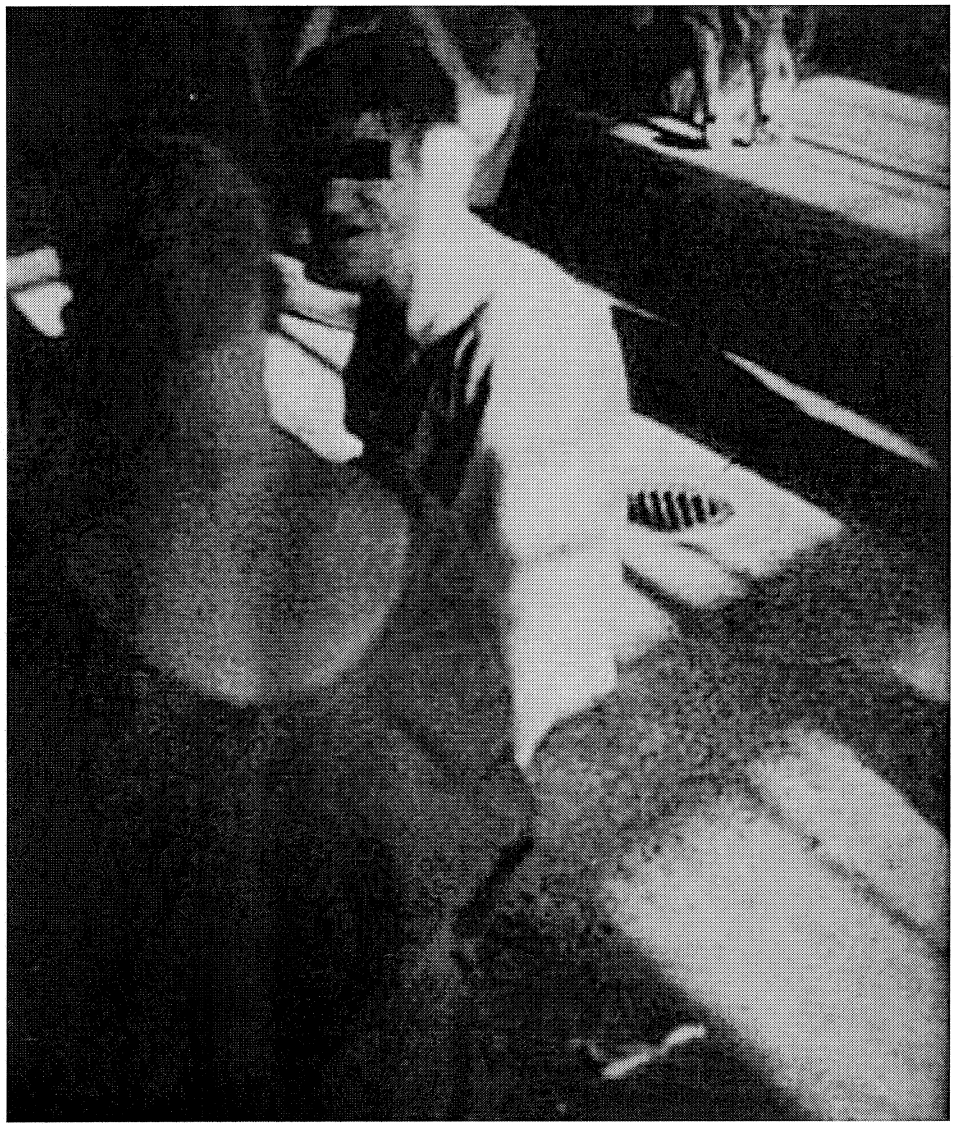
"I sometimes wish that God were back. . ."



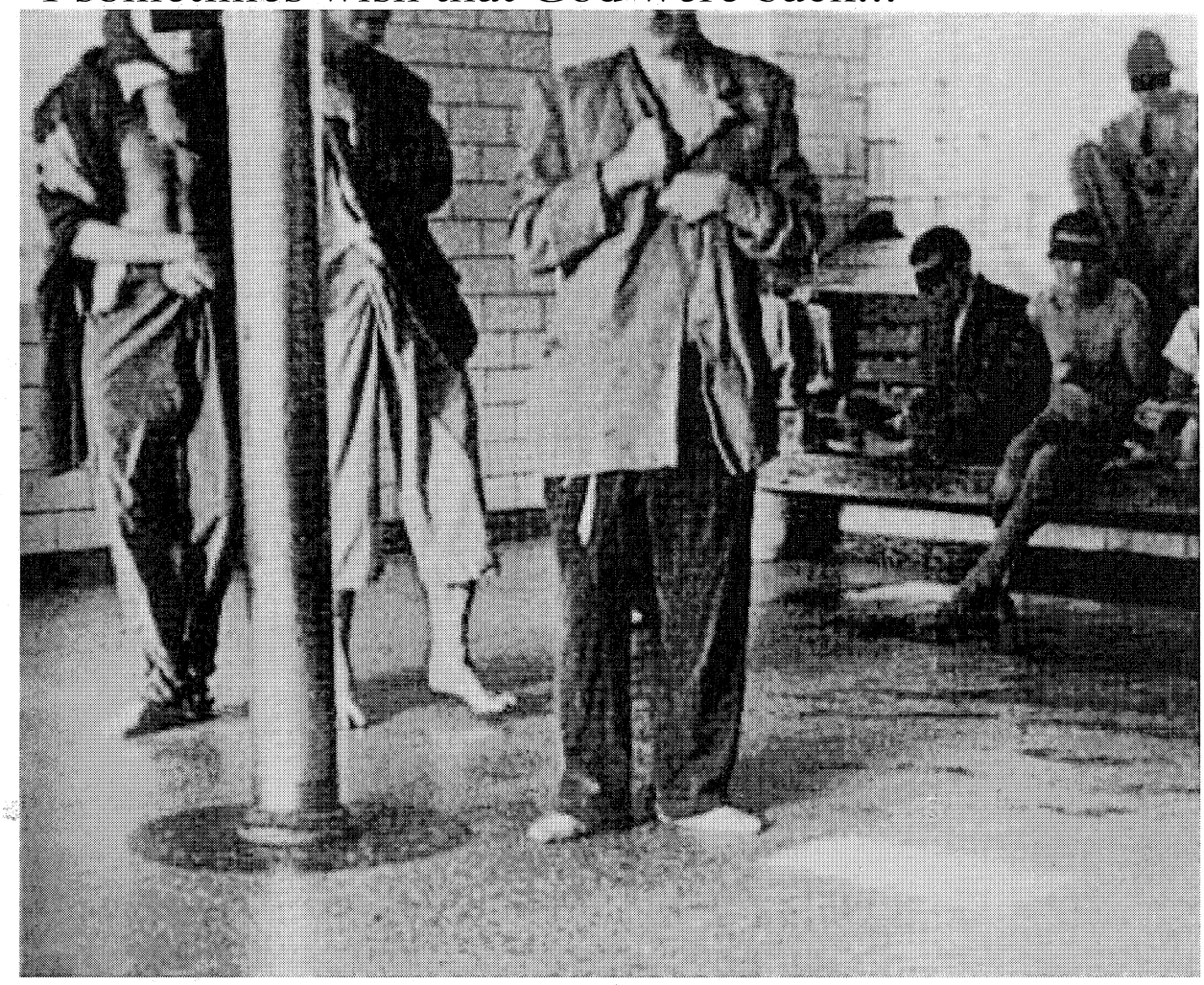
Christmas in Purgatory

"He is never less at leisure than when at leisure."

Cicero



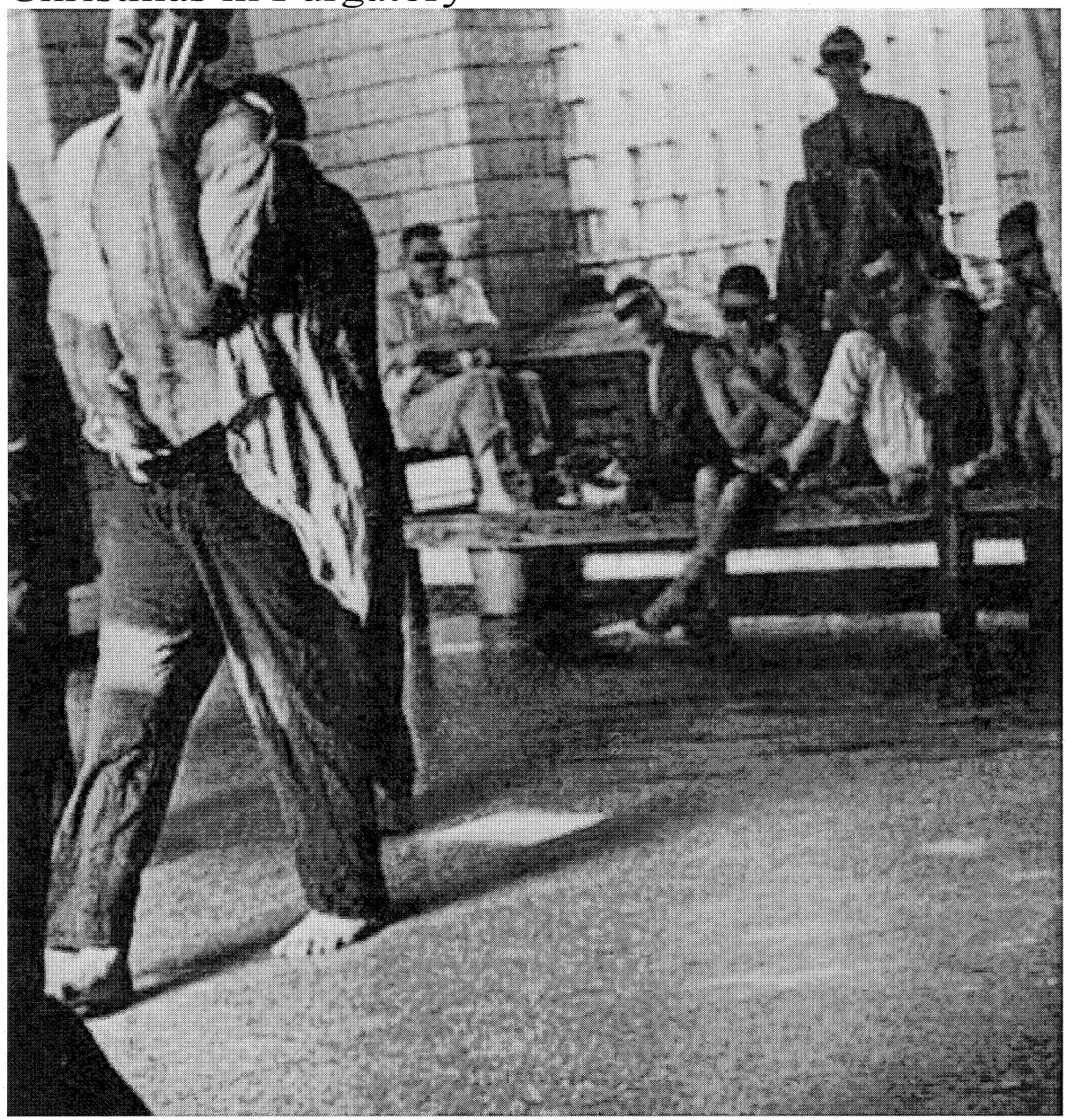
"I sometimes wish that God were back..."



"Thank heaven the crisis-The danger is passed,
and the lingering illness is over at last— And the
fever called 'Living' Is conquered at last."

Edgar Allen Poe

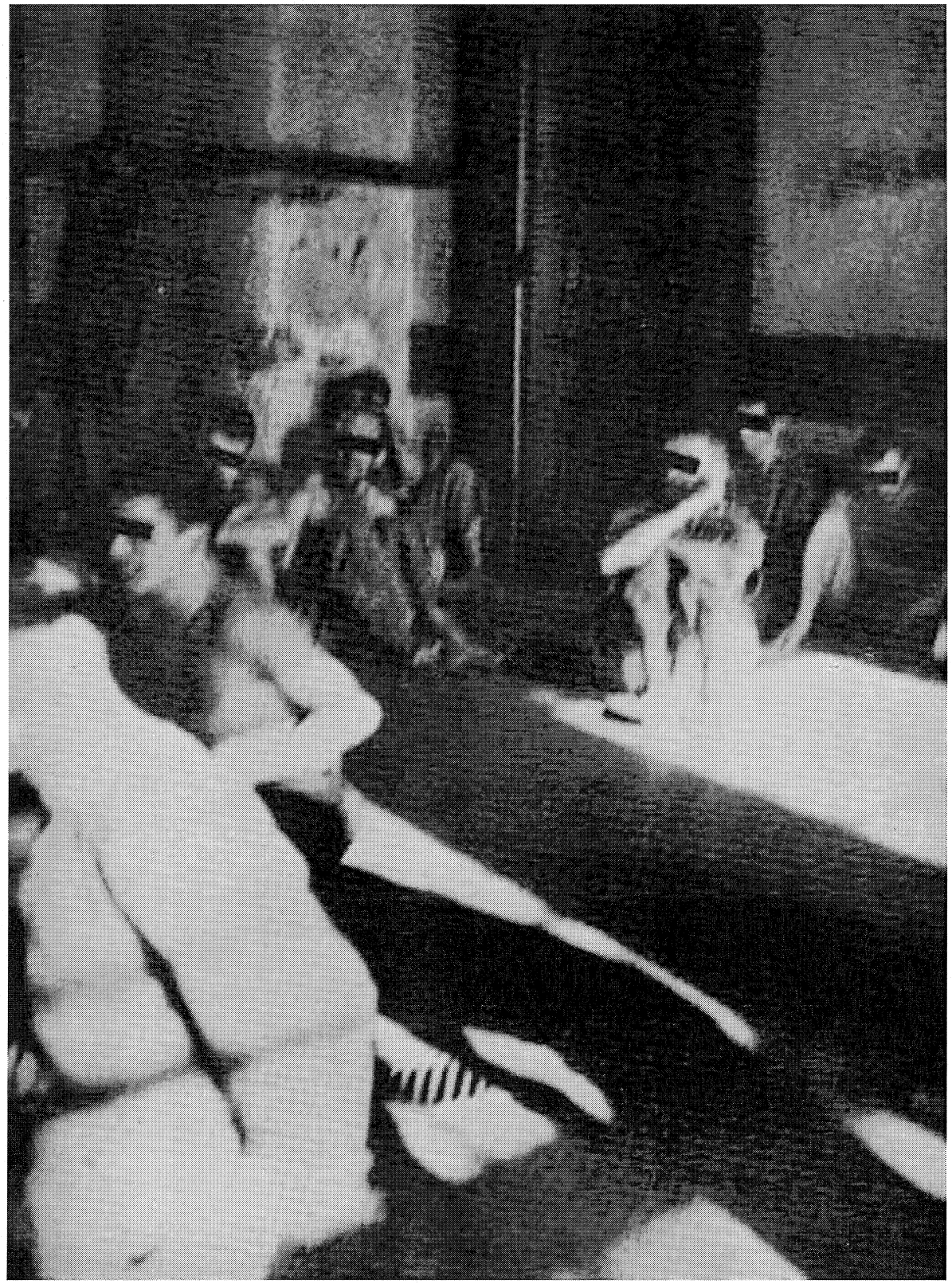
Christmas in Purgatory



"Stupid or mentally deficient patients (during the early nineteenth century) because they seemed passively to endure whatever was inflicted upon them, gave rise to the popular assumption that they were insensitive to hunger, cold, and pain even though the opposite was proven by their obvious emaciation, by their frozen members, and by their dying from injuries. The result was that their suffering was looked upon as self-evident and unalterable while the significance of their plight was never fully appreciated.

Emil Kraepelinj

"I sometimes wish that God were back.. ."

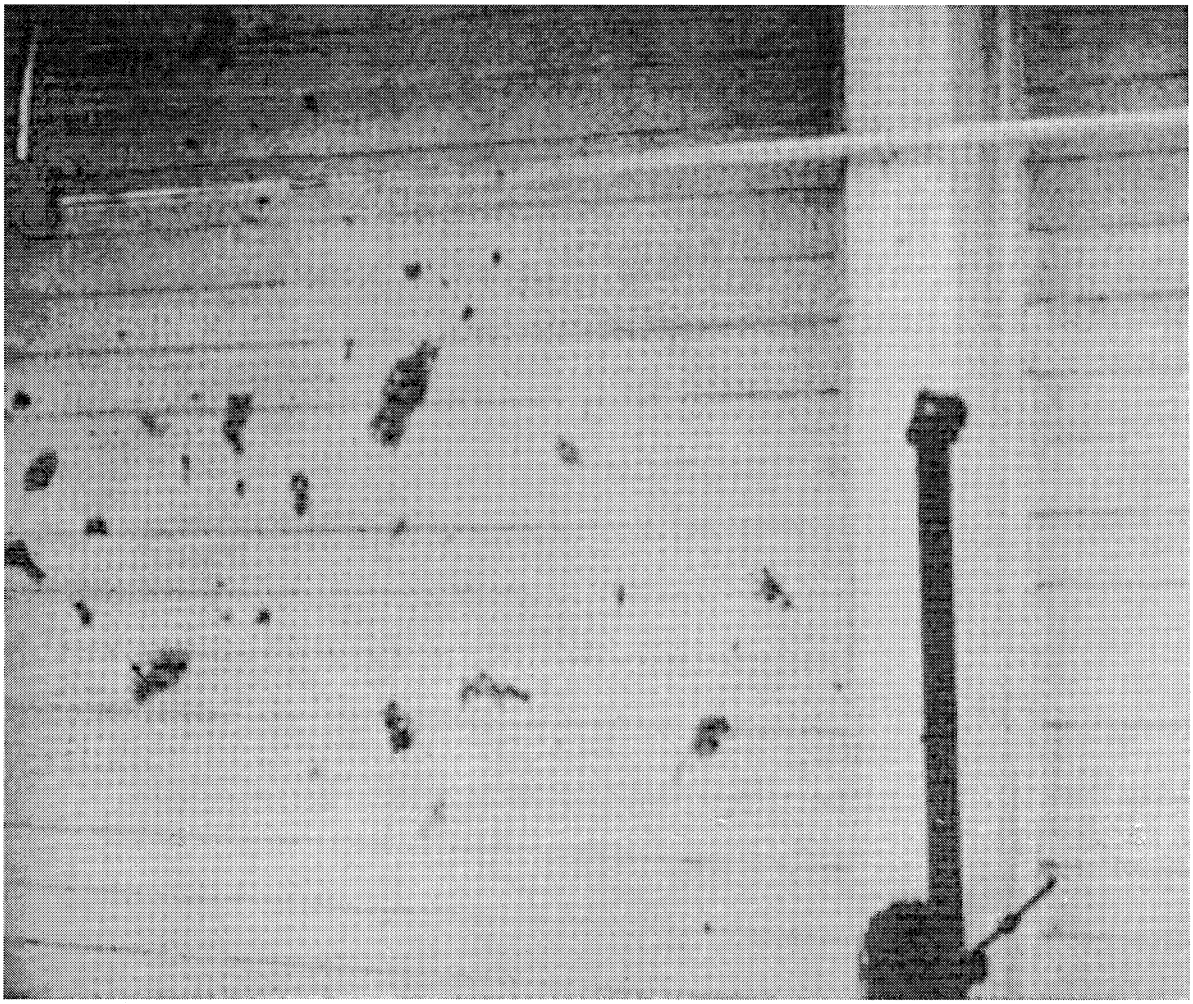


Christmas in Purgatory

"You shall not wrong a stranger or oppress him, for you were strangers in the land of Egypt."

Exodus, 23:5

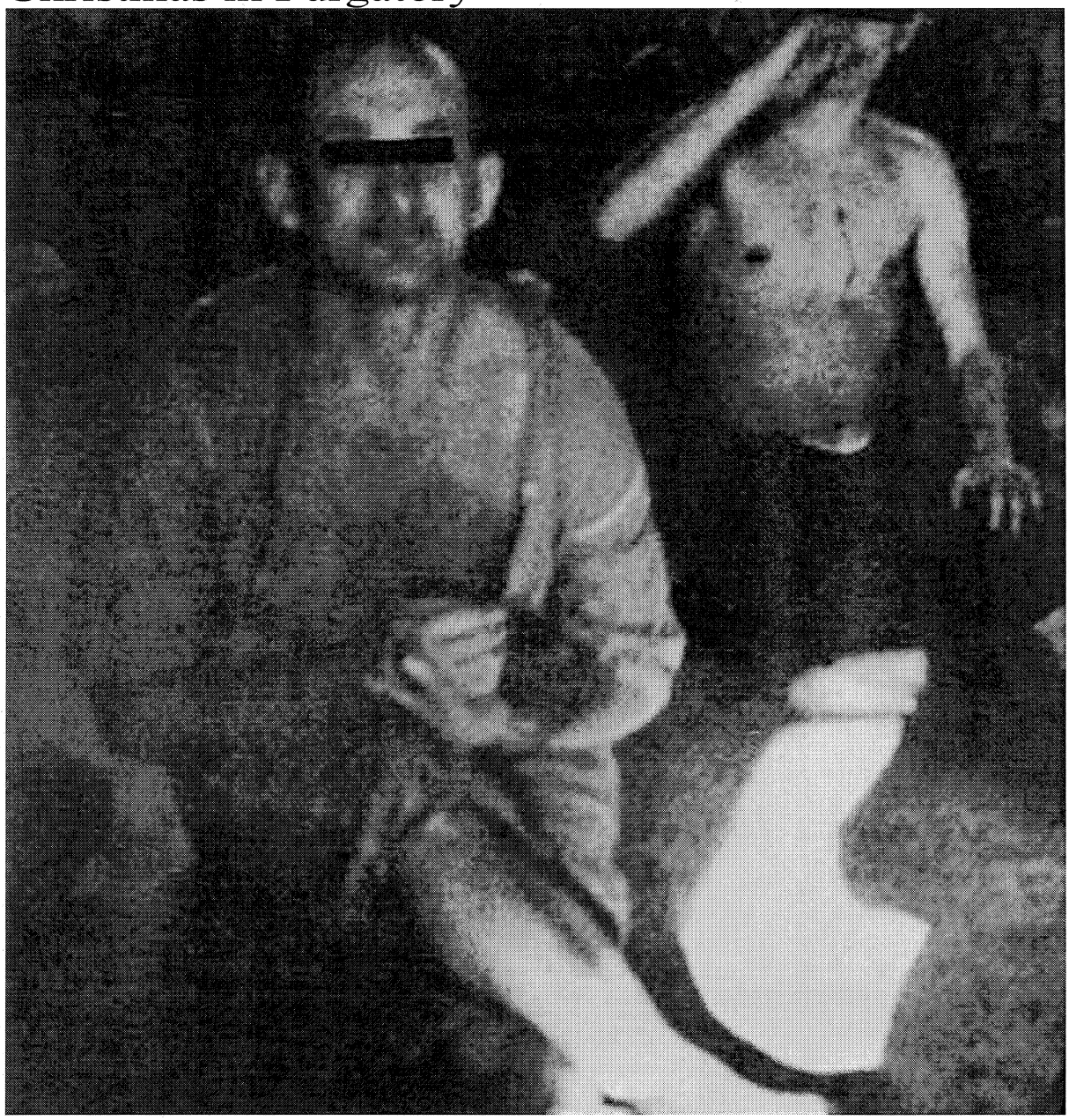
"I sometimes wish that God were back..."



"A humanitarian is bound to shudder when he discovers the plight of the unfortunate victims of this dreadful affliction; many of them grovel in their own filth on unclean straw that is seldom changed, often stark naked and in chains, in dark, damp dungeons where no breath of fresh air can enter. under such terrifying conditions, it would be easier for the most rational person to become insane than for a mad man to regain his sanity,"

Anonymous, 1795

Christmas in Purgatory



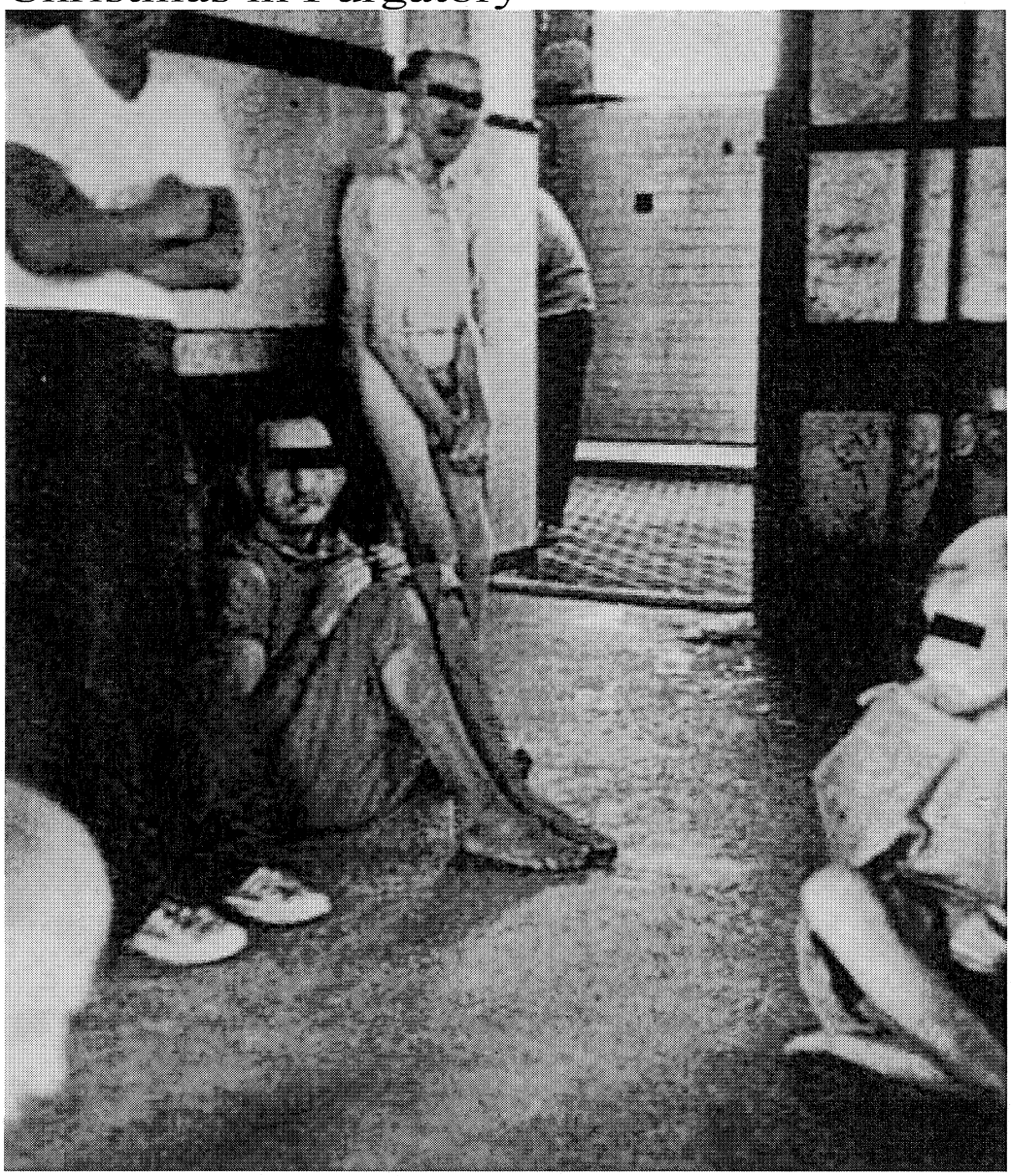
"Am I my brother's keeper?"
Genesis IV, 9

I sometimes wish that God were back..."

"In the asylum in Berlin those who are stark raving mad are isolated for the duration of their madness; they are locked naked. . ."

Hoch, 1804

Christmas in Purgatory



"I saw patients naked, with rags or nothing more than straw to protect them against the cold, damp weather. I saw how in their wretched state they were deprived of fresh air to breathe, of water to quench their thirst, and of the basic necessities of life. I saw them turned over for safe keeping to brutal jailers. I saw them chained in damp, cramped holes without light or air; people would be ashamed to keep in such places the wild animals that are cared for at great expense in our large cities. This is what I observed almost everywhere in France, and that is how the mentally ill are treated almost everywhere in Europe."

Esquirol, 1818

"I sometimes wish that God were back..."

"While the difference between <u>becoming</u> or not becoming mentally subnormal may often be slight, the difference between <u>being</u> and not being mentally subnormal may be considerable,"

Albert T. Murphy

PURGATORY I

"Suffer the little children..."

"Suffer the little children..."

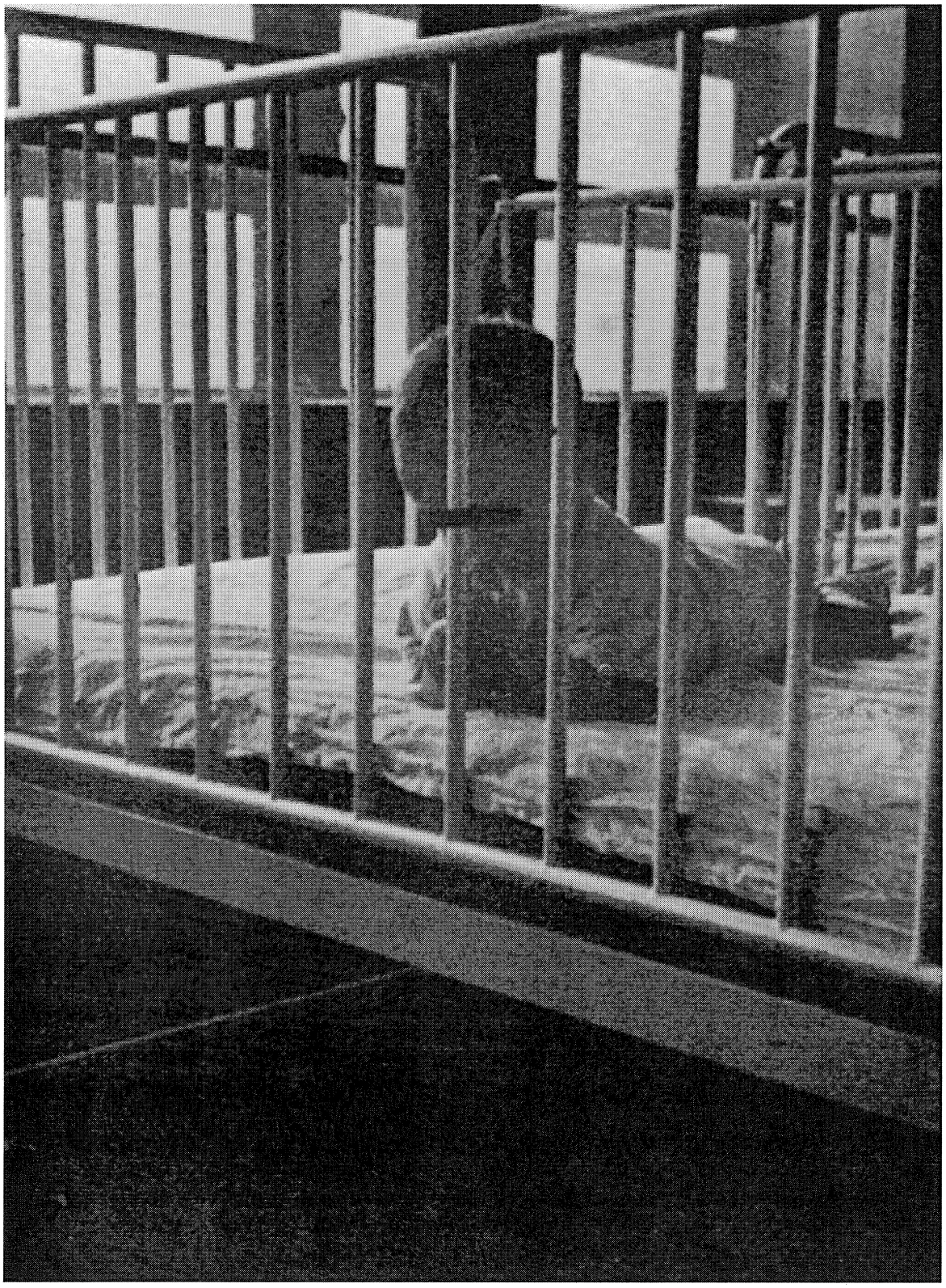
The infant dormitories depressed us the most. Here, cribs were placed—as in the other dormitories—side by side and head to head. Very young children, one and two years of age, were lying in cribs, without interaction with any adult, without playthings, without any apparent stimulation. In one dormitory, that had over 100 infants and was connected to 9 other dormitories that totaled 1,000 infants, we experienced a heartbreaking encounter. As we entered, we heard a muffled sound emanating from the "blind" side of a doorway. A young child seemed to be calling, "Come. Come play with me. Touch me." We walked to the door. On the other side were forty or more unkempt infants crawling around a bare floor in a bare room. One of the children had managed to squeeze his hand under the doorway and push his face through the side of the latched door. His moan was the clearest representation we have ever heard of the lonely, hopeless man. In other day rooms, we saw groups of 20 and 30 very young children lying, rocking, sleeping, sitting—alone. Each of these rooms were without toys or adult human contact, although each had desperate looking adult attendants "standing by."

In another dormitory, we were taken on a tour by the chief physician who was anxious to show us a child who had a very rare medical condition. The doctor explained to us that, aside from the child's dwarfism and misshapen body, one of the primary methods for diagnosing this condition is the deep guttural voice. In order to demonstrate this, he pinched the child. The child did not make any sound. He pinched her again, and again—harder, and still harder. Finally, as if in desperation, he insured her response with a pinch that turned into a gouge and caused the child to scream in obvious pain.

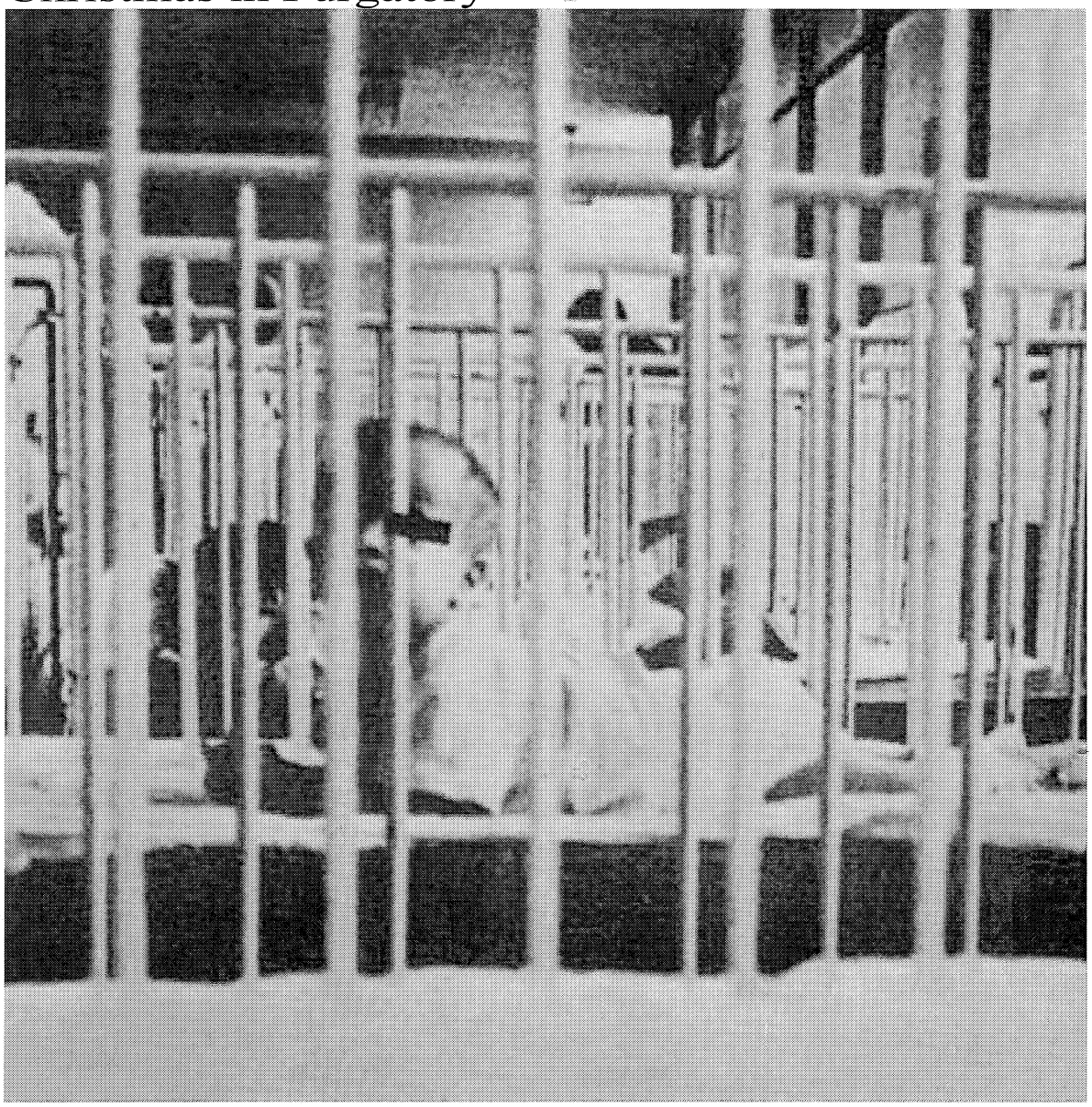
In some of the children's dormitories we observed "nursery programs." What surprised us most was their scarcity and the primitiveness of those in operation. Therefore, we were not unprepared to see several children with severe head lacerations. We were told these were "head bangers." Head banging is another condition that some people think is inevitable when confronted with young severely mentally retarded children. We challenge this. We have reason to believe that head banging can be drastically reduced in an environment where children have other things to do.

The "Special Education" we observed in the dormitories for young children was certainly not education. But, it was special. It was among the most especially frightening and depressing encounters with human beings we have ever experienced.

"Suffer the little children..."



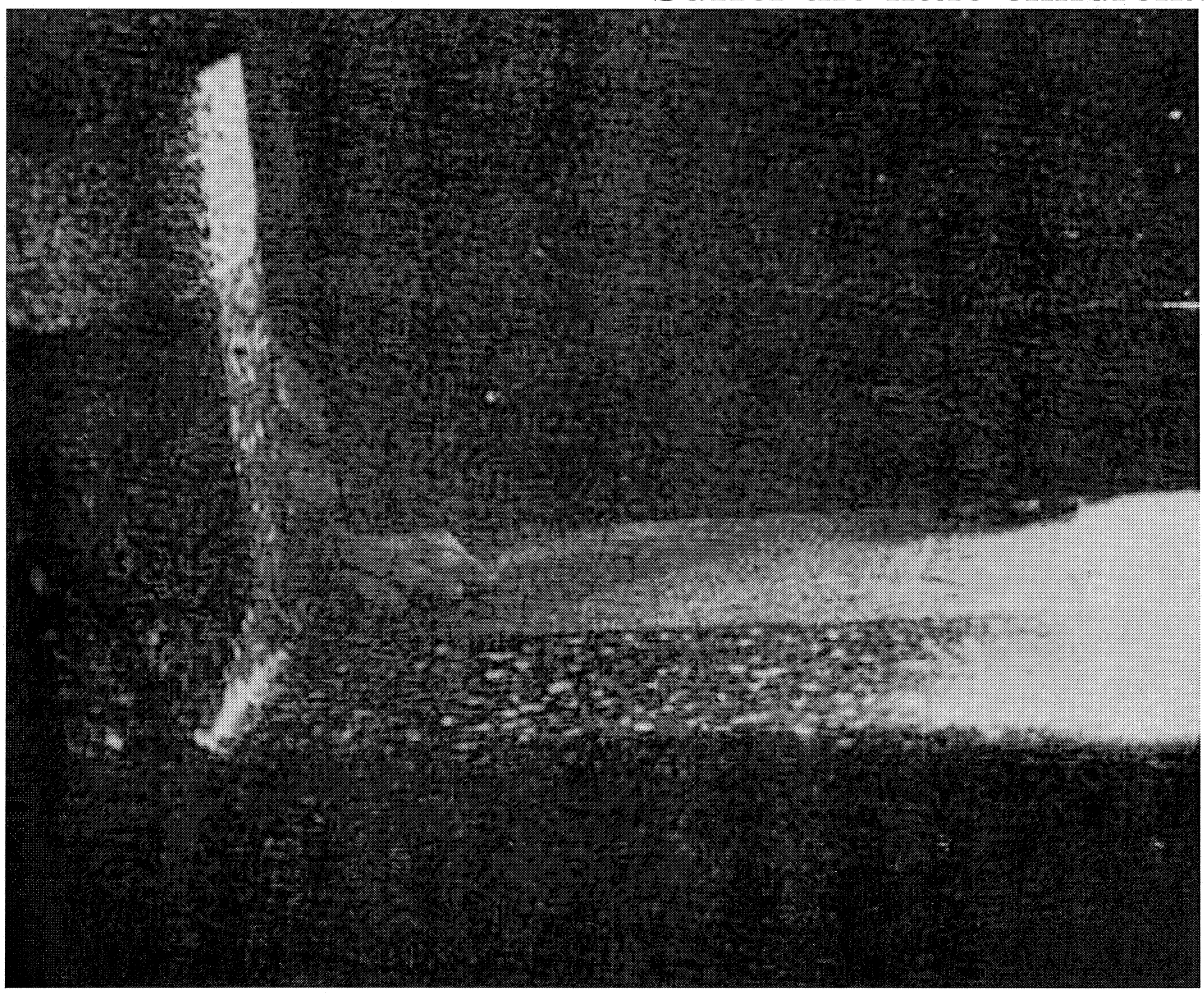
Christmas in Purgatory



"Cast upon this globe without physical strength or innate ideas, incapable in himself of obeying the fundamental laws of this nature which call him to the supreme place in the universe, it is only in the heart of society that man can attain the pre-eminent position which is his natural destiny. Without the aid of civilization he would be one of the feeblest and least intelligent of animals. . ."

Jean-Marc -Gaspard Itard

"Suffer the little children..."

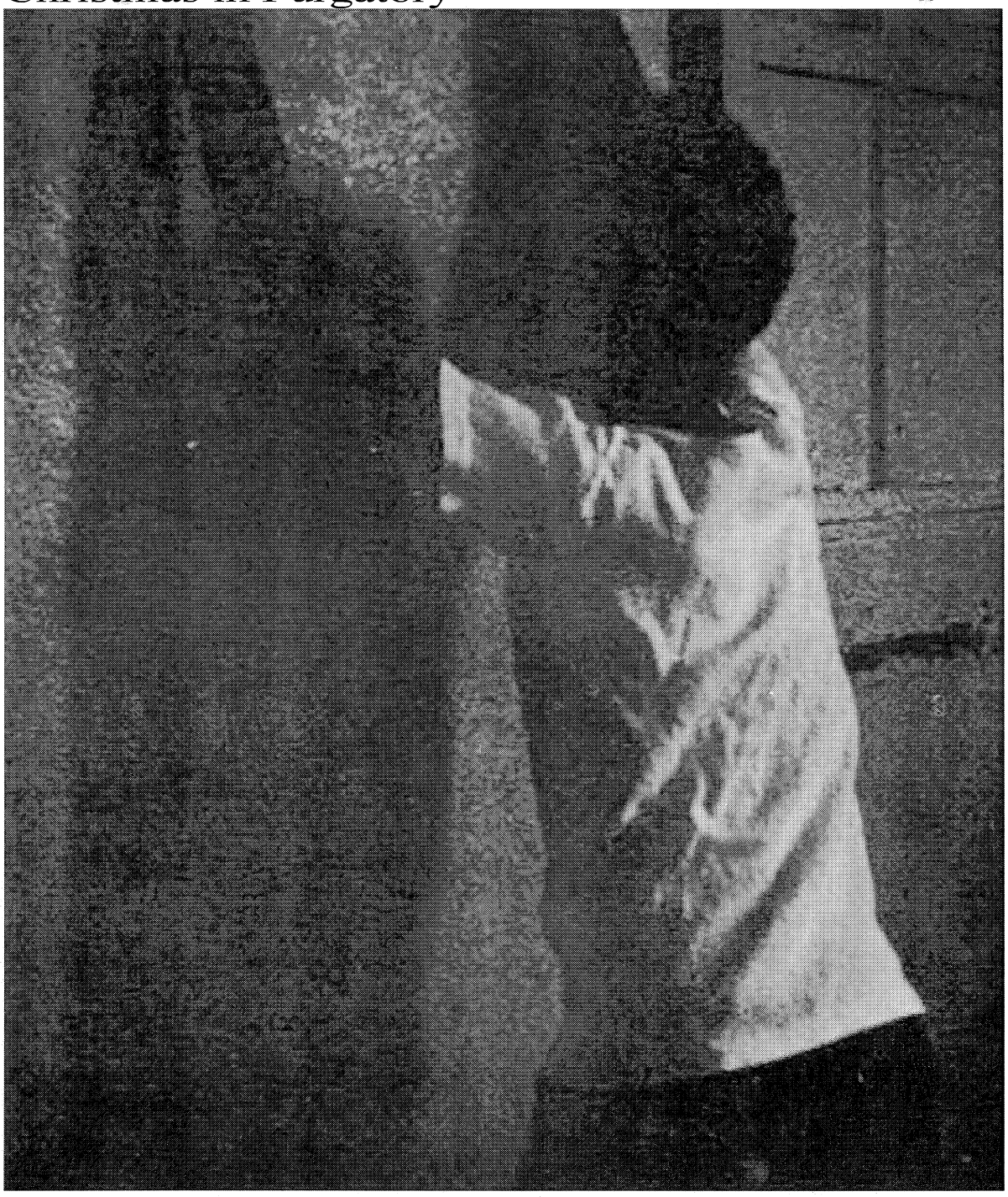


"It is not good that man should be alone."

Genesis II, 18

V

Christmas in Purgatory

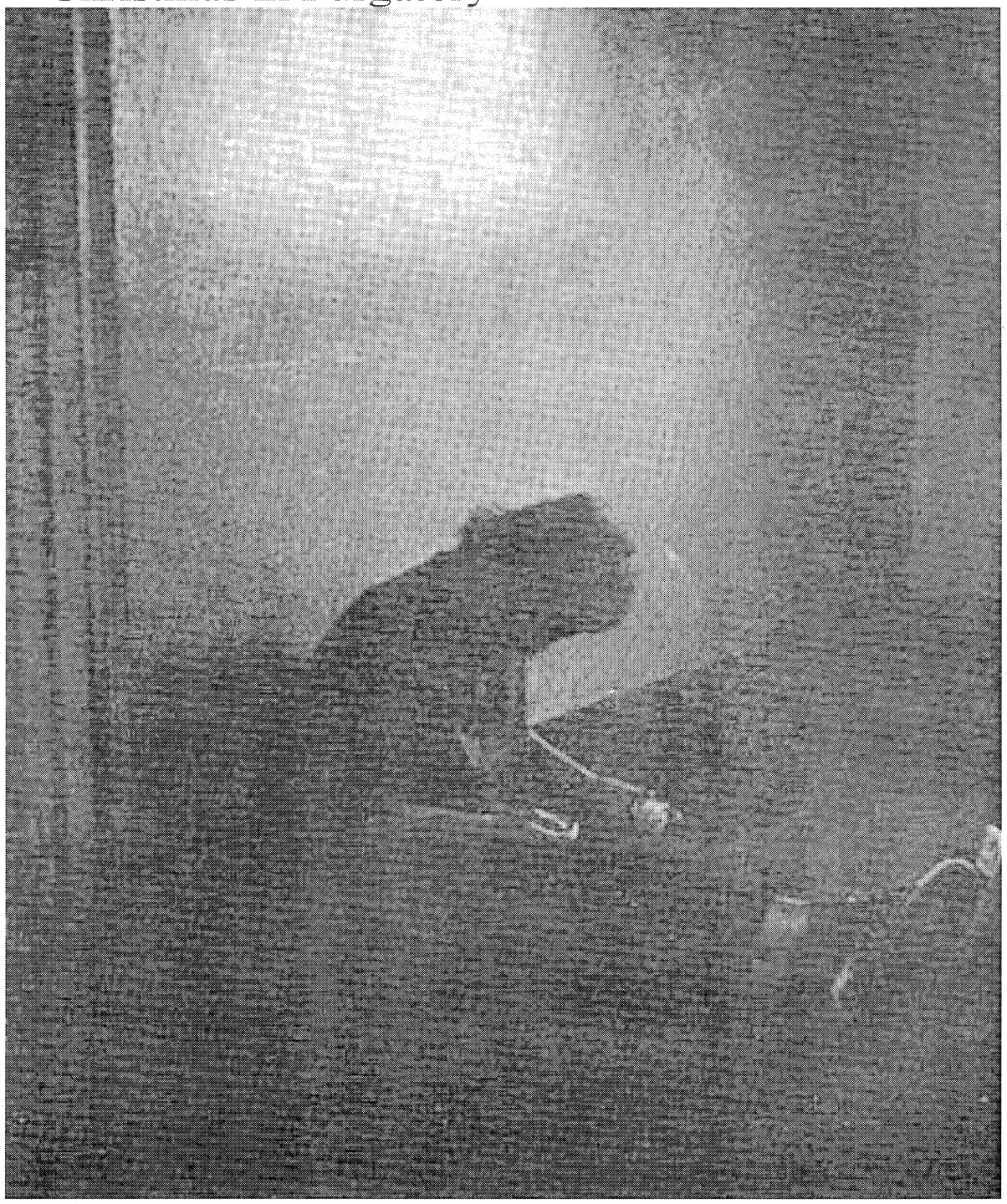


"Every one in the world is Christ and they are all crucified."

Sherwood Anderson

"Suffer the little children..."

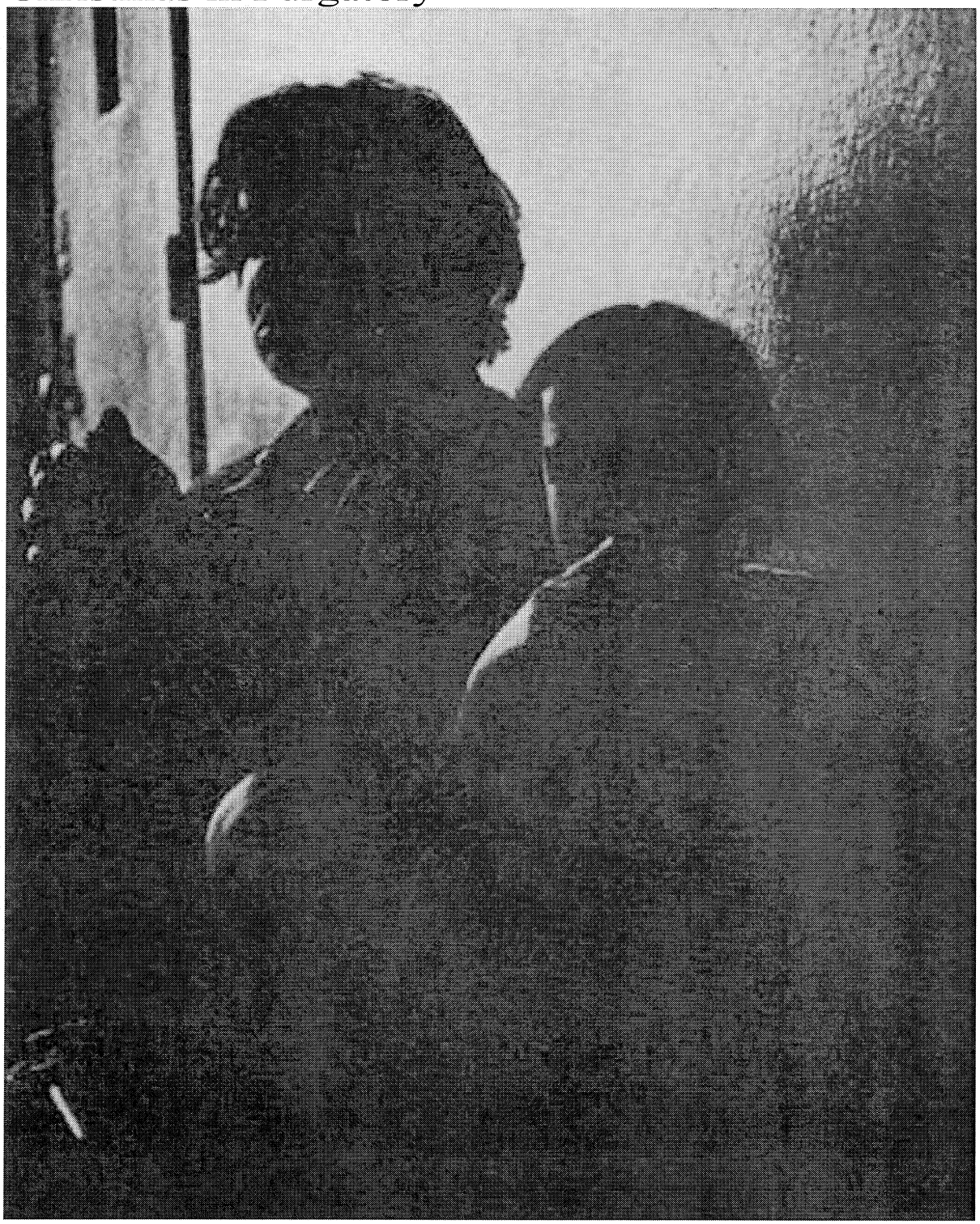
"Friday's child is full of woe." Anonymous



We are wrestling with our own retardation to cope, ultimately, with the retardation of others.

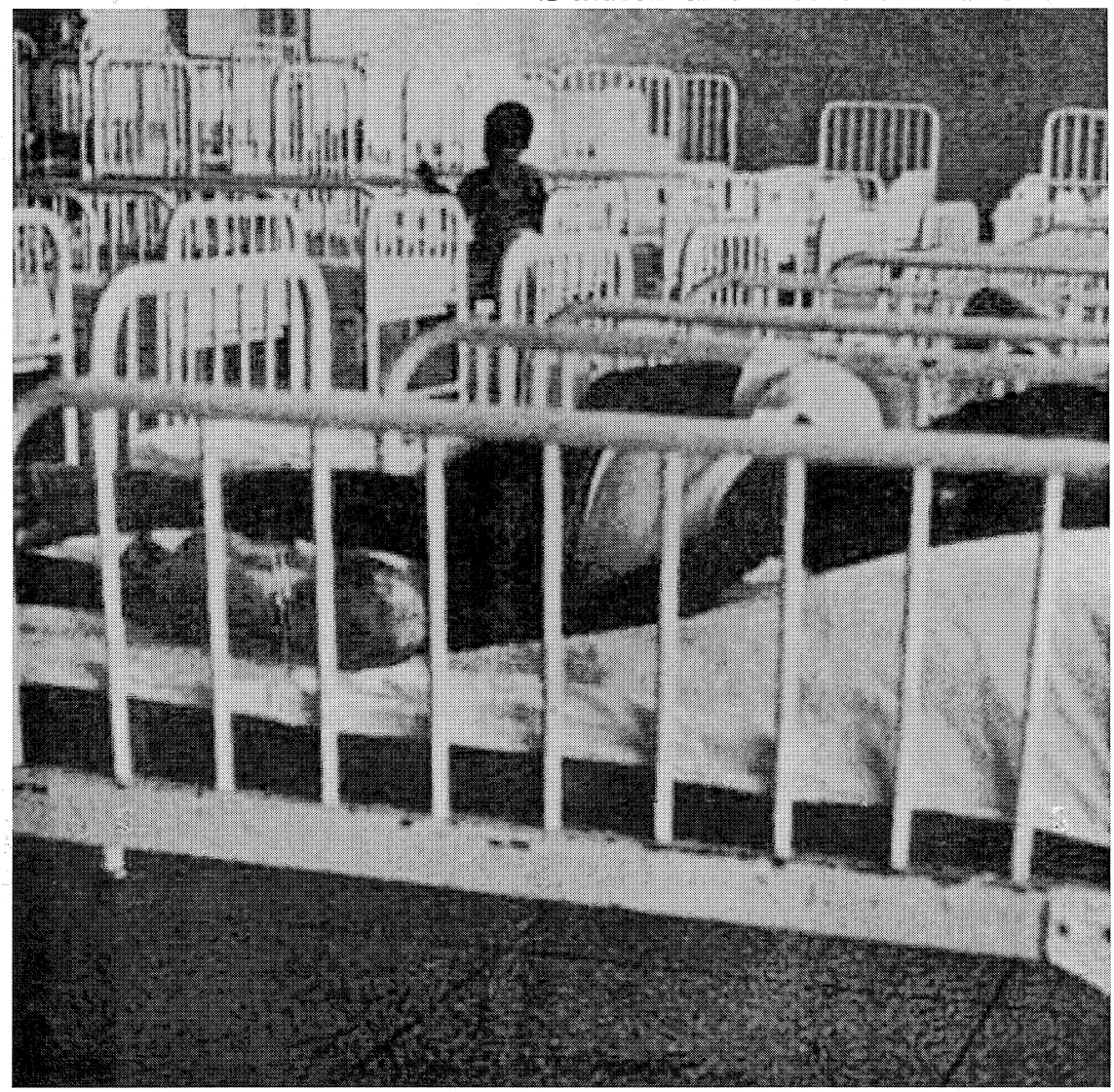
"Suffer the little children..."

Christmas in Purgatory

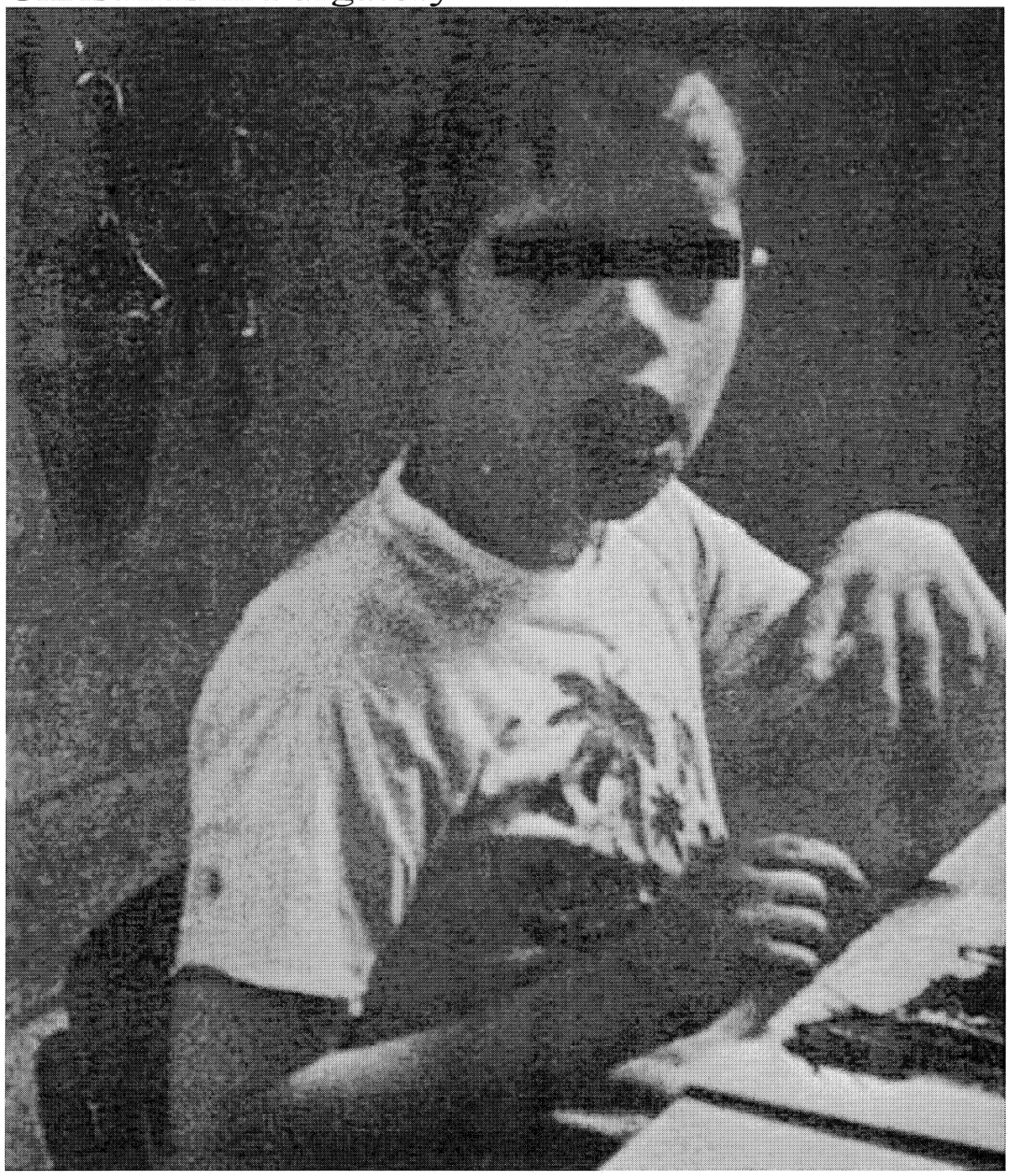


"Now we see through a glass, darkly." 1
Corinthians XIII, 12

"Suffer the little children..."



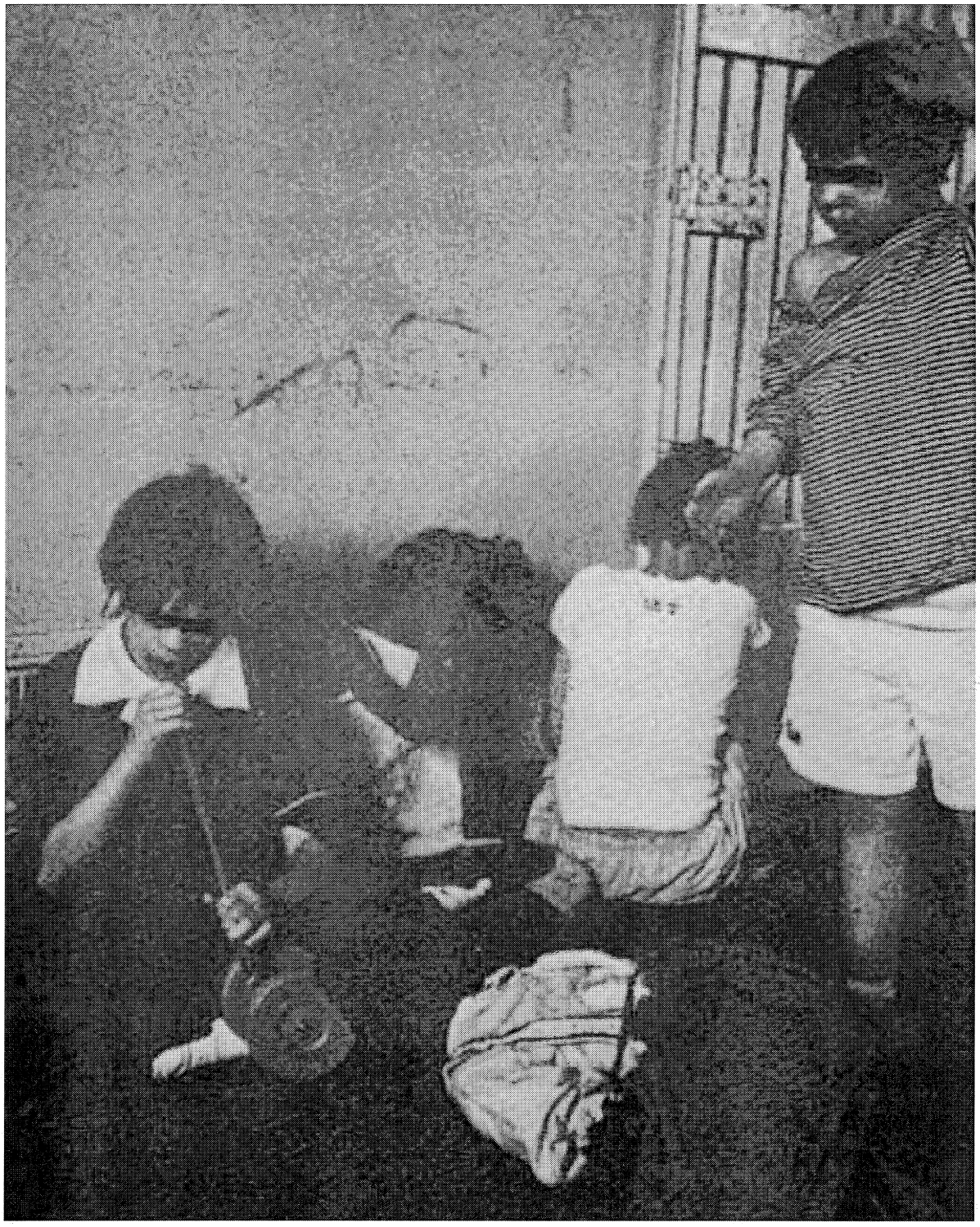
Christmas in Purgatory



"The academic scene is now strewn with the hopes of deadened classes wherein competent teachers are stifled by children of such heterogeneity that survival becomes the major goal rather than progress. The same can be said for well-selected classes managed by poorly prepared and poorly supervised teachers. By upgrading these three areas, we can make our major contribution toward making special education something constructively special."

Herbert
Goldstein

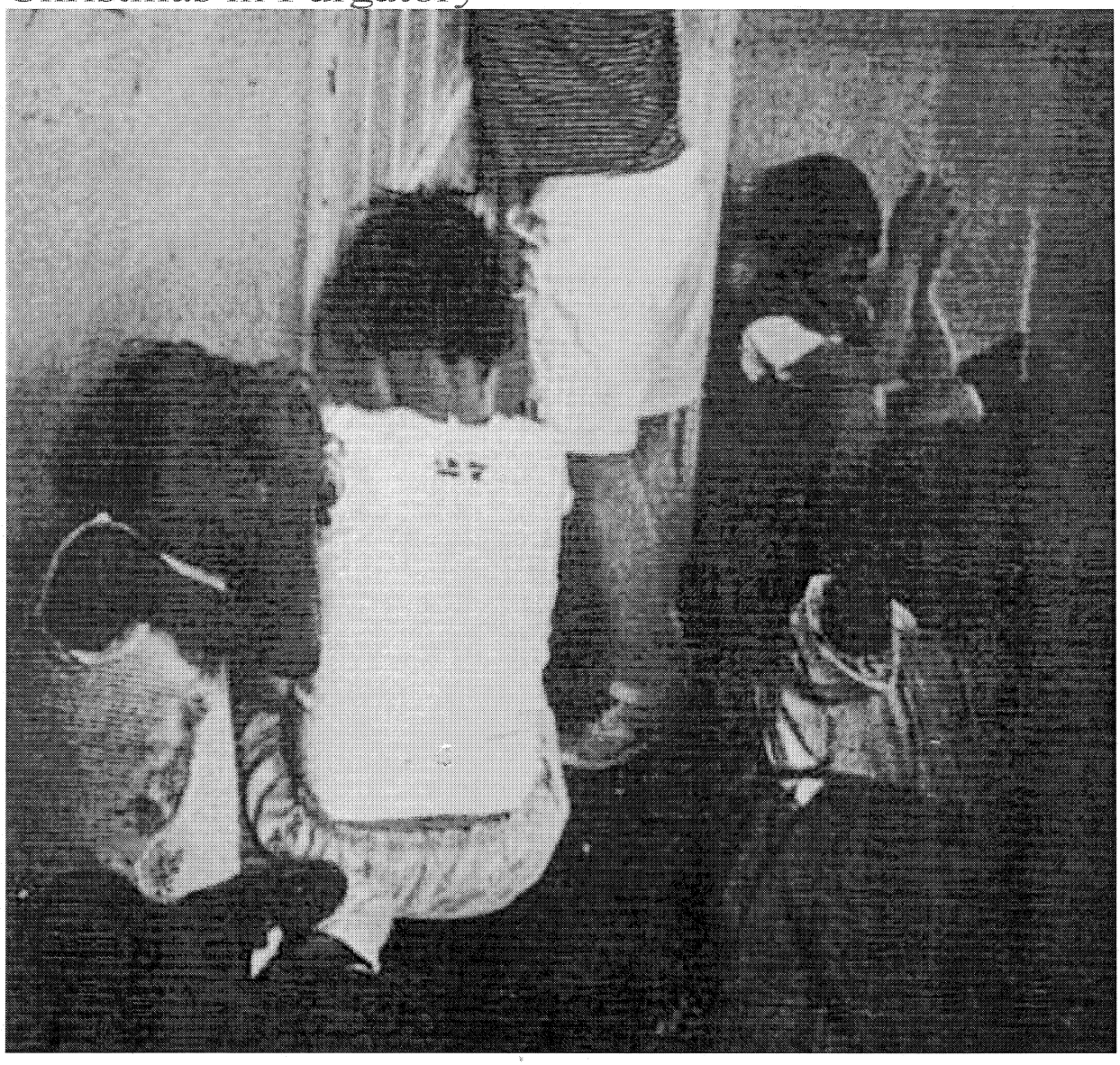
"Suffer the little children..."



"There are only two things wrong with most special education for the mentally handicapped; it isn't special, and it isn't education."

Alice Metzner

Christmas in Purgatory



". . .the offspring of the inferior, or of the better when they chance to be deformed, will be put away in some mysterious, unknown place. . ."
Plato

PURGATORY I

"The wretched souls..."

"The wretched souls of those who lived
Without all praise or blame."
Dante

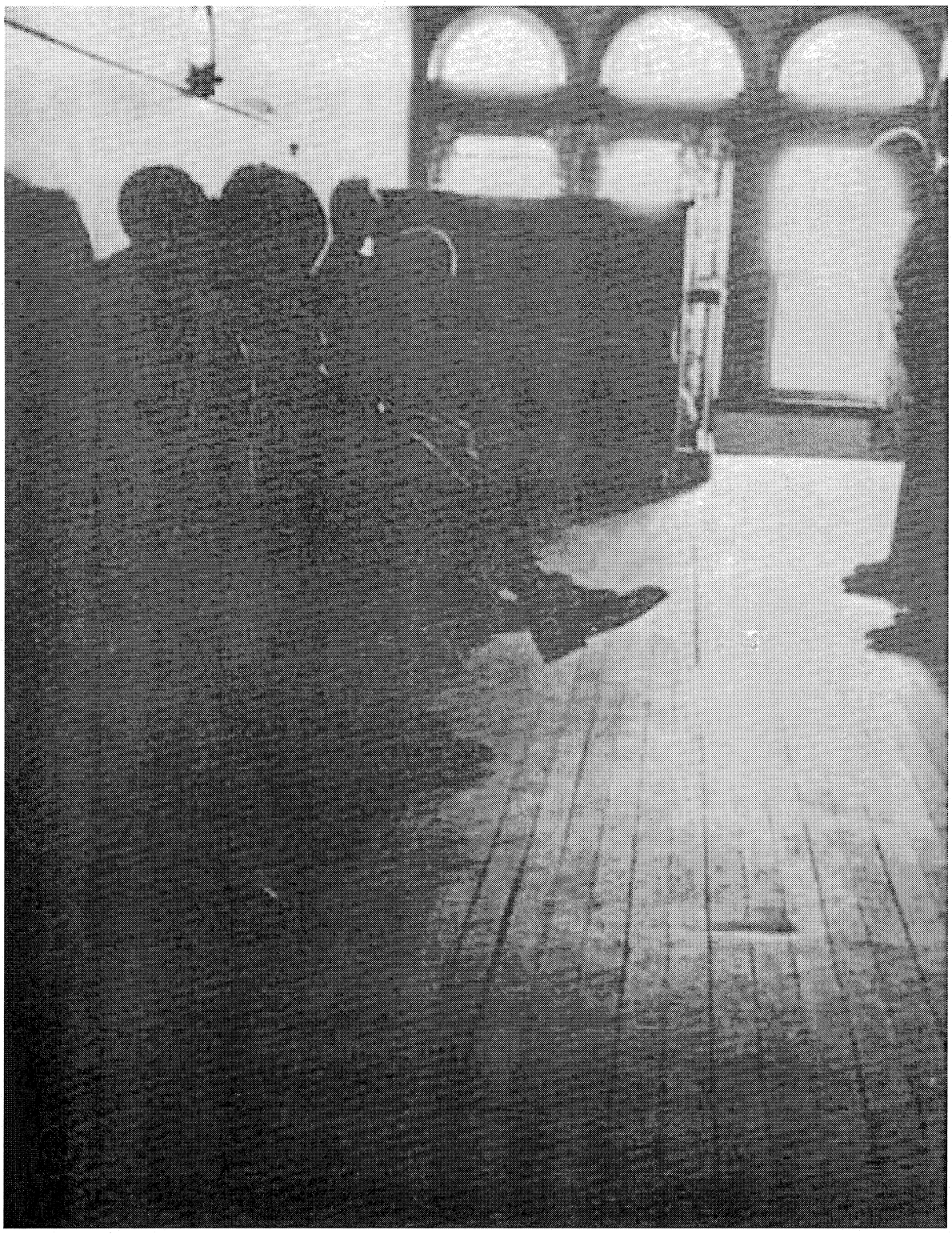
The living quarters for older men and women were, for the most part, gloomy and sterile. There were the rows and rows of benches on which sat countless human beings, in silent rooms, waiting for dinner call or bedtime. We saw resident after resident in "institutional garb." Sometimes, the women wore shrouds— inside out.

We heard a good deal of laughter but saw little cheer. There were few things to be cheerful about. A great many of the men and women looked depressed and acted depressed. Even the television sets, in several of the day rooms, appeared to be co-conspirators in a crusade for gloom. These sets were not in working order. Sadly, the residents continued to sit on their benches, in neat rows, looking at the blank tubes. We observed adult residents during recreation, playing "ring-around the-rosy." Others, in the vocational training center, were playing "jacks." These were not always severely retarded patients. However, we got the feeling very quickly that this is the way they were being forced to behave.

Christmas in Purgatory

"My friends forsake me like a memory lost."

John Clare



"... in an institution there is always tomorrow so that he who starts out a student ends up, by default, an inmate

Richard H. Hungerford

Christmas in Purgatory

"Where ever men go, in heaven, or earth, or hell they find themselves, and that is all they find."

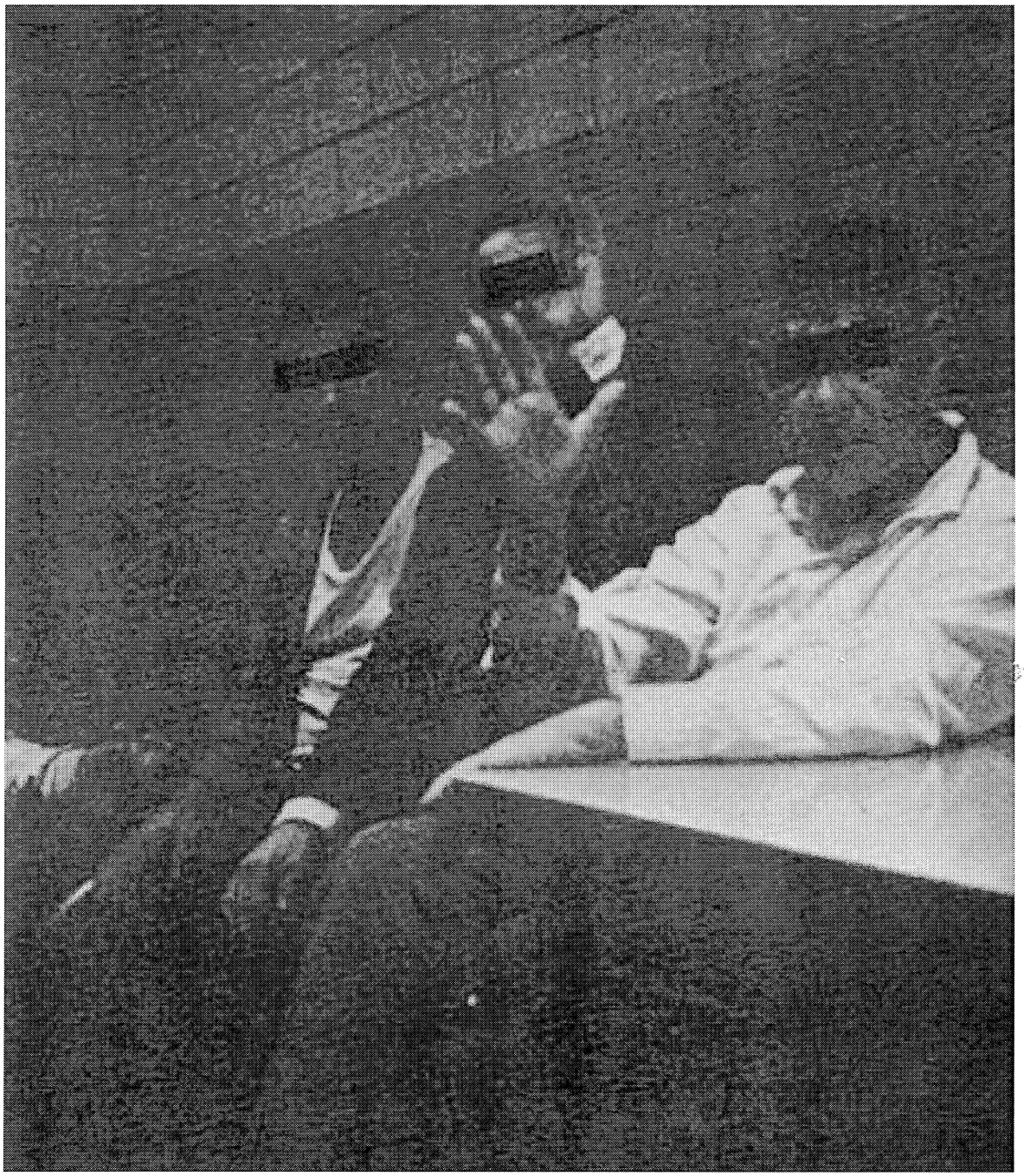
Samuel Valentine Cole

"The wretched souls..."

"Man is a pliable animal, a being who gets accustomed to everything!"

Fyodor Dostoyevsky

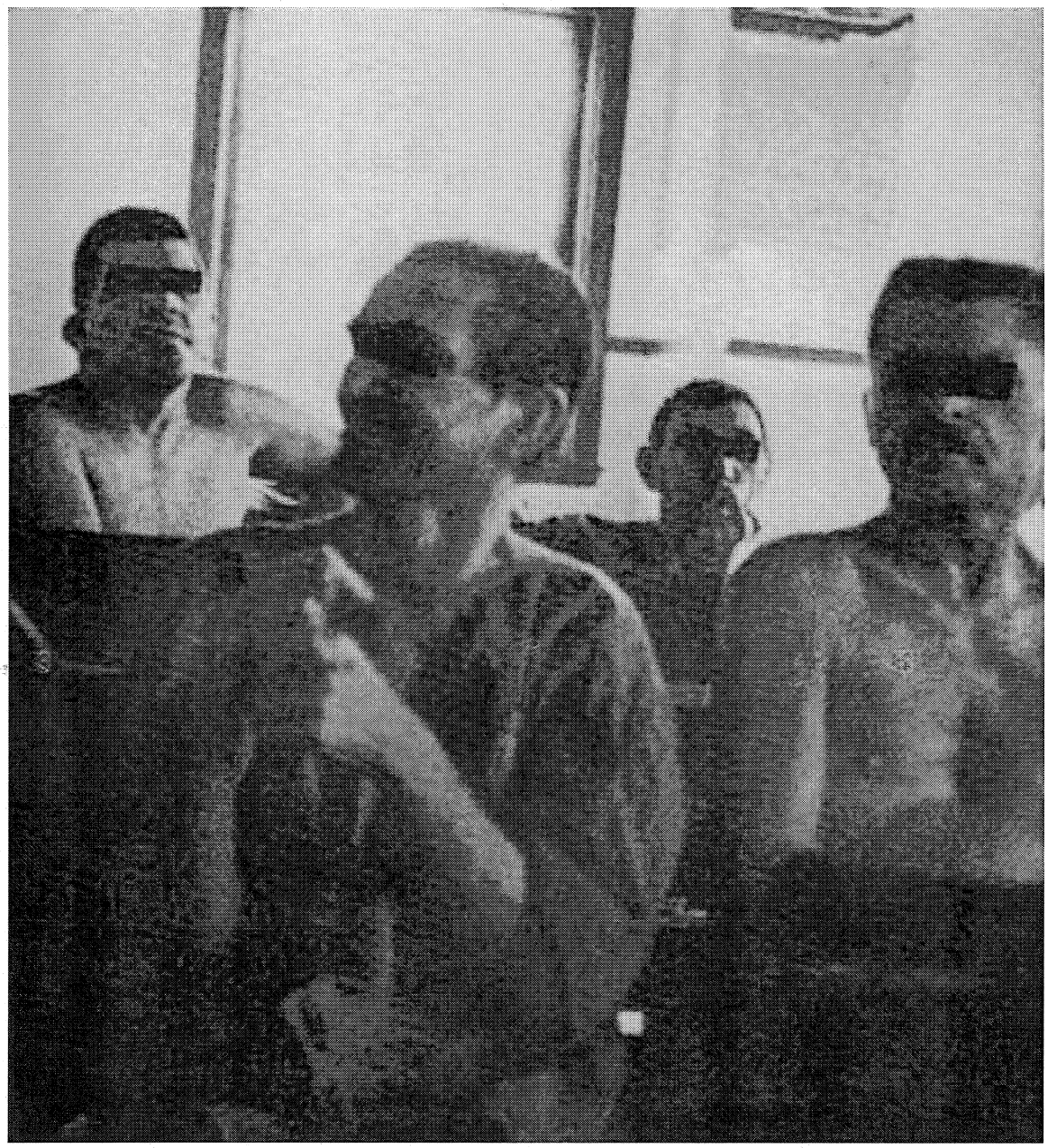
Christmas In Purgatory



" 'We lock these unfortunate creatures in lunatic cells, as if they were criminals,' exclaimed Reil in 1803, 'We keep them in chains in forlorn jails, near the roosts of owls in hidden recesses above the gates of towns, or in the damp cellars of reformatories where no sympathetic human being can can ever bestow them a friendly glance, and we let them rot in their own filth. There fetters scrape the flesh from their bones, and their wan, hollow faces search for the grave that their wailing and our ignominy conceals from them.' "

Emil Kraepelin

"The wretched souls..."



"Our troubles emanate not from biological idiots but from social ones; and social idiots are produced by society, not by genes. It is therefore the social, not biological, therapy that is indicated"

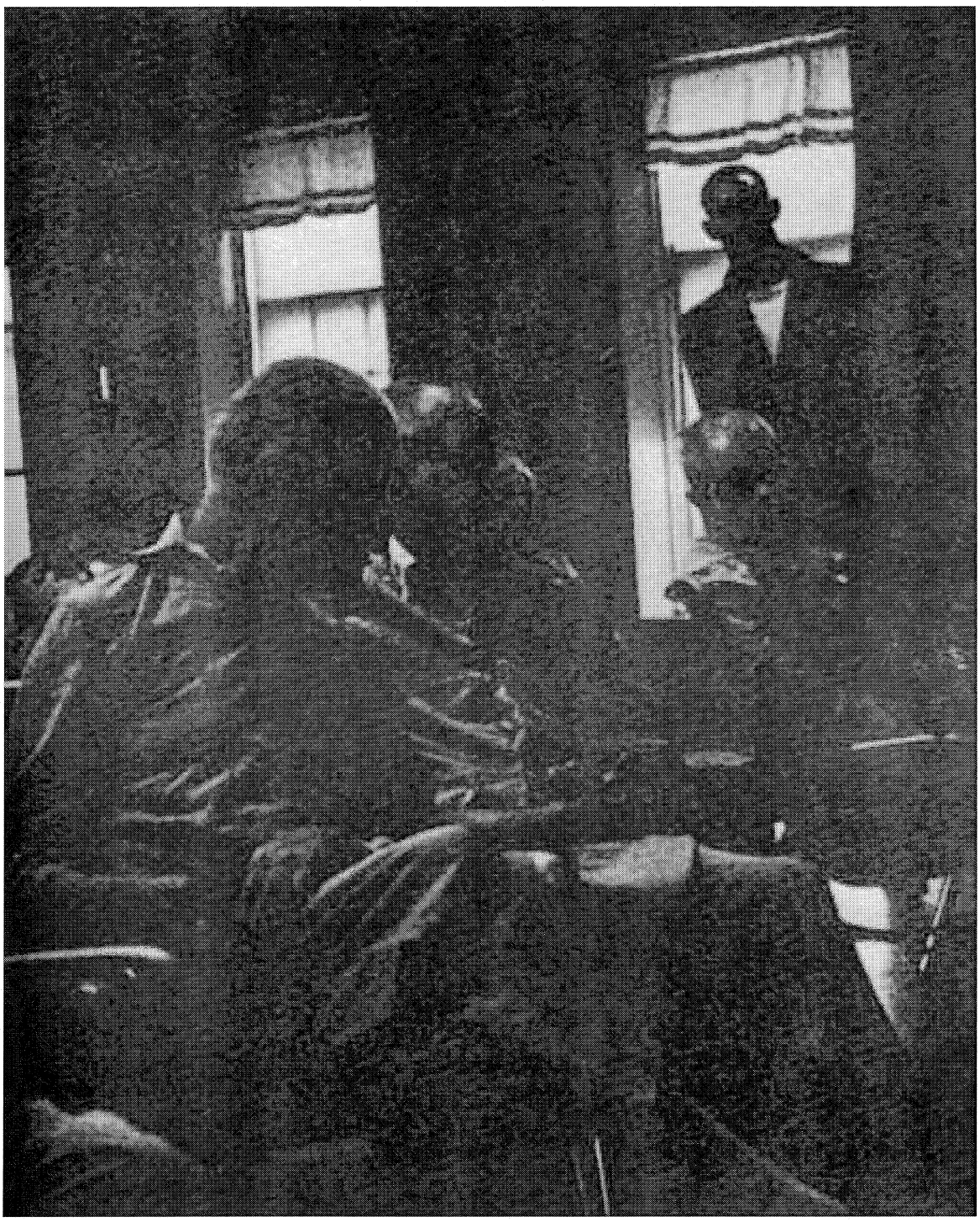
Ashley Montagu

Christmas in Purgatory

"No man is an Island, unsure of itself; every man is
a piece of the Continent, a part of the maine. . ."

John Donne

"The wretched souls..."



"Until you have become really, in actual fact, a brother to every one, brotherhood will not come to

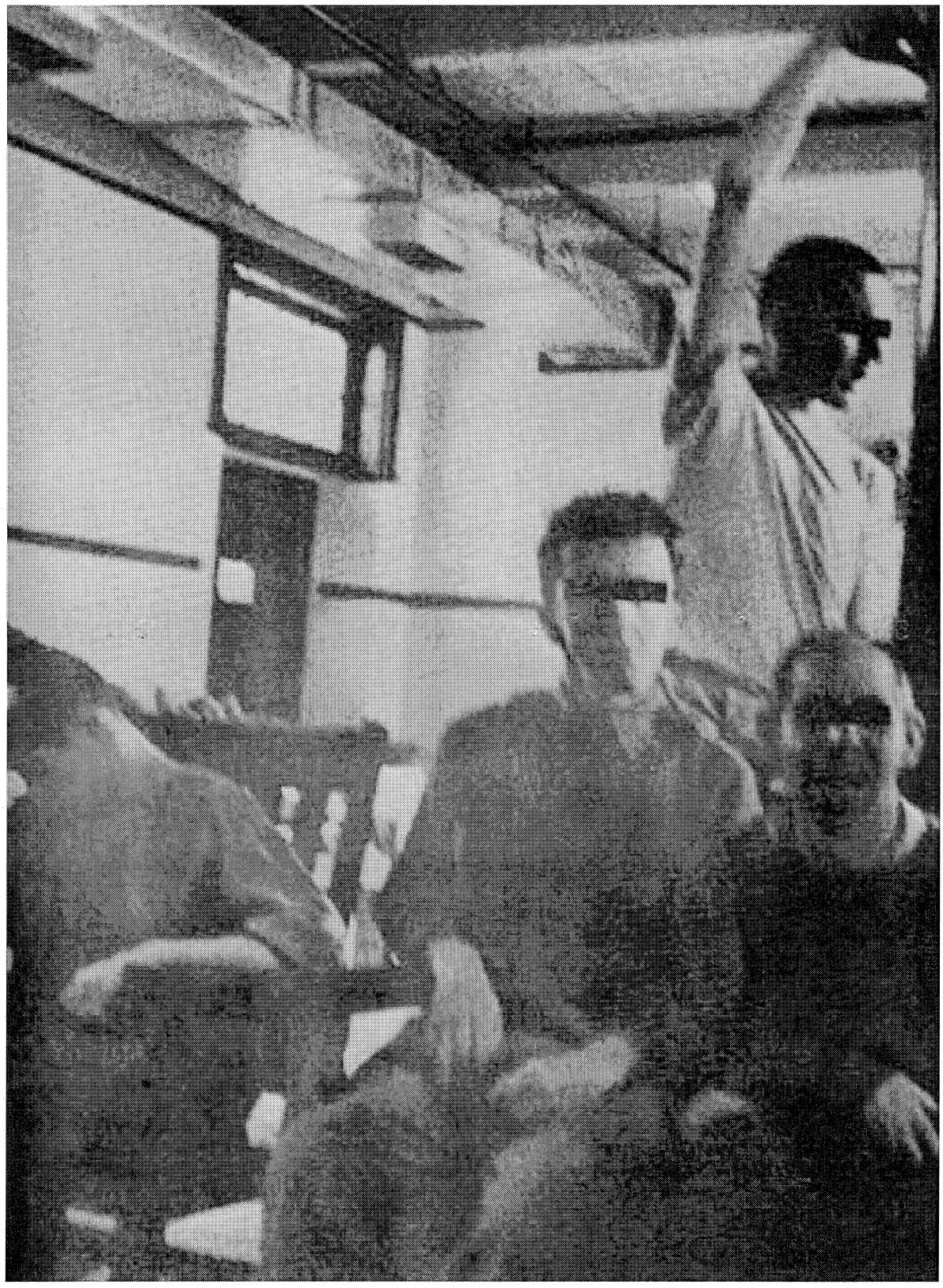
Fyodor Dostoyevsky

Christmas in Purgatory

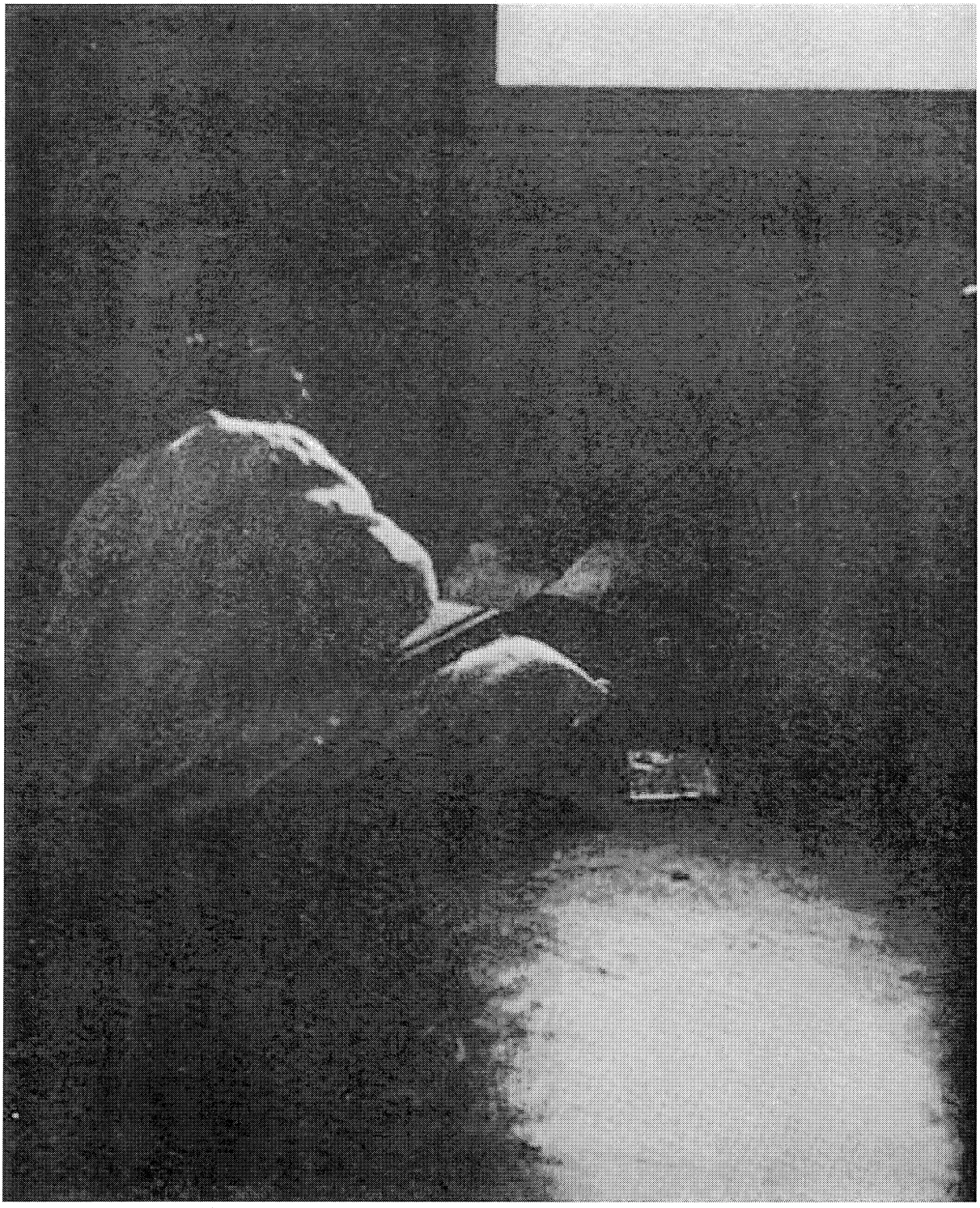
"One handicap tends to beget another."

Albert T. Murphy

"The wretched souls.. ."



Christmas in Purgatory

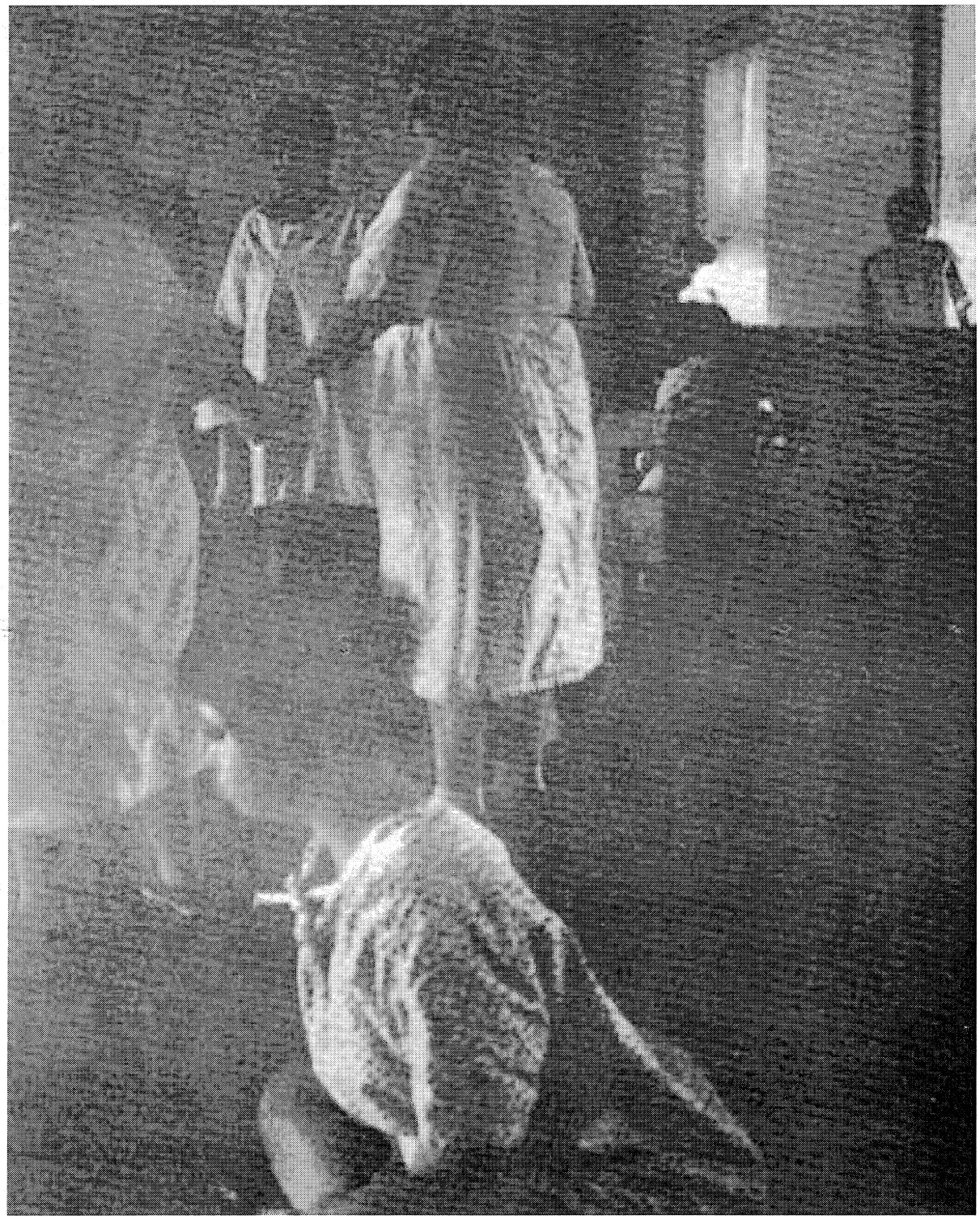


"God hath chosen the foolish things of the world to confound the wise; and God hath chosen the weak things of the world to confound the things which are mighty.

1 Corinthians I, 27

"The wretched souls.. ."

Christmas in Purgatory



"Time buries the mistakes of many school programs."

Richard H. Hungerford

PURGATORY I

"In bed we laugh..."

"In bed we laugh, in bed we cry; And, born in bed, in bed we die. The near approach a bed may show Of human bliss to human woe."

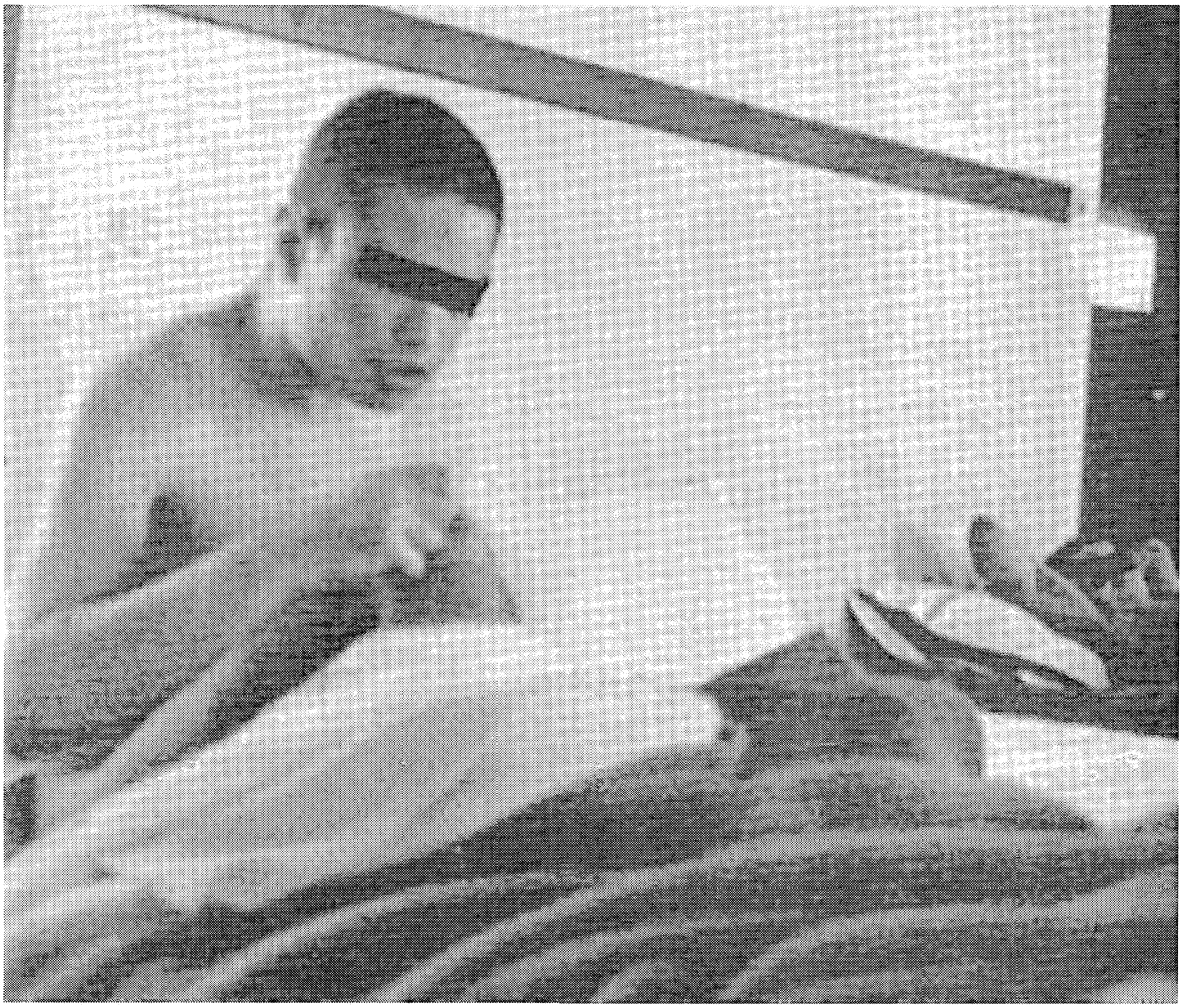
Isaac de Benserade

Among the things we will remember are the beds and the benches. Early in the evening, sometimes as early as 5 P.M., patients are put to bed. This is to equalize the work load among the different attendant shifts. During the day, we saw many patients lying on their beds, apparently for long periods of time. This was their activity.

During these observations, we thought a great deal about the perennial cry for attendants and volunteer workers who are more sympathetic and understanding of institutionalized retarded residents. One of the things we realized was that attendants might be sympathetic, might interact more with patients, if institutional administrators made deliberate attempts to make patients cosmetically more appealing. For example, adult male residents should shave-or be shaven-more than once or twice a week. Dentures should be provided for any patient who needs them. It seems plausible to believe that it is much more possible to make residents more attractive and, therefore, more interesting to attendants than it is to attempt to convince attendants that they should enjoy the spectacle of unwashed, unkempt, odoriferous, toothless old men and women.

Lastly, we viewed old women and very young girls in the same dormitories and old men and young boys as comrades in the day room. In the "normal" world, there is something appealing-even touching—about such friendships. In an institution residents would benefit by companionship from patients their own age.

"In bed we laugh..."

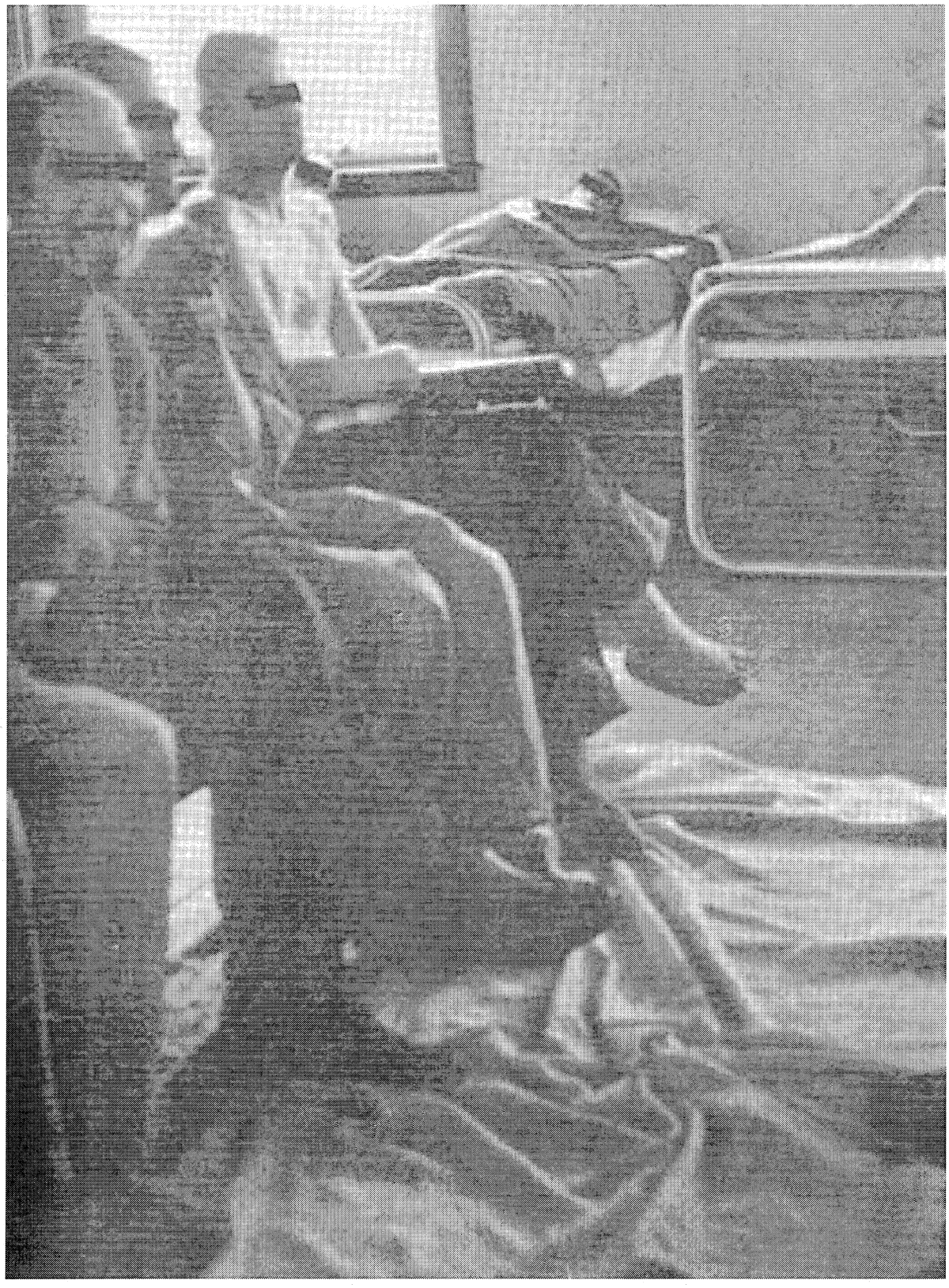


"In bed we laugh..."

Christmas in Purgatory

"Man is born unto trouble, as the sparks fly upward."
Chronicles V, 7

"In bed we laugh..."



Christmas in Purgatory

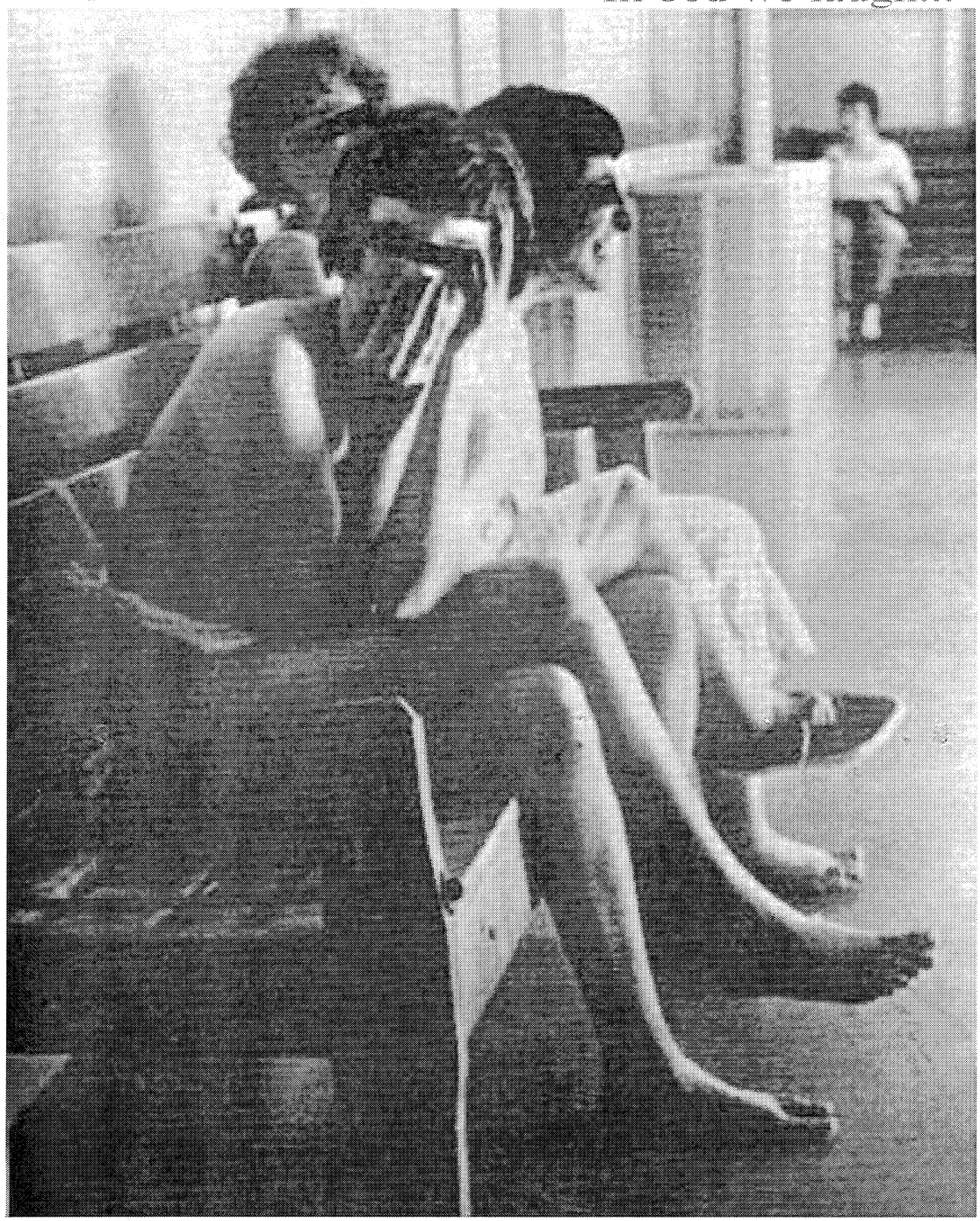
"Had I been present at the creation, I would have given some useful hints for the better ordering of the universe."

Alphonso the Learned

"In bed we laugh..."

Christmas in Purgatory

"In bed we laugh..."



"I sometimes hold it half a sin to put in words the grief I feel."

Alfred, Lord Tennyson

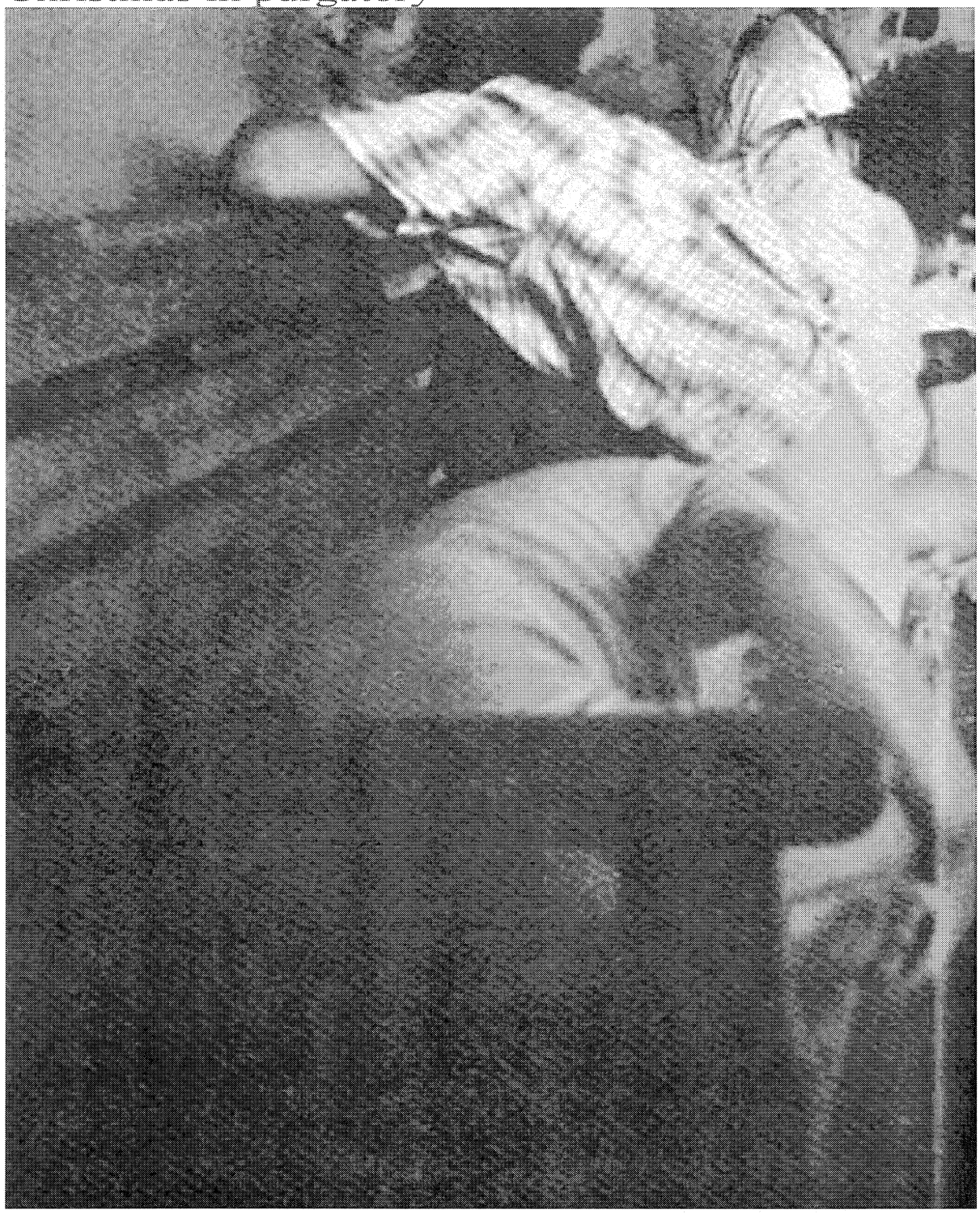
Christmas in Purgatory

" A danger of early institutional training programs was their separateness from the reality of the outside world. This was something more than the poor personal habits—unhygienic, amoral, uncouth-which breed within walls. Rather it was the unconscious furthering of irresponsibility and provincialism. For conformity and withdrawal are the bulwarks of mass management; and both are alien to the rough-and-tumble world. . ."

Richard H. Hunger ford

"In bed we laugh..."

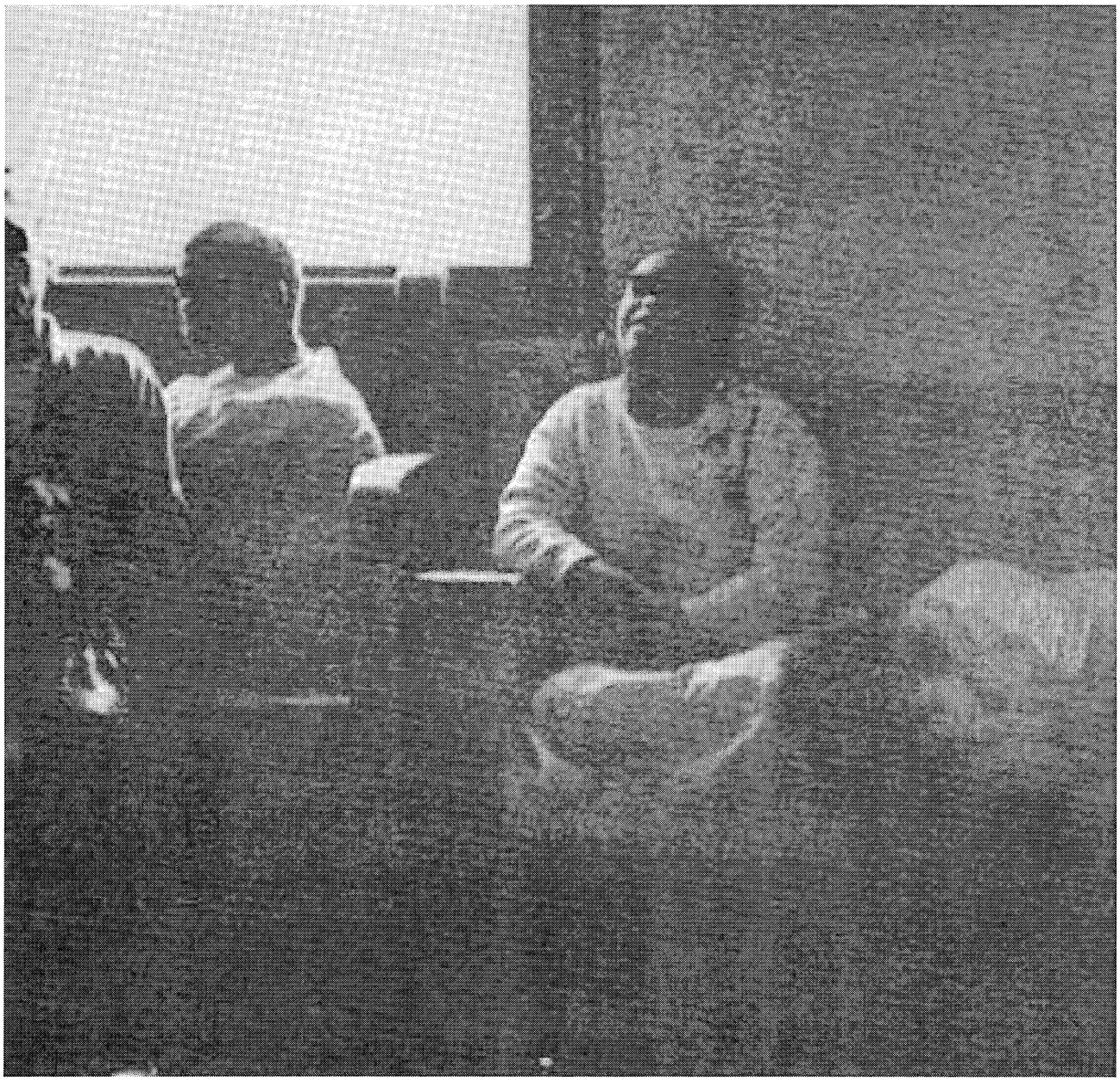
Christmas in purgatory



One may find his religion in the clinical setting

Albert T. Murph

"In bed we laugh..."



"Only the brave dare look upon the gray-upon the things which cannot be explained easily, upon the things which often engender mistakes, upon the things whose cause cannot be understood . . ."

Richard H. Hungerford

"The Promised Land..."

"The Promised Land always lies on the other side of a wilderness."

Havelock Ellis

About ten years ago, I made several trips to a large state institution for the mentally retarded, one not visited during the current study. I became interested in and, for several days, visited a dormitory housing severely retarded ambulatory adults —one that was very similar in population to those living quarters discussed in Part I. However, this dormitory was different in a very important way. What made this dormitory different can best be illustrated with the following story.

On the occasion of one such visit, I was hailed by one of the attendants and asked to come into the day room. The attendant called over a 35 or 40 year old, partly nude male and said, "Dr, Blatt, you remember Charlie. Charlie has learned how to say hello since your last visit. Charlie, say hello to Dr. Blatt." Charlie grunted and the attendant went into a kind of ecstasy that is rarely shown by adults and, when it is, radiates warmth for everyone lucky enough to be touched by it. It should not be misunderstood that Charlie's grunt resembled anything like a hello, or any other human utterance, In a way, this attendant's reaction, to Charlie might have been considered as a kind of psycho-pathology of its own. However, we have a different understanding of it.

What kind of man was this attendant? In 1938 he walked, literally off the streets, into that institution—an alcoholic, without a home of his own, purposeless and without a future — and asked for a job. For twenty-eight years he has served as an attendant in a dormitory for severely retarded patients at this institution. He knows every "boy" there and actually thinks of them as his children and they of him as their father.

Sometimes, in despair and helplessness, we ask ourselves why were these severely retarded human beings born. When one observes an attendant of the kind we have just described, it is possible to find an answer. If not for the mentally retarded this attendant might have been a drifter, an alcoholic, much less of a person than he actually is. Would it be unfair to say that this attendant needed mental retardation in order to fulfill his own destiny and obtain the greatest good he could render to society?

Mental retardation can bring out the best in some people —as well as the worst. At The Seaside, it brings out the best in a lot of different adults who are involved professionally, inter-personally, and tangentially, with the residents. The Seaside has more of the people of the kind we have just discussed, than do other places for the mentally retarded-notwithstanding the fact that every institution, large as well as small and those discussed in Part 1 as well as The Seaside, has superb and dedicated attendants and professional staff as well as its quota of mediocre and poor staff. In our opinion, The Seaside has more superior personnel and fewer of the inefficient and disinterested. We believe this is a major difference between The Seaside and other institutions for the mentally retarded.

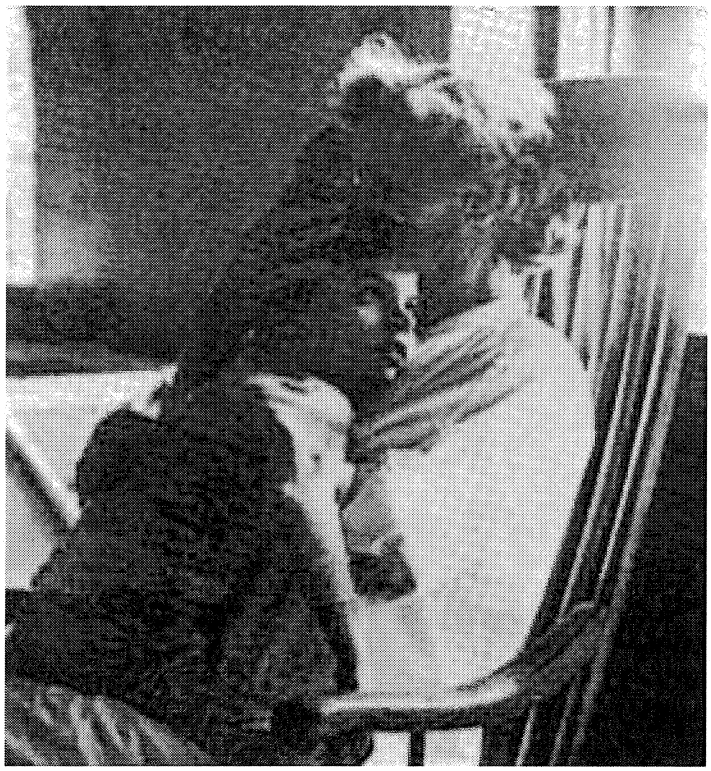
The following portion of a report, written by a Seaside nursery teacher, concerning a child with whom she is working, speaks volumes about such matters as clinical sensitivity, thoughtful-ness, and the value one human being is capable of placing another. The investment and dedication of one person to another is the significant history of any case study illustrating behavioral change:

> She came into our Day-Care a fiery-haired five-year old with a temper the same shade. Cerebral palsied, and unable to talk, she lashed out at an unfair world with an unspeakable fury. Torn by the mixed emotions of her parents who had alternately spoiled and dis-

ciplined her, this extremely sensitive child seemed beyond control when she entered our little group. The hurricane raged for several weeks while I probed all the recesses of my mind to find the eye of the storm. We learned to duck with agility all that she threw, to keep a level head, and to follow, with the strictest adherence, a routine designed for the comfort and growth of all the children. We ignored her nonconformities. Her actions, for all intents and purposes, were not getting through to me. Furthermore, they were not impressing her classmates.

All this time she watched me. She wanted me to be angry too for this was her trick in trade. Oh how I wanted to spank her for her tirades and inconsideration but I did not because this procedure would be old hat to her.

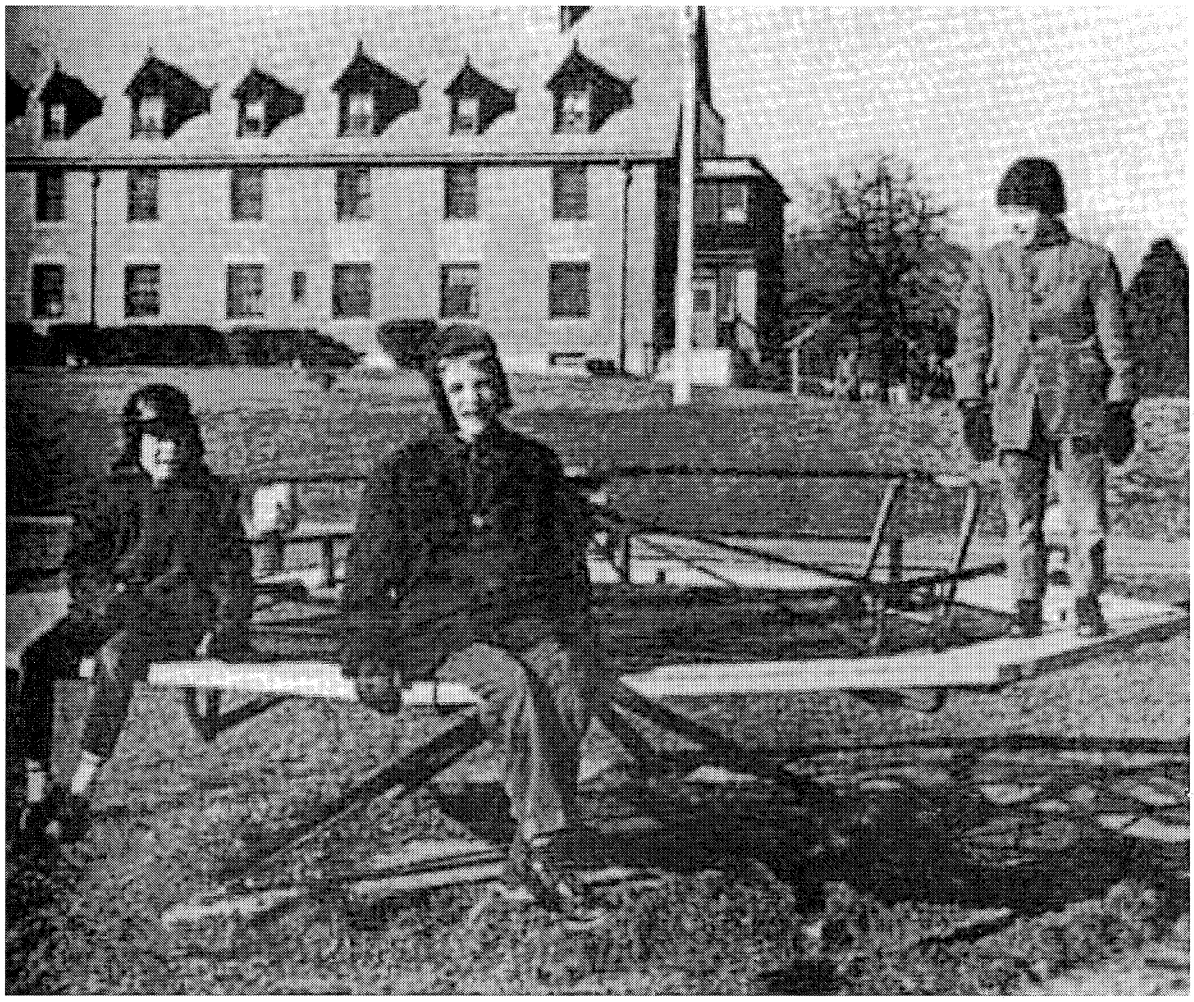
One day I was particularly tired and discouraged and she must have sensed something amiss. Spilling milk is not unusual in a preschool situation, but our little firebrand made a last stand. She threw her milk at me with deadly accuracy. I sat stunned for a minute. As the milk dripped from my hair, I deliberated-one false move could undo everything. I felt an angry tear in my eye. She looked at me, her face red and contorted with emotion. I didn't move. Suddenly, she staggered from the room. Still I sat, knowing I must take some action. A few moments passed, She came running back into the room, hands dripping with wet paper towels. I didn't move. She smoothed back my hair and wiped my face and clothes with erratic, awkward hands. She had suddenly dissolved into a compassion she failed to comprehend because she had never needed it; it was a brand new experience. Involuntarily my arms went out and she flew in.



Christmas in Purgatory

"The mentally retarded continue to be the least of the last minority in the United States — the least understood, the most different, the least appreciated. Still it 'seems probable that, in the words of Voltaire, 'Their time has come.' and, in spite of the ignorance and general indifference of the public, the lot of the retarded is looking upward."

Richard H, Hungerford



"Cultural and educational deprivation resulting in mental retardation can also be prevented."

John Fitzgerald Kennedy

Christmas in Purgatory

"Can we ever have too much of a good thing?"

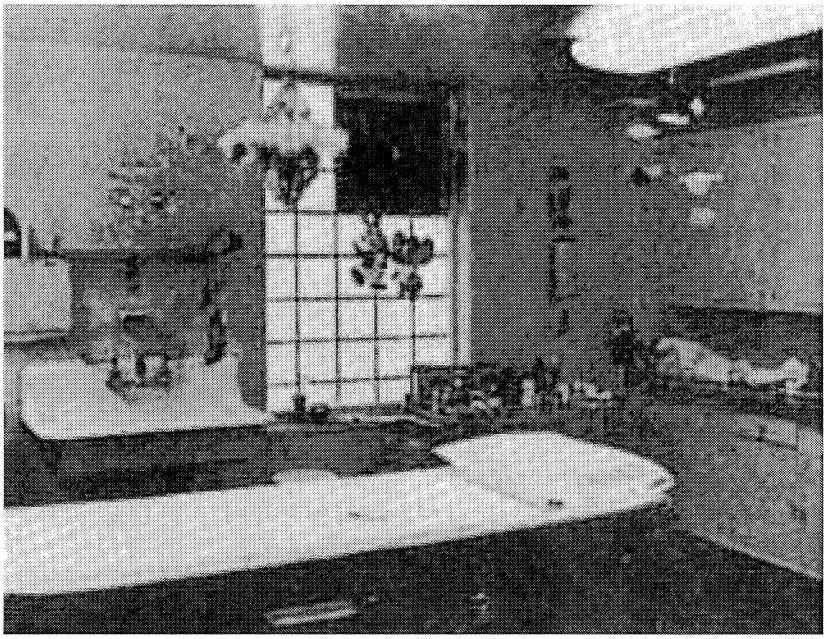
Miguel de Cervantes

"The Promised Land.. ."

"What would man be without Utopia? He must aim at the unattainable in order to realize the attainable and to make one step forward."

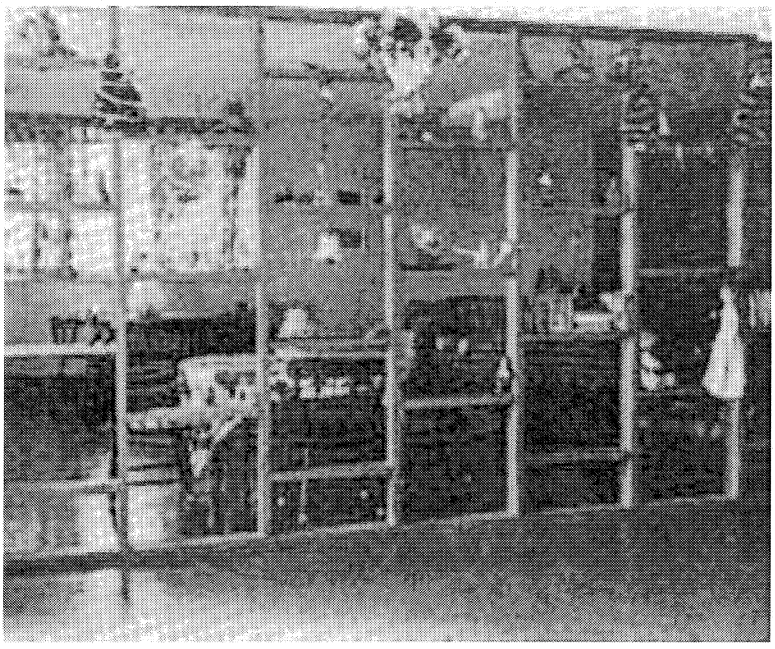
Thomas Mann

Christmas in Purgatory



"The wheels of humanitarianism never grind as fast as when they are aided by utilitarianism."

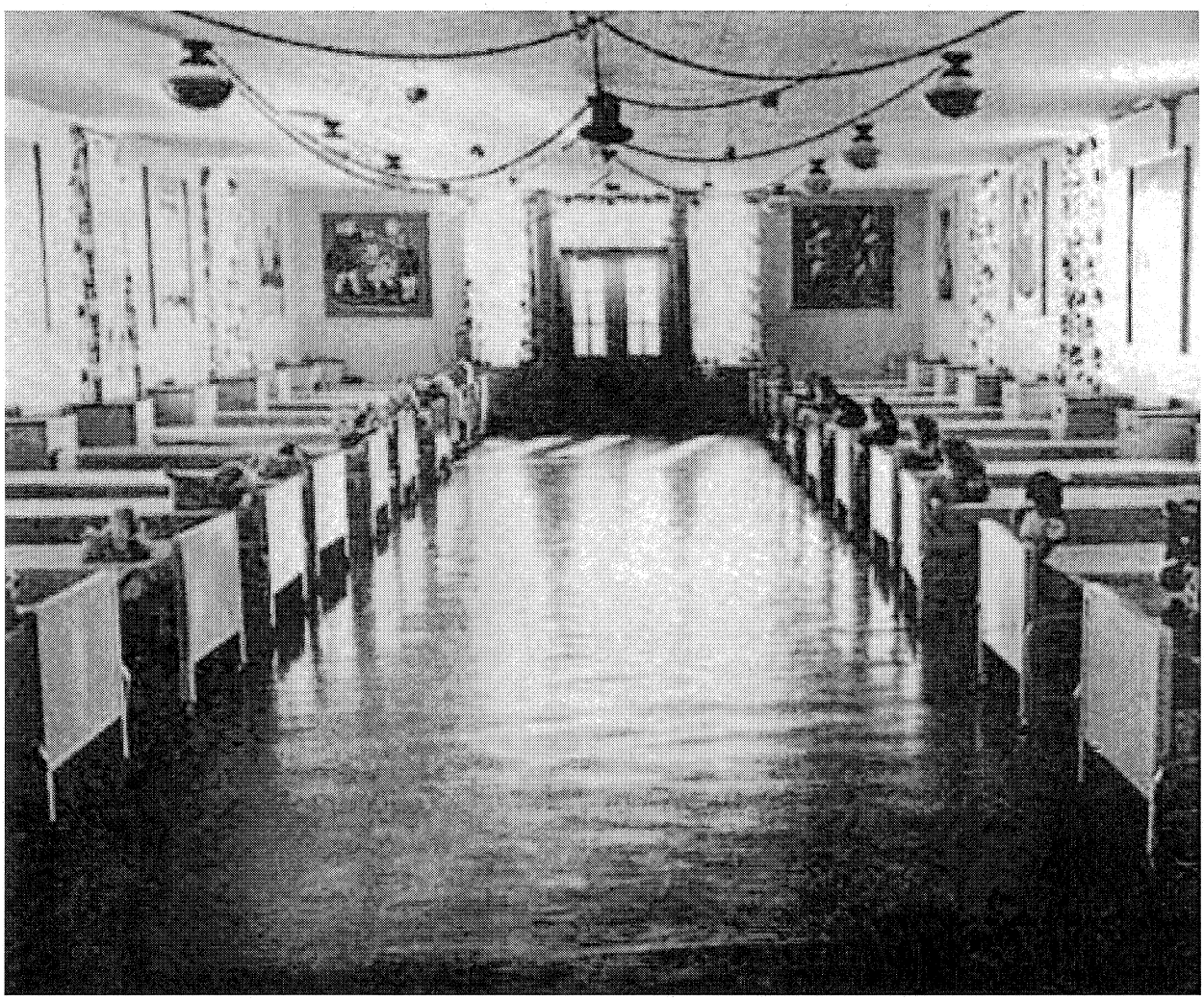
Richard H. Hungerford



"At Christmas play and make good cheer For Christmas comes but once a year,"

Thomas Tusser

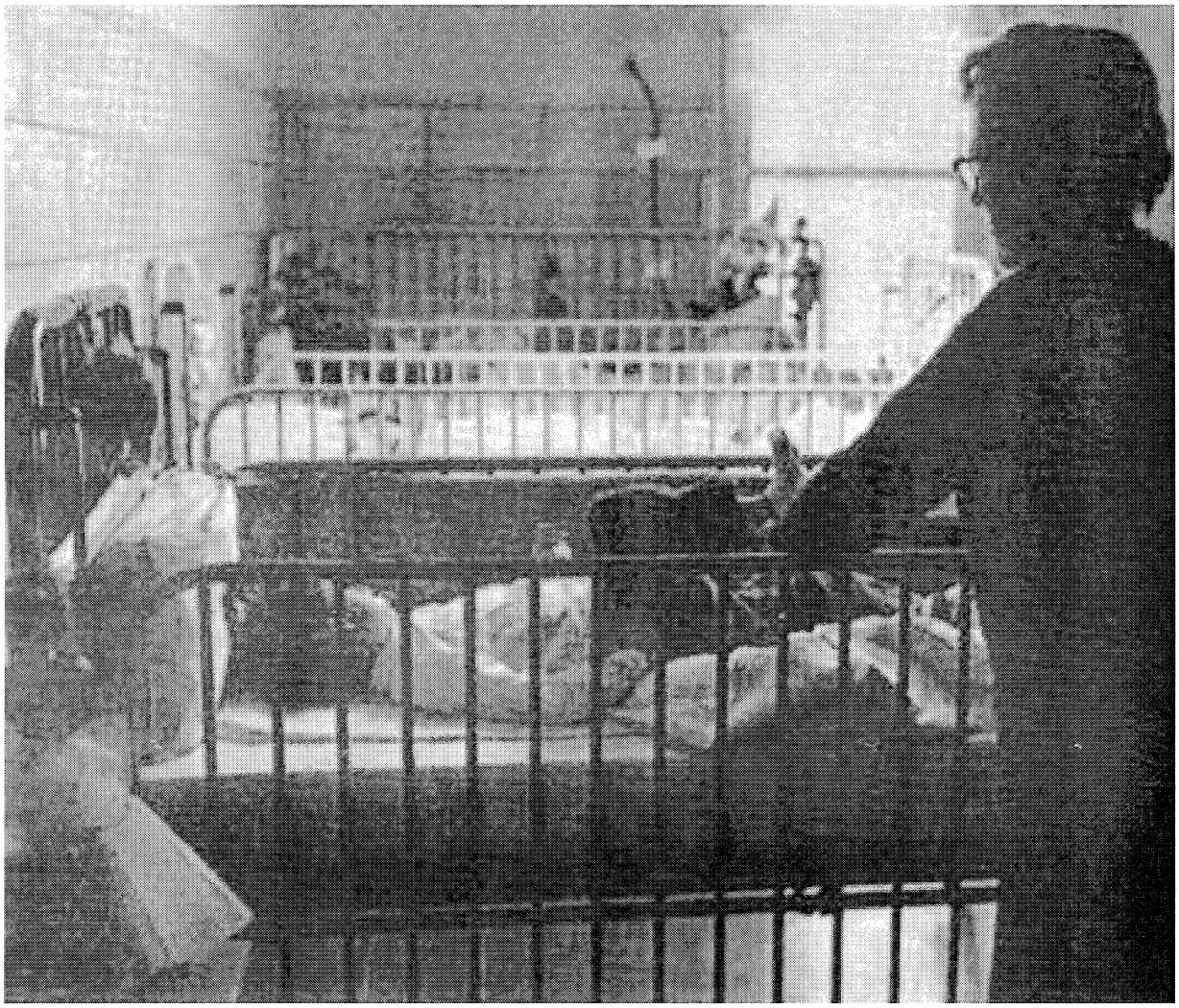
"The Promised Land..."



"During the eighteenth century the plight of the mentally ill was shocking almost everywhere in Europe. flighty, troublesome or dangerous patients were restrained and kept in a small room or stall in a private house, in 'lunatic boxes,' in cages or in other places of confinement that seemed appropriate for isolating them and rendering them harmless as a result of poor supervision, many committed suicide, perished through accidents or created serious disturbances. The tense and exasperating environment thus created and encouraged the establishment of the strictest preventative measures."

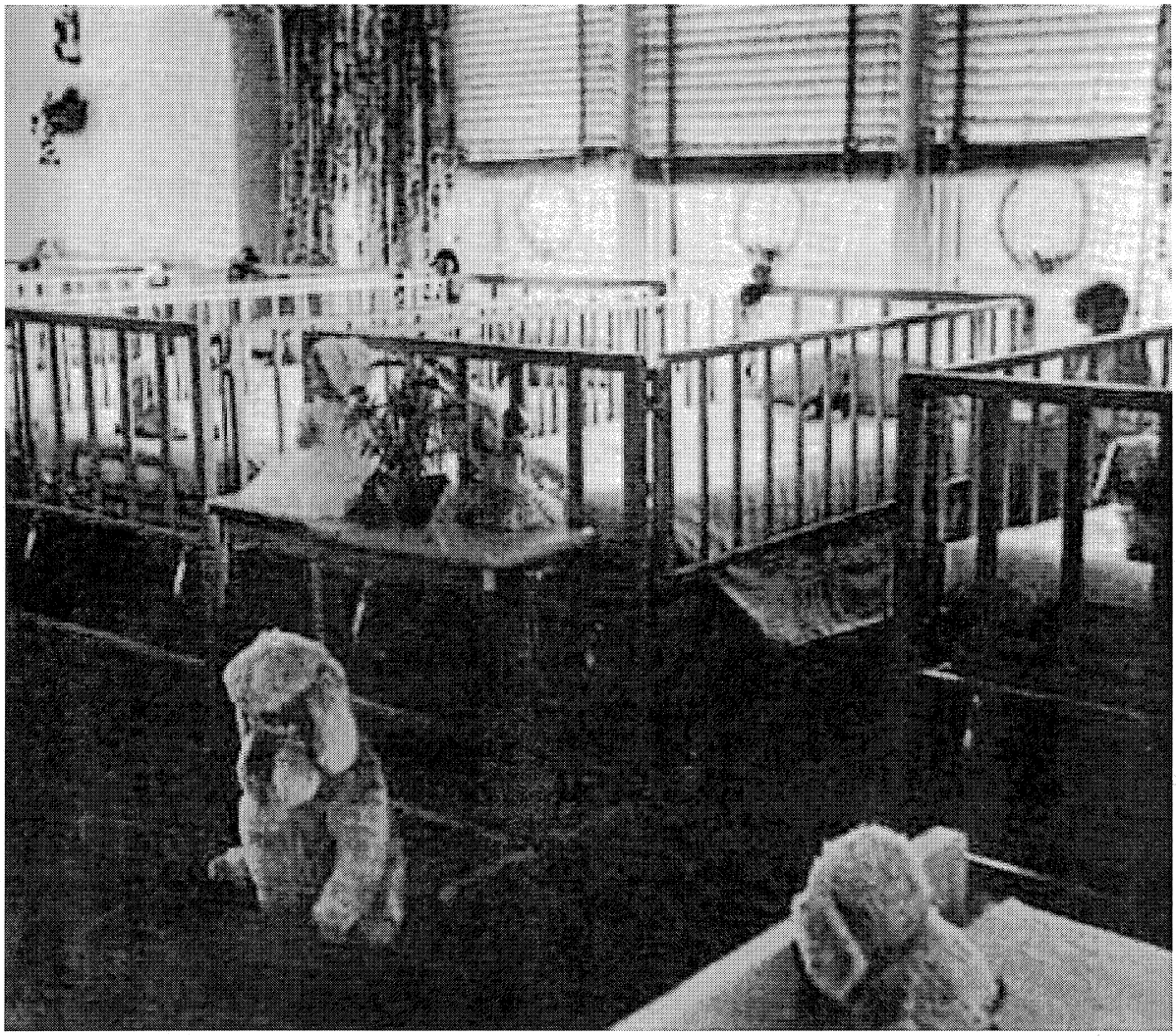
Emil Kraepelin

Christmas in Purgatory



Christmas in Purgatory

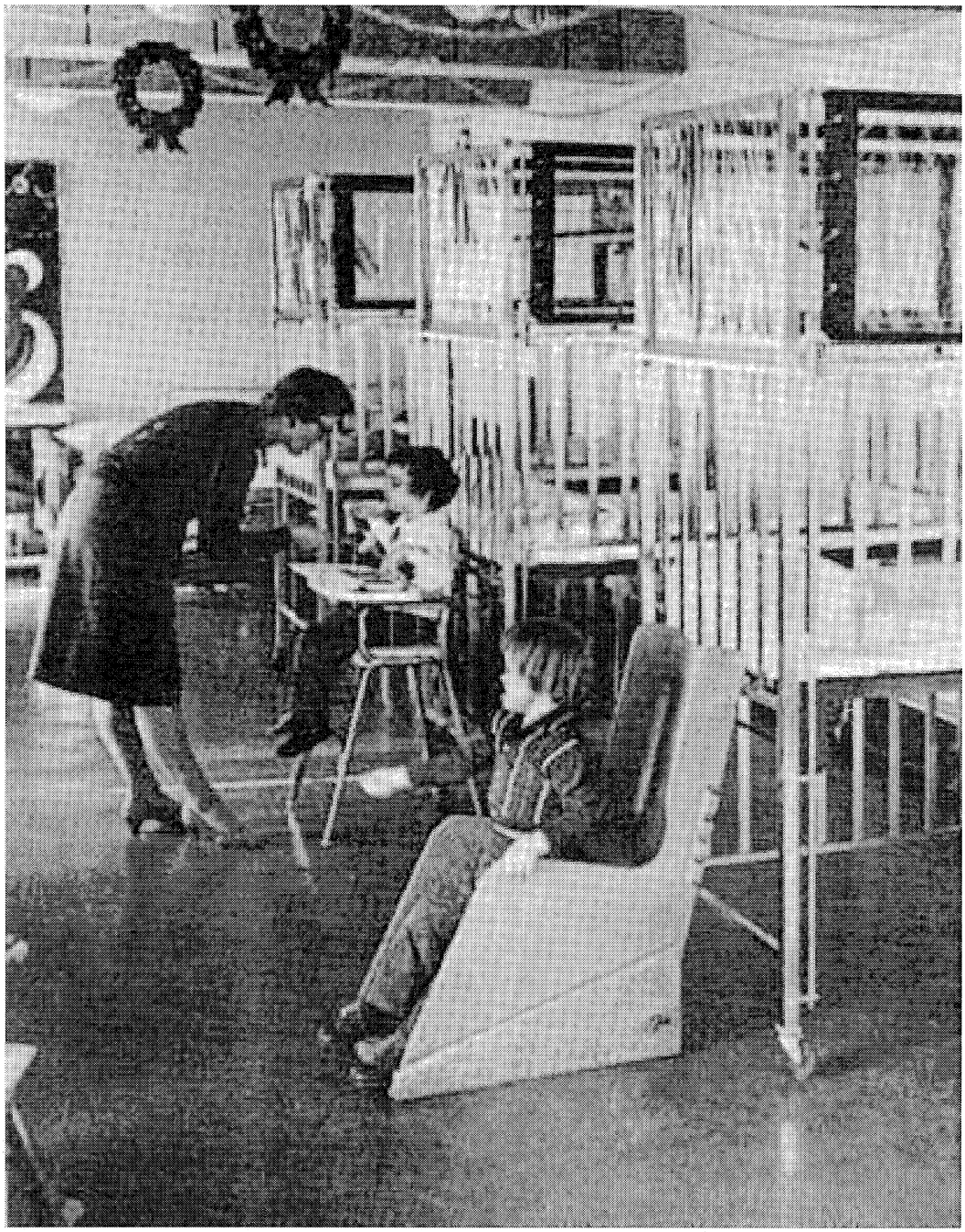
"The Promised Land..."



"Those who visited Bedlam in London in 1814 could see countless patients clad only in loose shrouds and chained by their arms or legs to the wall in such a way that they could stand upright or remain seated. One patient for 12 years wore rings around his neck and waist and was tethered to a wall; because he had resisted attempts to control his movements by means of a chain manipulated from a neighboring room, the warden had also taken the precaution of lashing his arms to his sides. An administrator explained that chains were the surest device for restraining recalcitrant mental patients. Even Dr. Monro stated in response to an investigating committee of the House of Commons that no one dared use chains on noblemen, but that they were indispensable in dealing with the poor and with those in public institutions."

Emil Kraepelin

Christmas in Purgatory



"Have you had a kindness shown? Pass it on."

Henry Burton

"We have developed a myth..."

"We have developed a myth revolving about the specialness of our curricula efforts to date. In some important ways, there is as great a myth concerning the specialness of the children the curricula seek to serve."

During one visit to a large state institution discussed in Part I, we were told about the development of a new research center on the institutional grounds. The assistant superintendent mentioned to us that the "materials" for the research center would come from the institution and this center would require the addition of approximately 30 or 40 "items." We were confused by the statement and, as a result of some verbal fumbling and embarrassment, we finally understood. At that institution, and apparently at others in that state, patients are called "material" and personnel are called "items."

It was so difficult not to believe that this assistant superintendent was "pulling our leg" with his terminology that during our subsequent visits to dormitories in that institution we asked the attending physician "How many items do you have in this building? How much material do you have?" To our amazement, he knew exactly what we were asking for and gave us the numbers immediately.

The Seaside does not deal with "material" and "items." The Seaside is a small institution of approximately 250 residents and somewhat over 100 staff. As importantly, the Center services the community where it is located. Many children and adults living at home with their families attend preschool classes, recreation groups, sheltered workshops, and other activities sponsored by the institution. The uniqueness of The Seaside results from an extraordinarily dedicated and involved staff in a setting small enough for every child-care worker —as well as every teacher, nurse, and administrator —to know each child in the institution, and vice versa.

At The Seaside there is time, time for teaching a young child to use a spoon or fork, time for helping a child learn to use a zipper, time to heal a wound-physical or emotional. But there is no time for tomorrow at The Seaside. There is a fight against inertia. Children must be helped today, for in too few tomorrows children become adults and residents become inmates.

At The Seaside there is schooling. Some children attend school at the institution. The older and more capable youngsters attend public schools with other children who are living at home. The environment is designed for children. The lawns are filled with swings and jungle gyms and bicycle paths. During Christmastime, each room is decorated welcoming Santa Claus and the spirit of Christmas. Rooms are clean and orderly. Furniture is designed for children. Furniture for adults is designed for adults.

There are adult residents at The Seaside, but not in the same dormitories, and programs for adults are also separate. Adults have different needs and the following may illustrate how some of these are met.

One of our difficulties in photographing activities at The Seaside was our inability to take very many pictures of adult residents. Most of the adults at The Seaside are working during the day, on institutional jobs or out in the community. Some, who could not be returned to their own homes, live in a work training unit. Here they are with friends and co-workers under the careful supervision of a cottage mother and father. During the day they are on placement-working in the community —and in the evening they return to their "home" where they can receive special help and guidance in their successful attempts to integrate into normal communities and become contributing and useful members of society.

"And had a face like a Blessing." Miguel de Cervantes

"We have developed a myth. . ."

Christmas in Purgatory

"Youngsters are often not taught to feed themselves; it is easier to drape a sheet around their shoulders and arms and spoon feed them. They are often not given furniture or toys or help; they might get hurt. The meticulous attention paid to their corporal protection is in sharp contrast to the frequent failure to recognize those important aspects of personal dignity or feeling."

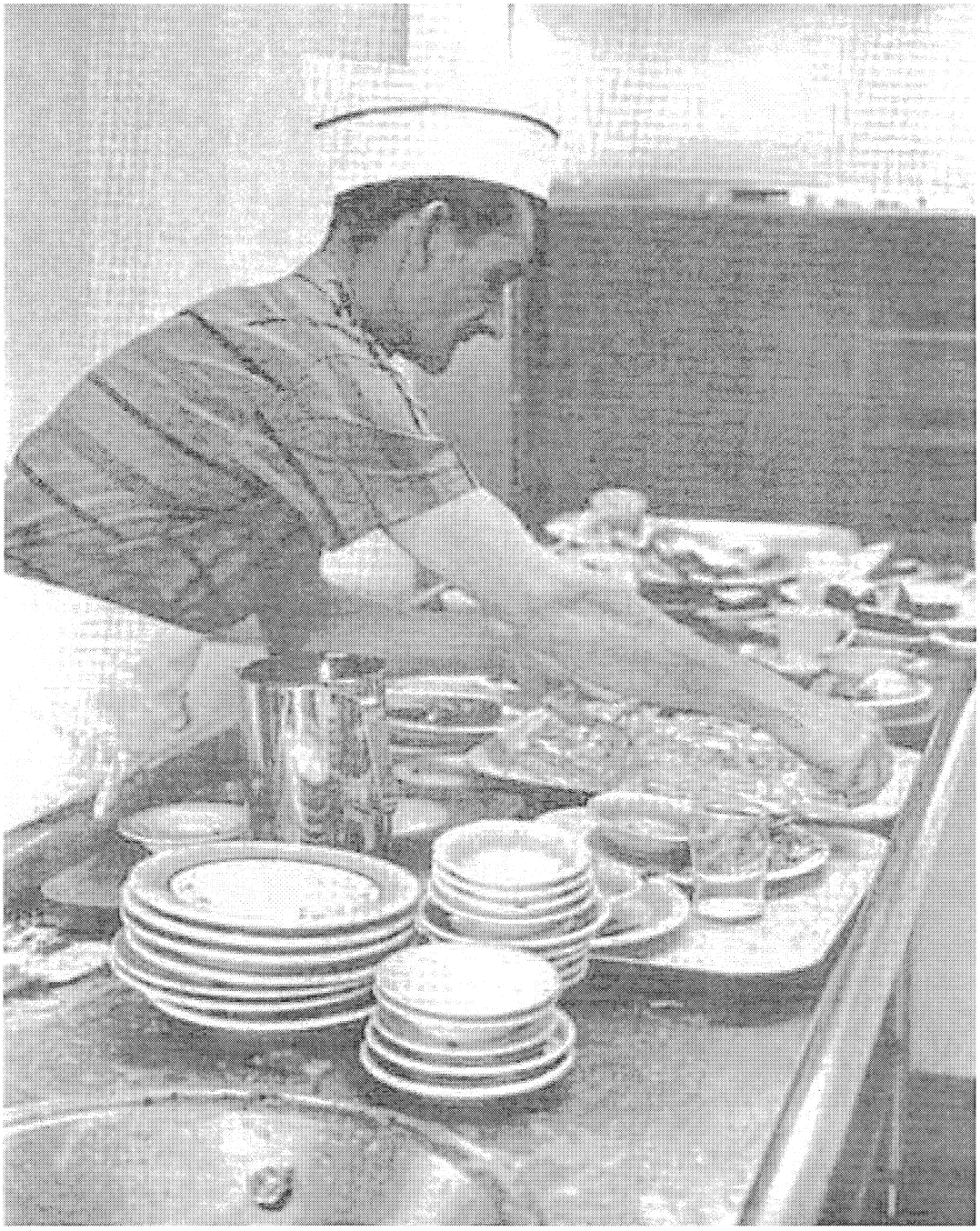
Lewis B. Klebanoff

"We have developed a myth..."

"Before we start experimenting it would be wise to find out what occurs in the natural situation."

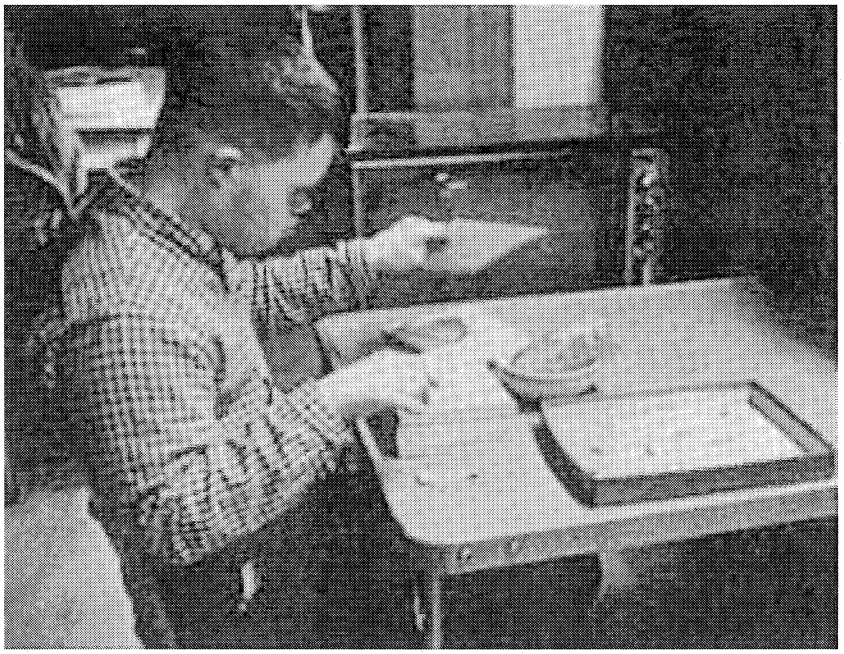
Seymour B. Sarason

"We have developed a myth..."



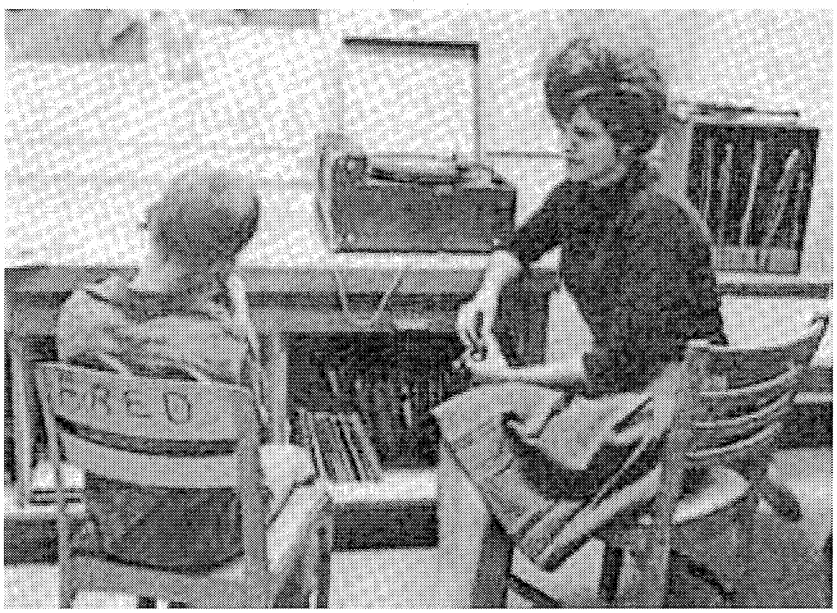
"The greatest discovery of my generation is that human beings can alter their lives by altering their attitudes of mind."

William James



"Genius, that power which dazzles mortal eyes, Is oft but perseverance in disguise."

Henry Willard Austin



"As with the child, the clinicians most important creation is himself."

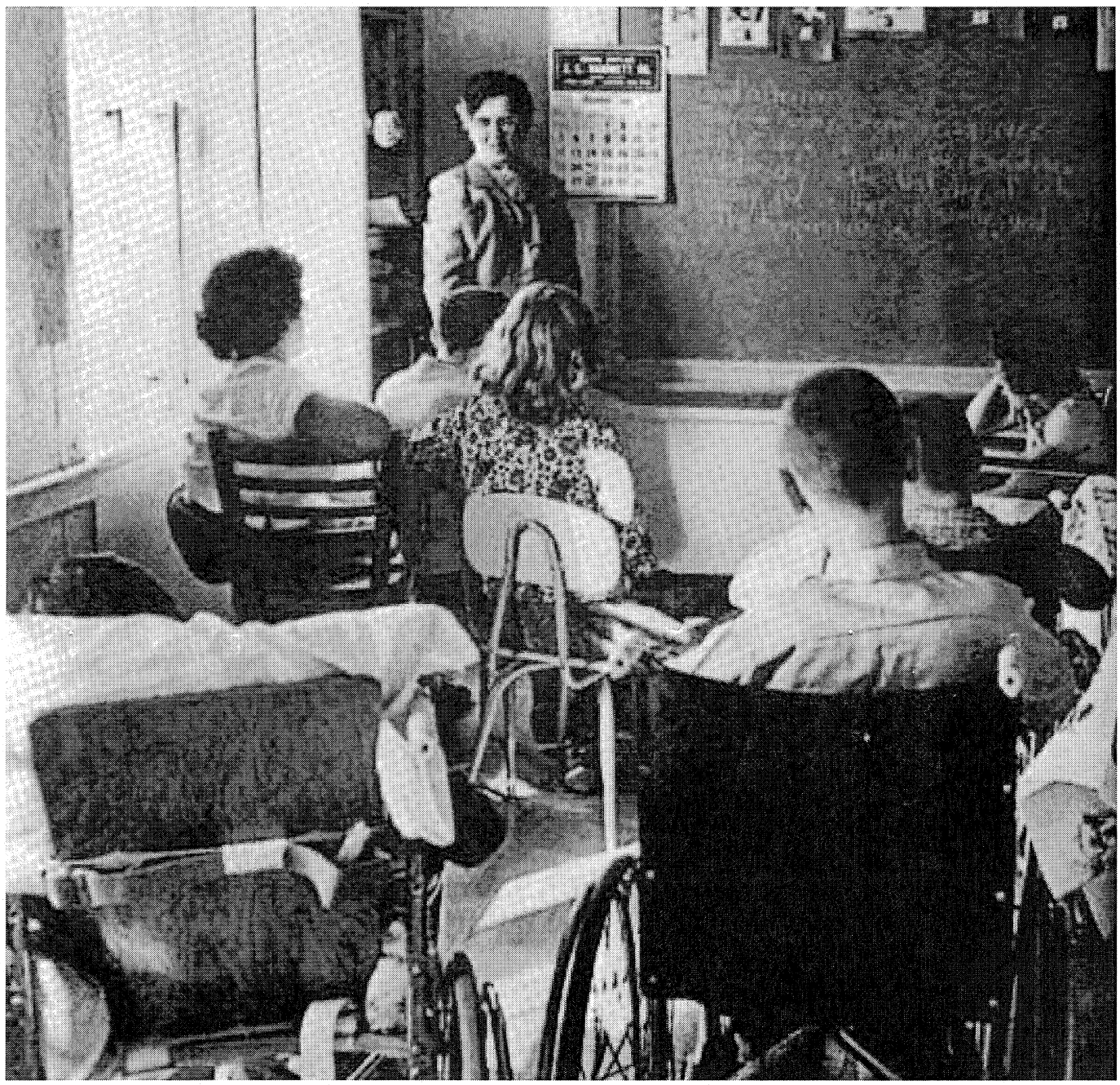
Albert T. Murphy

"We have developed a myth..."

"It is clear that there should be legislation about education and that it should be conducted on the public system. But consideration must be given to the question, What constitutes education and what is the proper way to be educated? "

Aristotle

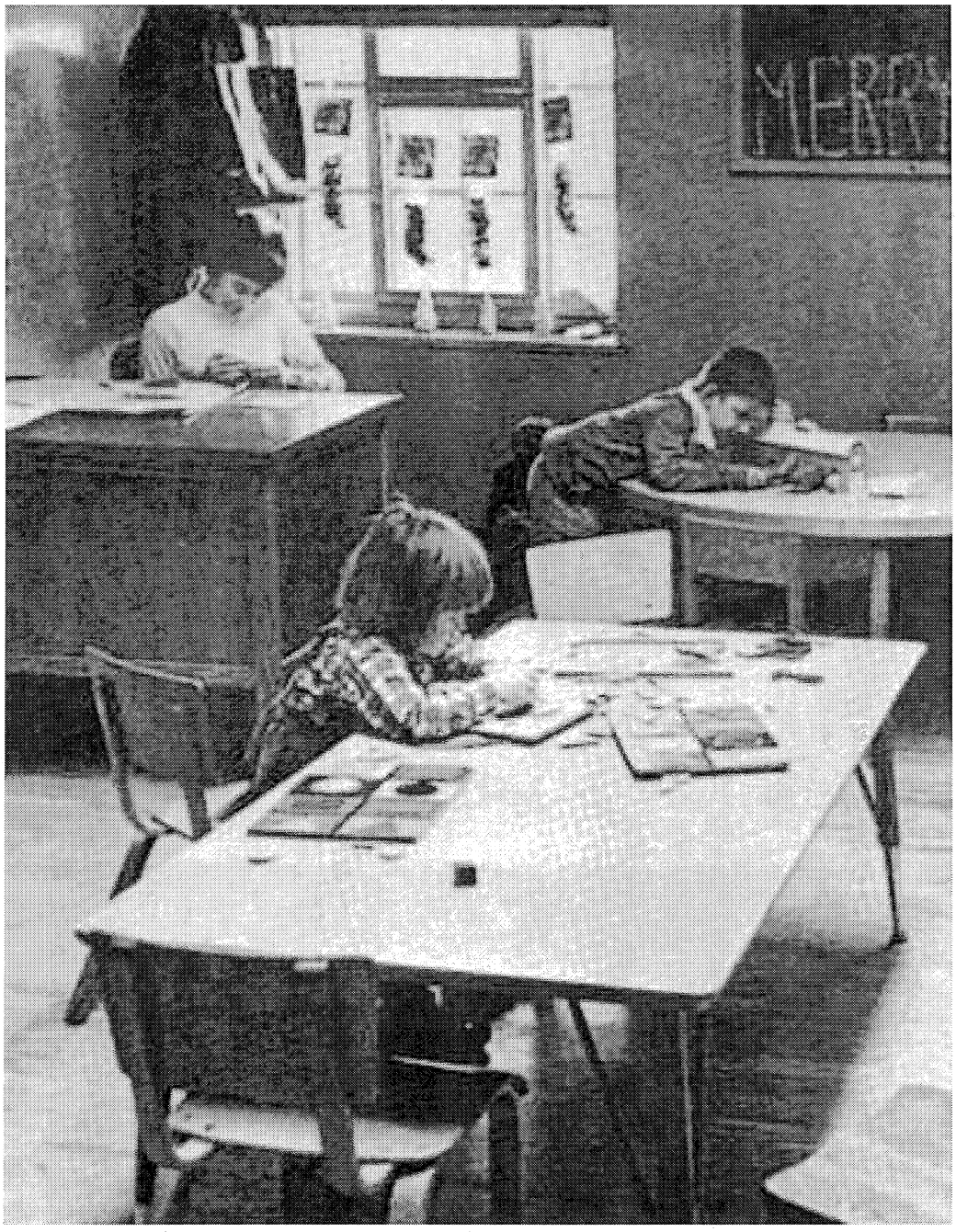
Christmas in Purgatory



"I was eyes to the blind, and feet was I to the lame."

Job XXIX, 15

"We have developed a myth..."

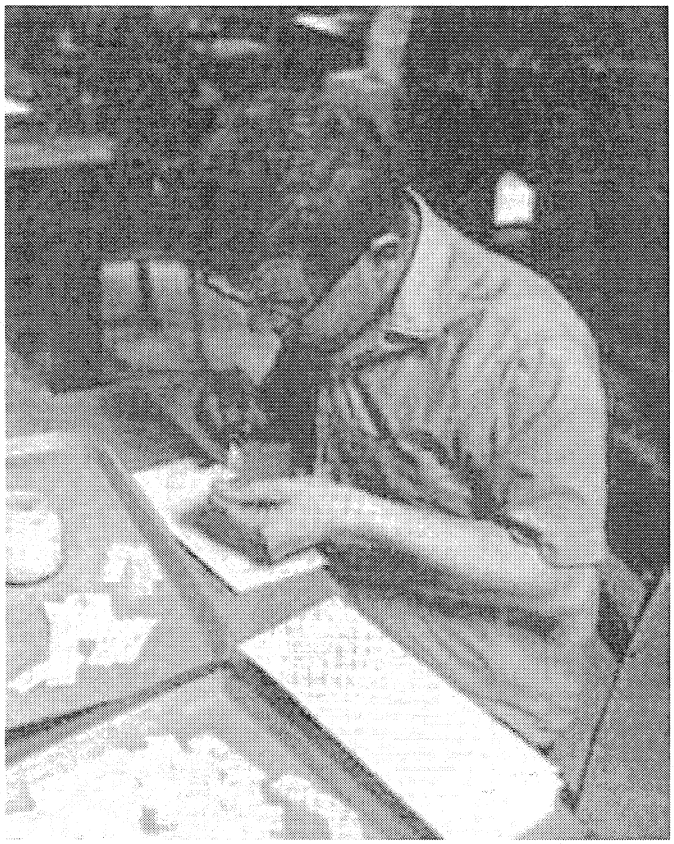


"A teacher who makes little or no allowance for individual differences in the classroom is an individual who makes little or no difference in the lives of his

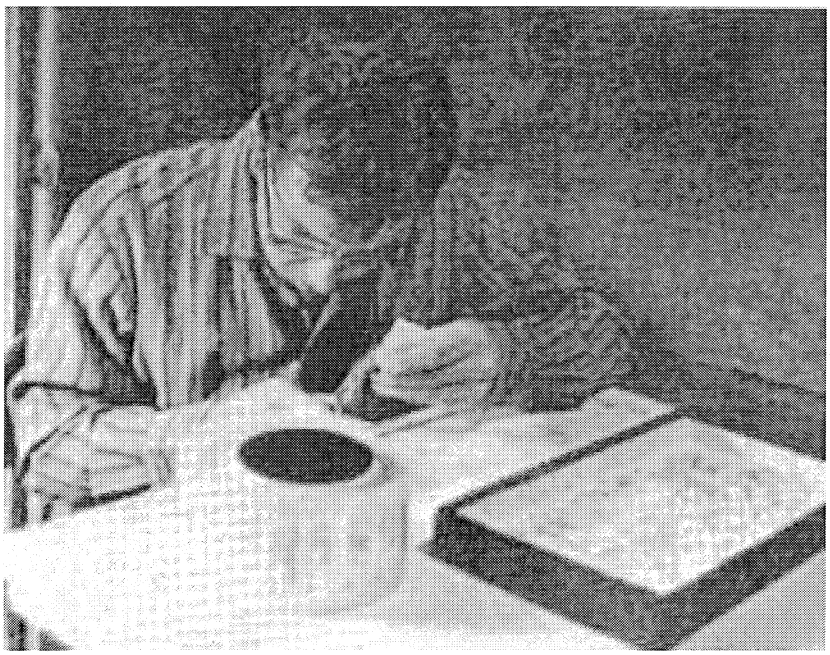
William Arthur Ward

Christmas in Purgatory

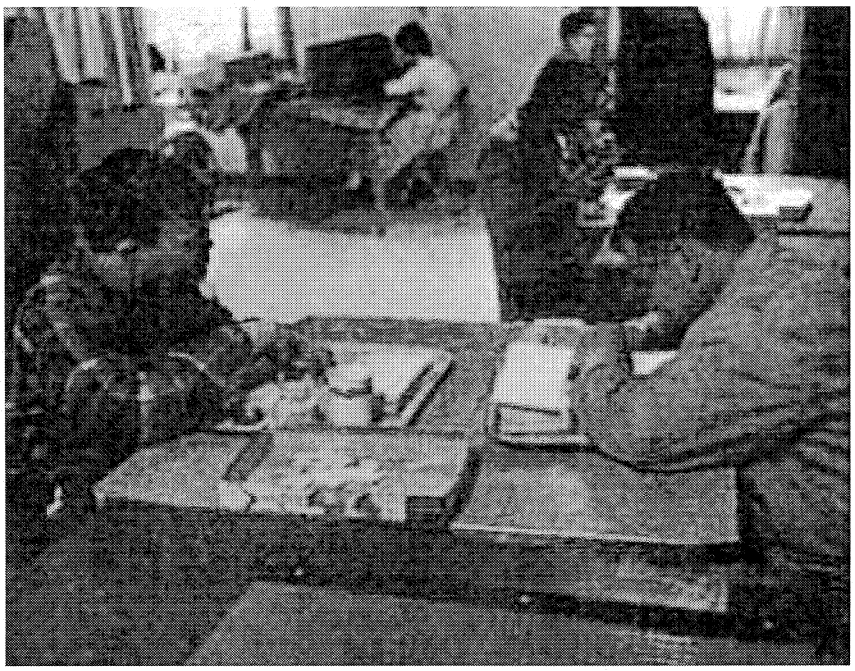
We have developed a myth. . ."

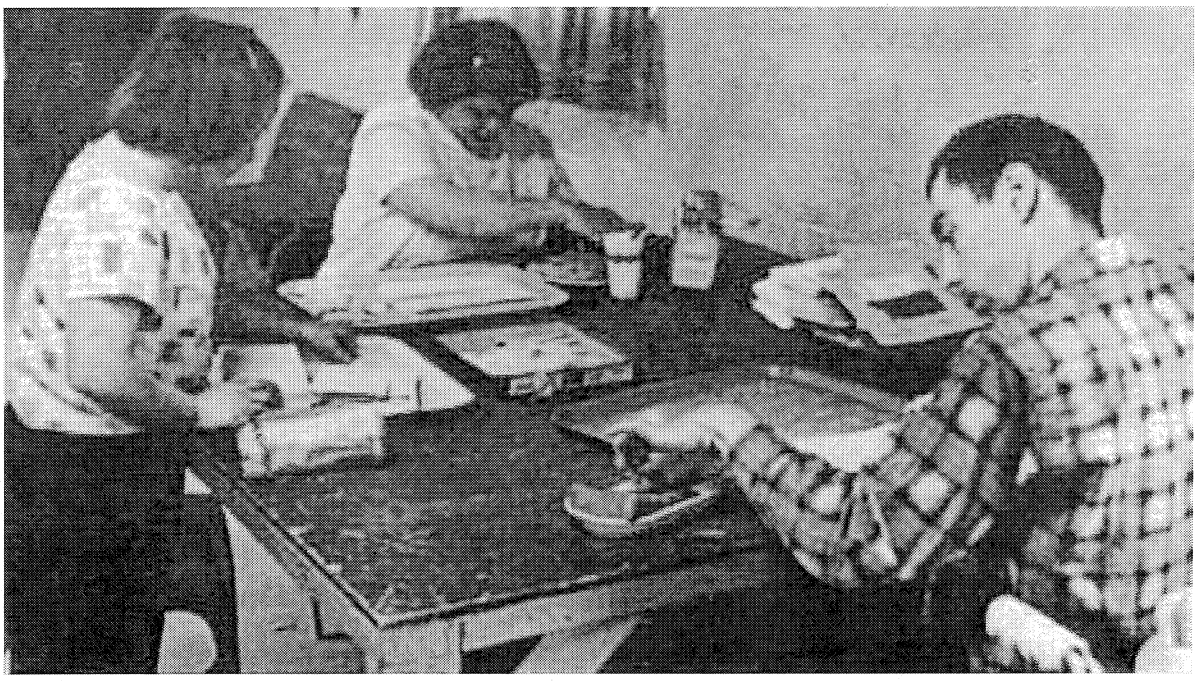


"Love is believing in the fulfillment of another human being."



"We have developed a myth.. ."

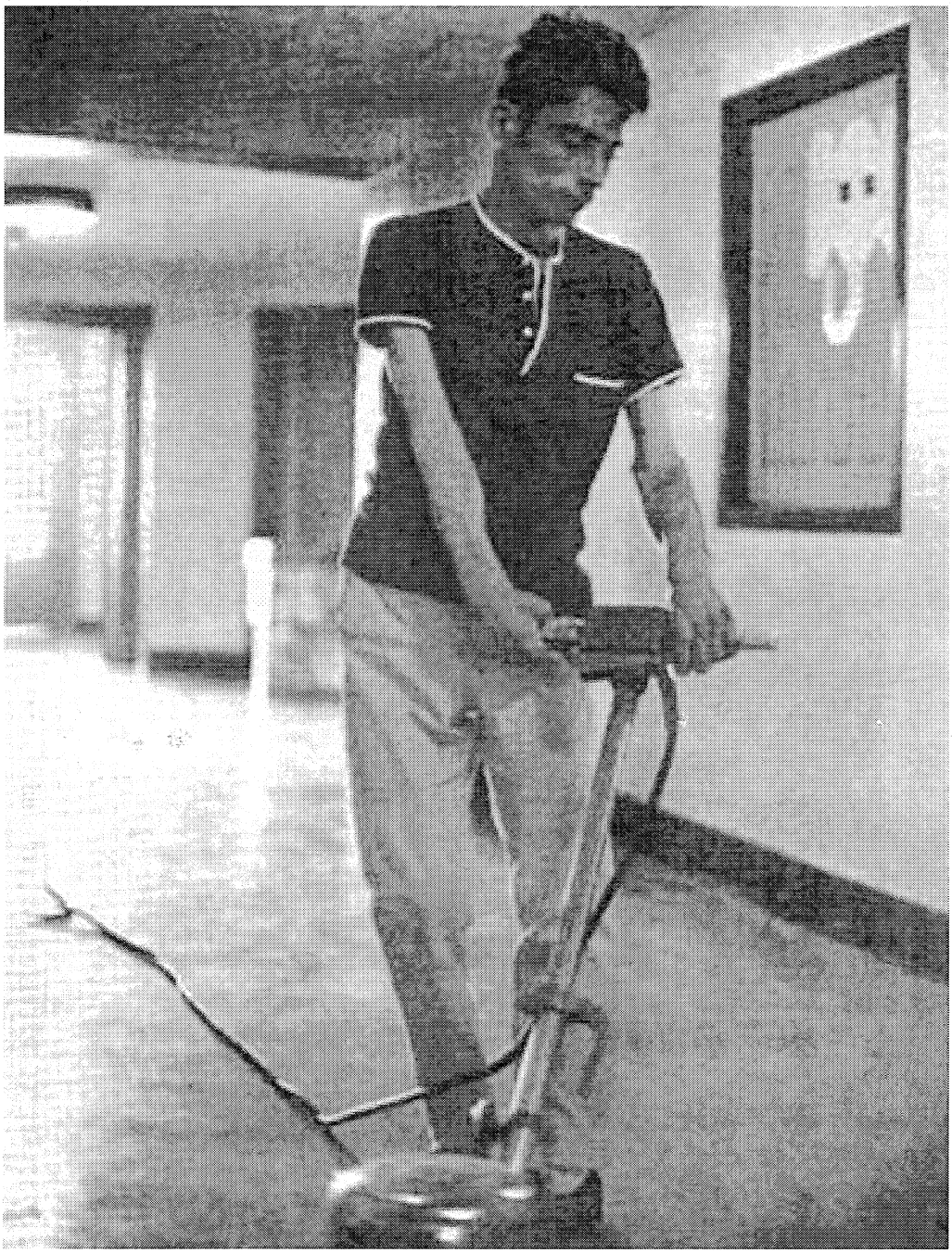




Christmas in Purgatory

"We have developed a myth,.. "

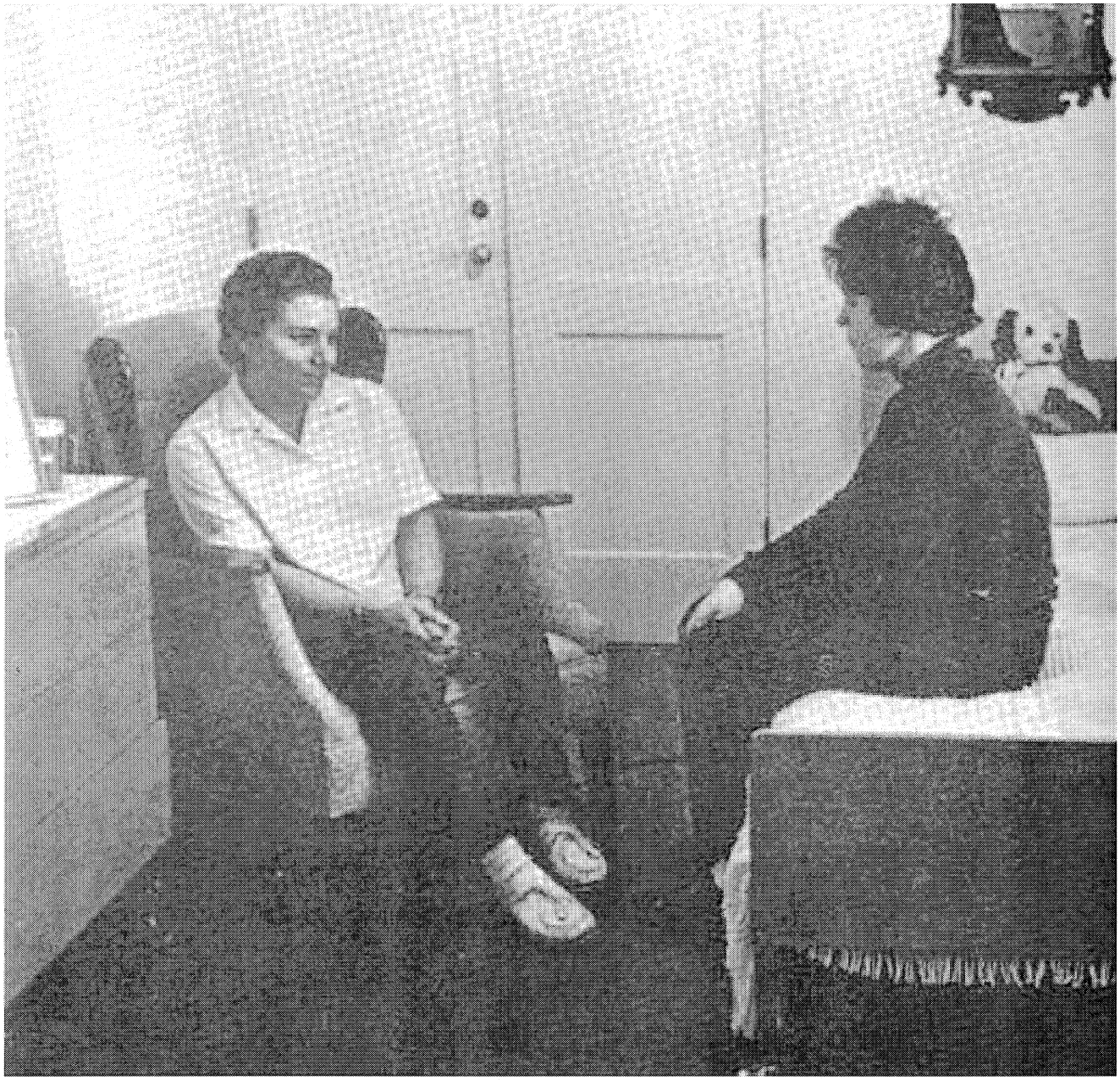
"We have developed a myth.."



"It could be argued with a good deal of persuasiveness that when one looks over the history of man the most distinguishing characteristic of his development is the degree to which man has underestimated the potentialities of men."

Seymour B, Sarason

Christmas in Purgatory



"Life is a struggle.. "

"Life is a struggle, but not a warfare."

John Burroughs

The Seaside is people. It is small. It is expensive to operate, but it isn't as expensive as one might expect. The Seaside appropriates approximately twice the amount, per patient, that other institutions do. In contrast with per capita costs in penal institutions, The Seaside has a very modest expenditure. In terms of human suffering and the potential for human growth—places like The Seaside are among the few really economical government-sponsored facilities of which we know.

There is a shame in America. Countless human beings are suffering needlessly. Countless more families of these unfortunate victims of society's irresponsibility are in anguish for they know, or suspect, the truth. Unwittingly, or unwillingly, they have been forced to institutionalize their loved one into a life of degradation and horror.

We challenge every institution in America to look at itself now. We challenge each institution to examine its programs, its standards, its admission, policies, its personnel, its budgets, its philosophy, its objectives. We challenge every institution —and every governor and every legislator—to justify its personnel and their practices, its size and development, and its budget.

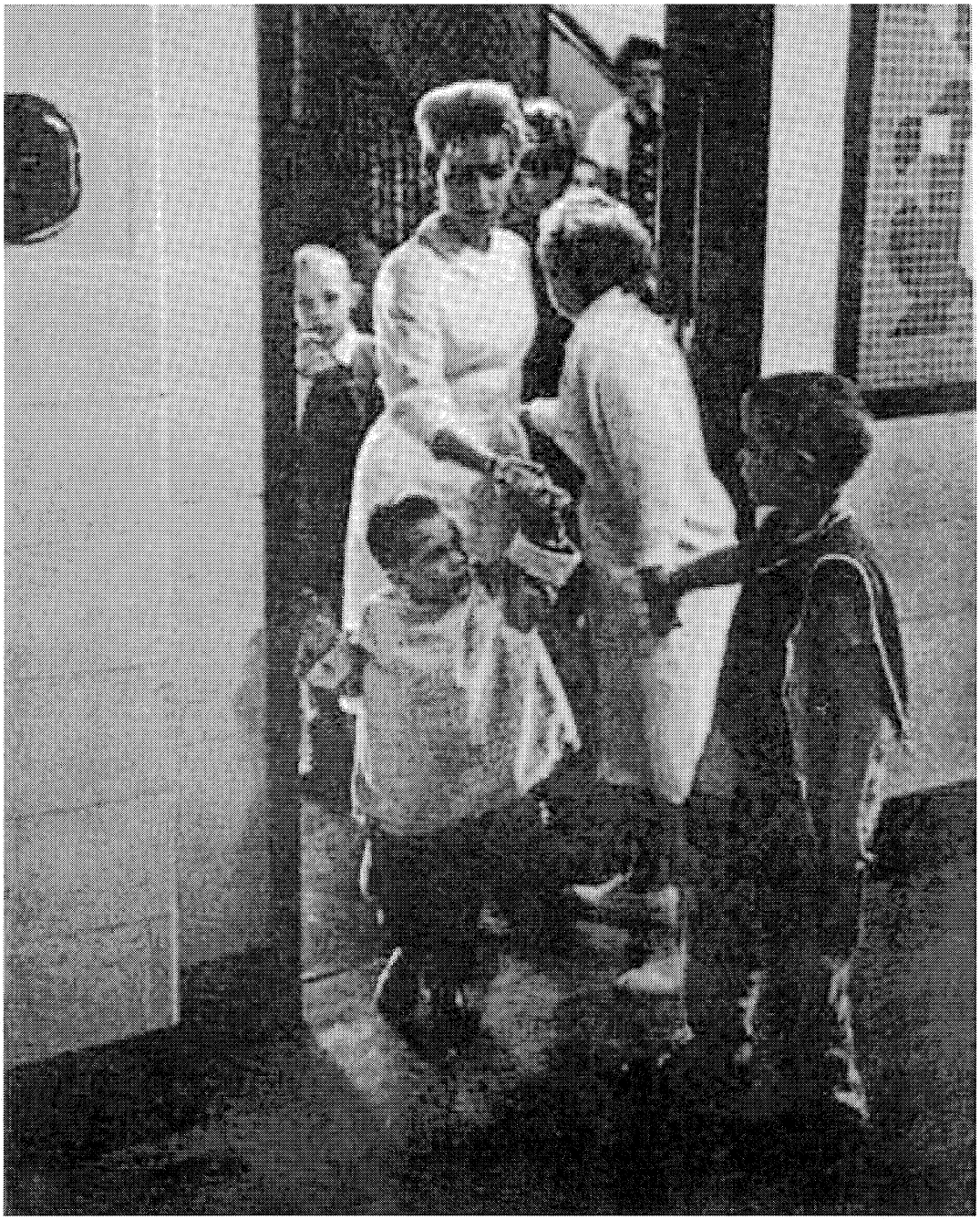
Our experiences during Christmas, 1965, require our calling for a national examination of every institution for the mentally retarded in America—an examination that will inspect the deepest recesses of the most obscure back ward in the least progressive state. We call for a national examination of state budgets for the care and treatment of the retarded. We hold each superintendent, each commissioner of mental health, each governor, each thoughtful citizen, responsible for the care and treatment of individuals committed for institutionalization in their state.

Christmas in Purgatory

My most productive moments with subnormal children come about as a consequence of allowing myself to try to experience a childlike sense of wonderment about them as intensely as they approach me with the same attitude."

Albert T. Murphy

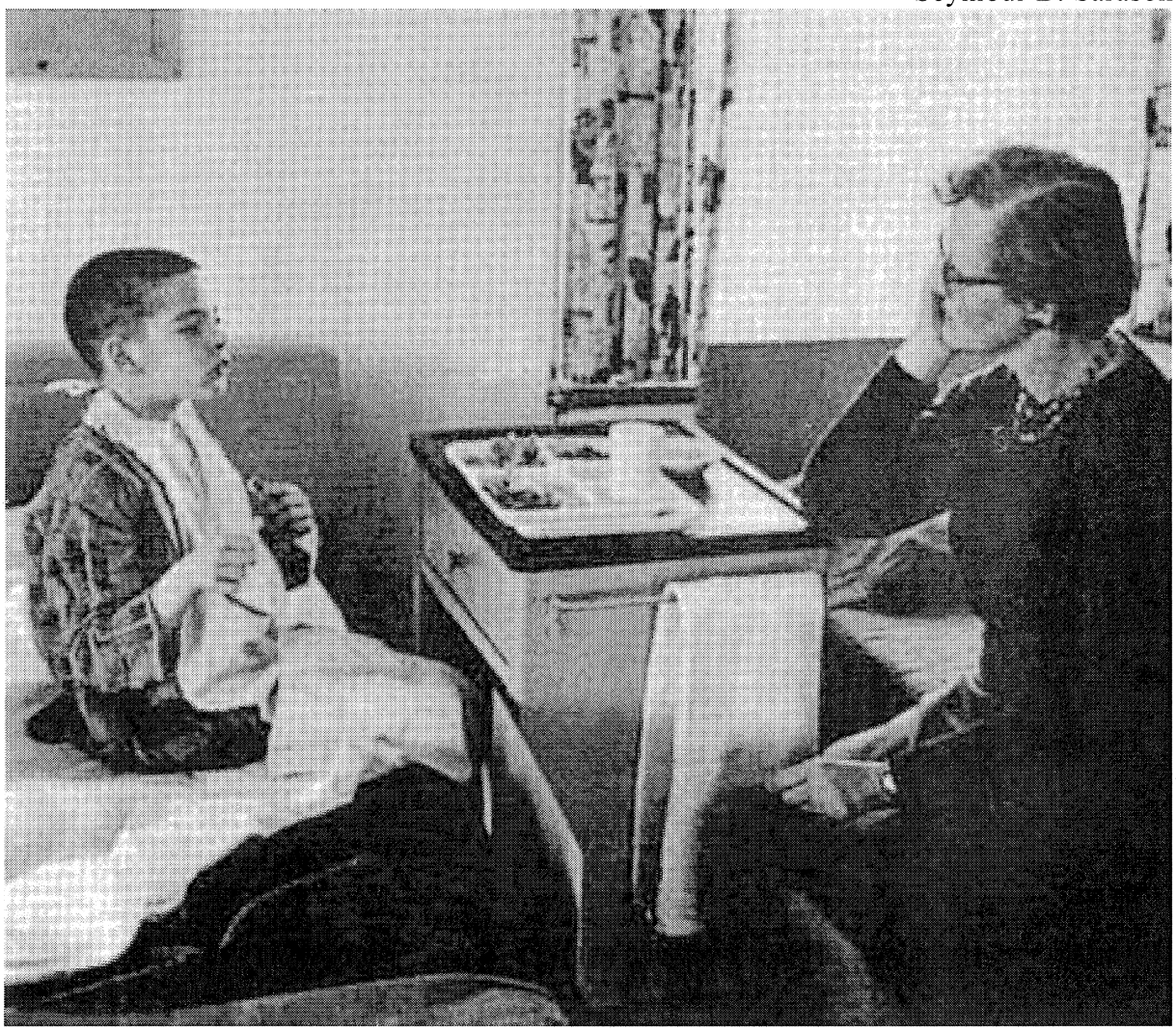
"Life is a struggle..."



Christmas in Purgatory

"At each step in history there was always a handful of individuals who saw beyond the man of his time and dreamed of a future when men would be capable of much greater acts in various realms, e.g., the social, moral, and intellectual spheres. Without this handful of individuals it is unpleasant to contemplate how things might have turned out."

Seymour B. Sarason

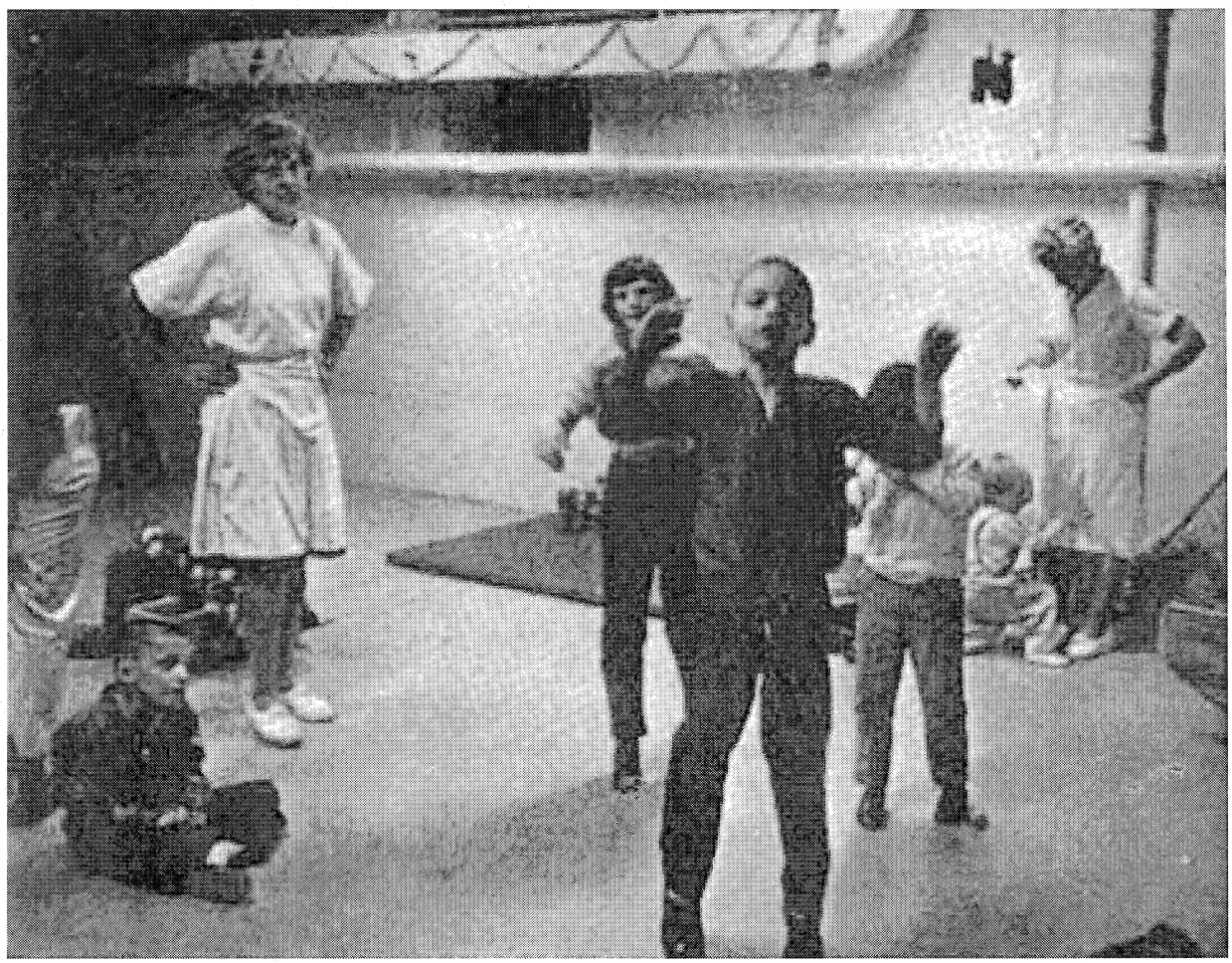


"Life is a struggle..."

"He who has once been happy is for aye Out of destruction's reach."

Wilfrid Scawen Blunt

Christmas in Purgatory



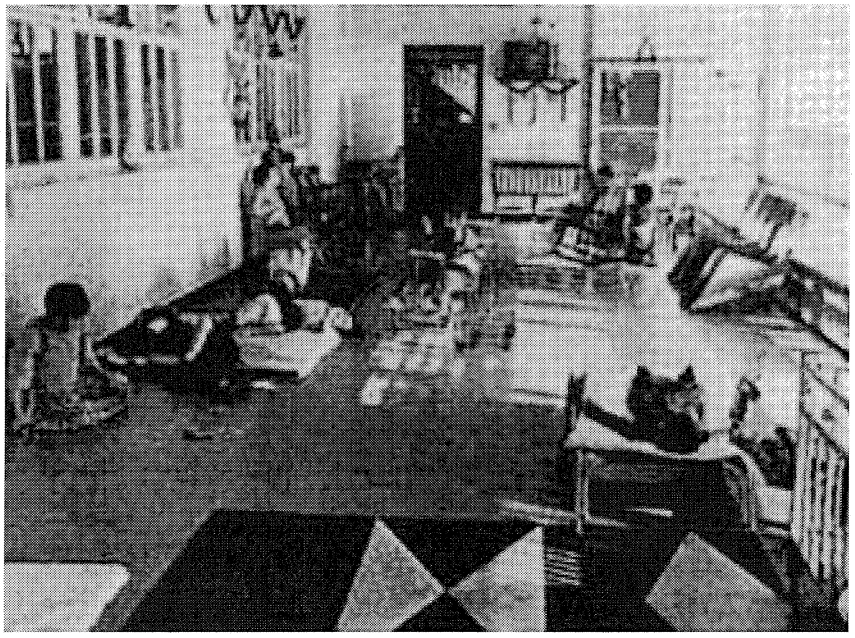
"I believe, like Moses, you can turn the serpent into a rod and learn the lessons which will help you all through life. Remember unless Moses had handled the serpent he would have had nothing but the bite. . . there is definitely a place for you and the Design for all of us holds nothing but good."

Margaret A. Neuber

"Life is a struggle..."

"There's a time for some things, and a time for all things; a time for great things, and a time for small things."

Miguel de Cervantes



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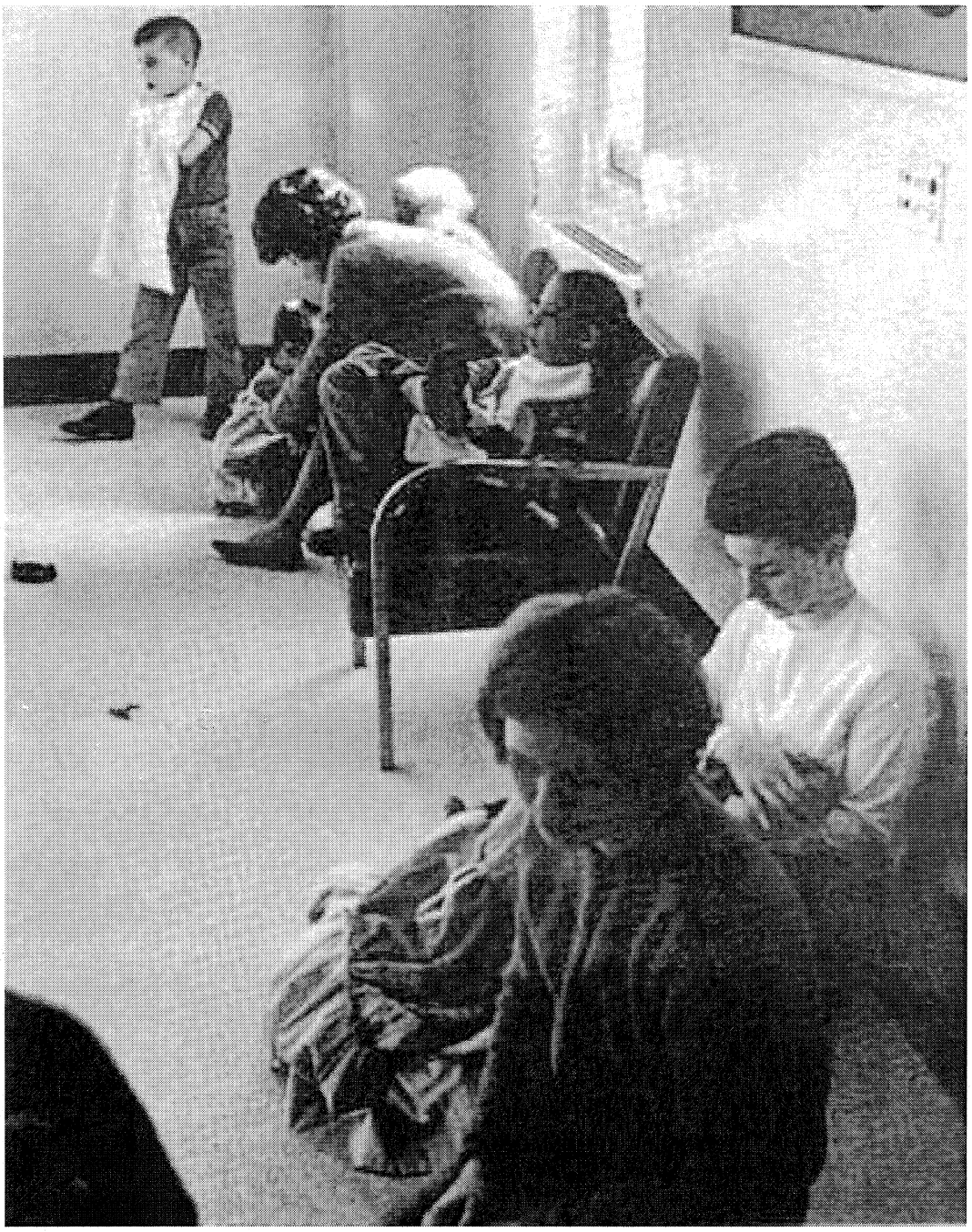
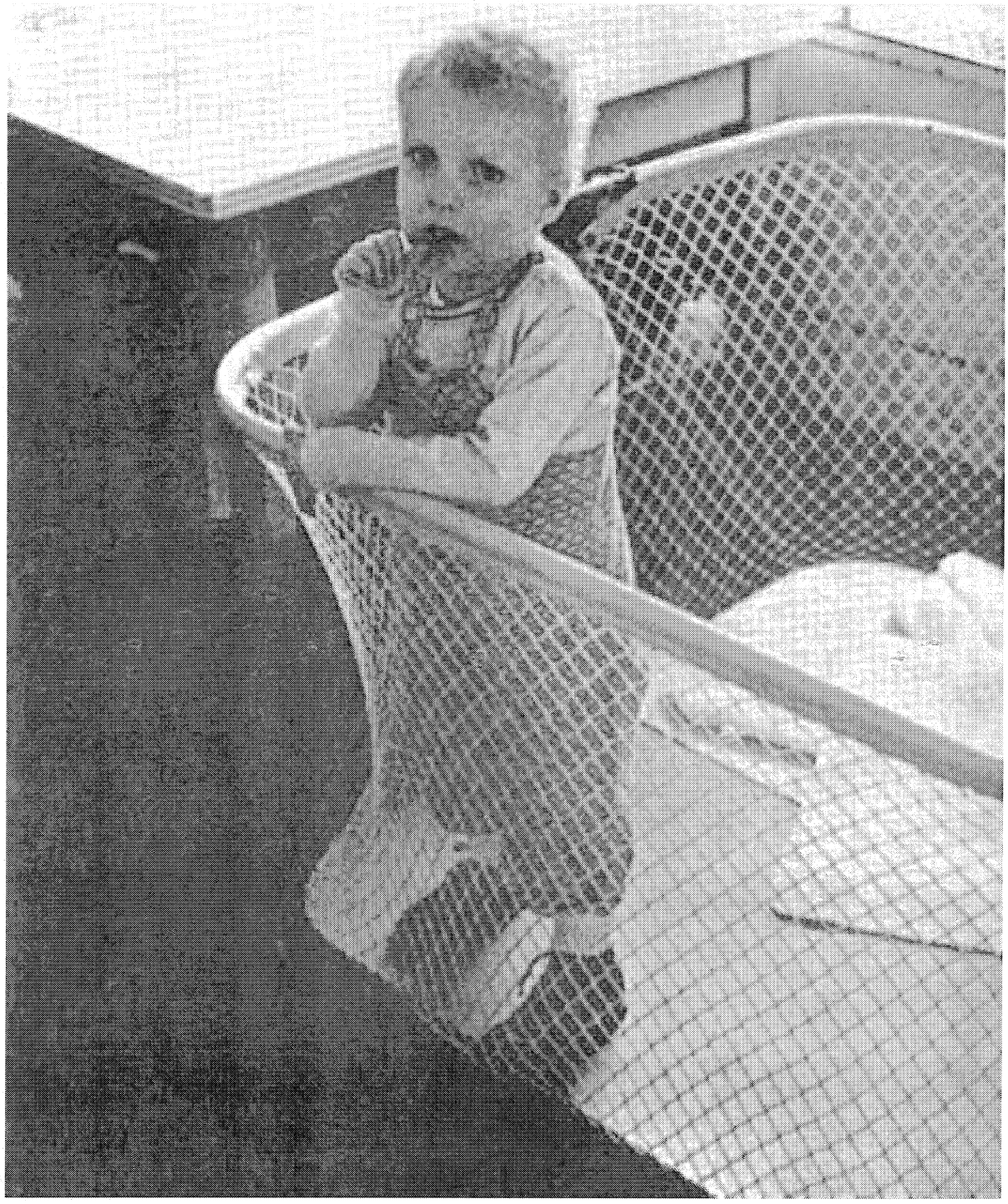


"Life is a struggle..."

"There is nothing inherent in disability to produce handicap. It is not for behavioral science to find out whether or not this is true, but to make it become true."

Frank Garfunkel

Christmas in Purgatory



"It is within man's province to educate his intelligence. However, this goal will not be achieved without a great deal of sustaining and integrated research."

"Life is a struggle..."

AFTERTHOUGHTS

"The triumph of evil requires
only that good men do nothing,"

Since we have visited the institutions described in this book, we have shown and discussed our story with a heterogeneous but carefully selected number of people. Their backgrounds range from those in very high public office to undergraduate college students preparing to be special class teachers. Editors of two of the largest and most influential news magazines previewed and discussed this book with us.

Popular opinion convinced us that this story must be brought to the American people as soon as possible. In discussing this work with so many very knowledgeable persons, we were able to resolve some of our anxieties about the possible adverse reaction to the publication of this study. Further, we were able to conceptualize a plan to correct those conditions we observed.

The major questions that dictated caution and deliberation before a thoughtful answer could be found were concerned with whether or not our work represented an invasion of privacy of certain individuals, on the one hand, and that the general public has a right to be protected from the knowledge of degradation, on the other. As far as invasion of privacy is concerned, we have learned that—from a legal point of view—this is a very ambiguous matter. Although we were forced to satisfy legal requirements for the insurance of individual's privacy—hence, the masking of eyes of patients shown in Part I — we must question privacy on moral grounds. We believe that the so-called privacy of the back wards of these institutions contributes to suffering, for outsiders do not know the conditions in these buildings and, therefore, do little or nothing to promote improvements. When privacy contributes to suffering, we must question the ideal of privacy. When privacy contributes to suffering, it loses its significance as a cherished privilege. For those who could so reason, we do not believe that there would be many in the institutions who would object to our exposure of these frightening conditions if such exposure offered some possibility for a better life for the residents. Lastly, as we discussed this issue with a number of people we began to wonder whose privacies were being protected, those institutionalized residents or the rest of us? This leads to the second consideration.

The American people have the right to know. In spite of what we wish to know, in spite of the pain that knowing may bring to us, we have the right to be informed about any serious conditions that affect our people. There is a maturity that comes to a people when it no longer needs the protection of ignorance. Only children, with their fantasies, or sick adults, with theirs, believe that ignoring a problem can make it go away.

Our recommendations derive from many sources: our "experiences prior to this study, what we observed during the study, the reactions of many astute individuals to this study, and the advice of students and colleagues. The core of our proposal was originally presented by Sarason and Gladwin a number of years ago in Sarason's book, Psychological Problems in Mental Deficiency, published by Harper and Row in 1959:

It is disappointing but true that the quality of research being done in our institutions is poor. The psychological personnel are for the most part geographically, financially, and socially apart from their professional brethren. The disinterest of behavior science departments (psychology, anthropology, sociology, psychiatry) in the area of subnormal functioning makes the solution of the problem most difficult. We must frankly state that we do not have any bright ideas of how to begin to go about remedying the situation. On the assumption that this particular problem will not change markedly in the foreseeable future, it might be profitable to consider a program which would allow the institutional worker to go for extended periods to certain centers where there is an active research and training program —a center where he can possibly learn new skills and content which he could apply to research in his own setting. This suggestion, however, presupposes that there will be several research centers which can offer this kind of opportunity. An increment in skill and knowledge sufficient to justify this kind of effort can probably not be attained in a one- or two-week workshop, but should rather be viewed as requiring at least a half-year or year training course (p. 651).

Can one any longer ignore the needed relationship between the state institution for the mentally retarded and the state university? In addition to the emergency need for at least doubling per capita expenditures in state institutions and for reducing the sizes of institutional populations wherever and however possible, our study of this problem leads to an additional set of recommendations that may contribute to an improvement of institutional programs and facilities:

1. In each state, a board of institutional visitors should be appointed by the governor or other constituted authority. This board would be responsible for reporting directly to the highest state officials. Appointments to this board should be made regardless of political party affiliation and these appointments should be contingent on both knowledge of the broad field of human welfare and demonstrated dedicated public service. Members of this board of visitors would not be, concurrently, members of any particular institution's staff or board of trustees.

2. Within each state institution for the mentally retarded, each department (e.g, medical, psychological, educational, nursing, cottage life) should have a board of advisors. This board of advisors, through periodic visits and consultations, would know the institution and its problems intimately and, thus, be in positions to advise and assist in the resolution of difficulties. In essence, the advisory board would be organized for direct consultation and assistance to the institutional staff. As this board would not be responsible for rating in stitutional personnel or recommending their salary increments or promotions, it is possible that members of this board would become involved with the most pressing and severe problems of the institution—without "endangering" the positions of the staff that trusts them. In this way, it would be possible for problems currently secreted from the outside world to be given the exposure and ventilation needed for satisfactory solutions to them.

3. In each state, a state university should be given responsibility and resources to provide comprehensive in-service training and consultation for all institutional employees, from the chief administrative officer to the attendant recruit.

4. In each state, one state institution for the mentally retarded should be designated as a center for the in-service training of all personnel to be employed for state service in institutions and clinics for the mentally retarded. As a condition for employment as institutional superintendent, psychologist, teacher, nurse, or attendant the candidate would have to spend a specified period of time at the training center. His preparation program would range from a few weeks to one calendar year, depending upon his background and experiences and the nature of the position he intends to assume. During this training program, the candidate would be involved in clinical experiences that relate directly *to* his future employment, would participate in seminars, colloquia, and other instructional experiences designed to prepare him for the sensitive and demanding activities of work with the mentally retarded. At the end of the candidate's training program, the director of this facility and his staff would rate the candidate and recommend him, or not recommend him, for employment. To the degree that this program is workable with currently employed staff, every inducement and encouragement should be provided to permit them to complete this preparation.

To some degree, all of us talk and behave as if we will not change. Yet, it is absolutely certain that we will change; what we profess now, in one way or another, we regret later. The most difficult truth each of us has to learn and live with is the knowledge that we aren't perfect. It was our intent to point out some of the more serious imperfections of institutions for the mentally retarded in this country. It is our belief that now that our most indefensible practices have been laid bare for public scrutiny, men of good will from all walks of life and all professions will sit down at the planning table and seek solutions to the plight of our brethren.

"I was very impressed with the sensitive presentation of the complex problem the mentally retarded pose for our communities and our country. The work that is being done at The Seaside certainly provides an example of the standard of dignity that should be accorded all people."

Senator Edward M. Kennedy
State of Massachusetts

"This is a dramatic presentation of conditions existing in far too many of our nation's institutions for the mentally retarded. It must be recognized that the mentally retarded should be more adequately served through a variety of community programs."

Governor George Romney
State of Michigan

"Having worked for some time with the problems of the mentally retarded, and being aware of the tremendous needs of state institutions, I was deeply impressed by your approach . . ."

Governor Karl F. Rolvaag
State of Minnesota

"A courageous book. Unless the problems of mental retardation are faced squarely, our progress will continue to move at a snail's pace."

Dr. Robert Kugel
Brown University

". . . fascinating . . . honest . . . a real eye-opener."

Professor James J. McCarthy
University of Wisconsin

"I spent a good part of the afternoon reading the book and recalling the accuracy of the situation described."

Dr. Julius S. Cohen
Syracuse University

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