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SUPREME COURT OF THE STATE OF WASHINGTON

SEIU 775

Appellant/Petitioner,

v.

STATE OF WASHINGTON, WASHINGTON STATE
DEPARTMENT OF SOCIAL AND HEALTH SERVICES,

Appellees/Respondents.

**BRIEF OF AMICUS CURIAE DISABILITY RIGHTS
WASHINGTON IN SUPPORT OF APPELLANT**

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I. INTRODUCTION

Amicus respectfully requests that the Court grant direct review of Petitioner’s Appeal. Resolution of this case will not only affect the thousands of personal care workers being asked to provide unpaid labor, but will significantly impact thousands of Washingtonians with disabilities who receive, or are eligible to receive their services through Washington’s personal care program. In amending the “informal support” rule and the “shared benefit” rule under WAC 388-106-0010 and WAC 388-106-0130 to authorize a reduced number of paid personal care hours for the same amount of work, Washington’s Department of Social and Health Services (DSHS) is thwarting the very purpose of the program—to enable people with disabilities and those who are elderly to remain in their own homes and communities by receiving care from individual providers selected by the service recipients. By subjecting the largest portion of the in-home care workforce to rules that assign them responsibility for unpaid caregiving tasks, Washington’s administration of the personal care program is jeopardizing access to essential services for its personal care clients.

Because personal care recipients need providers to be willing and available to deliver their services in order to avoid placements in more restrictive and costly facilities, the two rules that lower the number of

hours worked for which providers will be paid is placing countless individuals at serious risk of institutionalization in violation of Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. § 12132, *et seq.*, and its implementing regulations, Section 504 of Rehabilitation Act of 1973, 29 U.S.C. § 794(a) (“Section 504”), and its implementing regulations. Direct review is needed here to avoid exploitation, unnecessary institutionalization, and disability discrimination, all of which are broad and urgent issues of public importance.

II. INTEREST OF *AMICUS CURIAE*

Disability Rights Washington (DRW) is a nonprofit, statewide protection and advocacy system designated by the governor of the state of Washington to protect and advocate for the rights of Washington residents with physical or mental disabilities. RCW 71A.10.080. Disability Rights Washington operates under several Congressional mandates, including the Protection and Advocacy for Individuals with Mental Illness Act, 42 U.S.C. § 10801 *et seq.*; the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15041 *et seq.*; the Protection and Advocacy for Individual Rights Act, 29 U.S.C. § 794e; and the regulations promulgated thereunder. As the designated statewide protection and advocacy system for individuals with disabilities in Washington, Disability Rights Washington has the authority and the responsibility to pursue legal,

administrative, and such other appropriate remedies as may be necessary to protect and advocate for the rights of persons with disabilities in Washington. 42 U.S.C. § 15041 *et seq.*; 42 U.S.C. § 10801 *et seq.*; 29 U.S.C. § 794e; 29 U.S.C. § 2201; RCW 71A.10.080. Over the years, Disability Rights Washington conducted advocacy on behalf of its constituents to ensure appropriate access to personal care services.

III. STATEMENT OF FACTS

Amicus curiae adopts and incorporates herein, the statement of facts set forth by Petitioner.

IV. ANALYSIS

A. Direct Review In This Case Is Warranted to Address Significant Issues of Public Importance Relating to the Rights of People who have Disabilities.

1. Legal Standard for Direct Review

Under RAP 4.2(a)(4), the Supreme Court may accept direct review of an appeal from Superior Court if the case involves “a fundamental and urgent issue of broad public import which requires prompt and ultimate determination.” The issues in this case meet this standard. Indeed, this case is not the first time this Court has had occasion to urgently review DSHS’s rules for administering the in-home personal care program that thousands of DSHS clients need in order to avoid institutionalization. *See Jenkins v. Dept. of Social and Health Services*, 160 Wn.2d 287, 157 P.3d 388 (2007)

(certifying for direct review appeal of superior court’s invalidation of personal care rule); *Samantha A. v. Dept. of Social and Health Services*, 171 Wn.2d 623, 256 P.3d 1138 (2011) (granting personal care recipient’s motion to transfer). As deemed in these other cases involving challenges to personal care rules, the issues involved with this case about personal care services are also urgent and of broad public import.

First, ensuring appropriate access to Medicaid funded services is vitally important to the public interest. The state legislature has found that “the public interest would best be served by a broad array of long-term care services that support persons who need such services at home or in the community whenever practicable and that promote individual autonomy, dignity, and choice.” *Townsend v. Quasim*, 328 F.3d 511, 519 (9th Cir. 2003) (citing RCW 74.39A.005). Courts accordingly have found that there is a “robust public interest” in safeguarding access to community-based Medicaid services, which outweighs potential financial burdens. *M.R. v. Dreyfus*, 697 F.3d 706, 738 (9th Cir. 2012) (internal citations omitted); *see also Cota v. Maxwell-Jolly*, 688 F. Supp. 2d 980, 999 (N.D. Cal. 2010); *A. H. R. v. Washington State Health Care Auth.*, No. C15-5701JLR, 2016 WL 98513, at *17 (W.D. Wash. Jan. 7, 2016). Urgent resolution of this matter is necessary in order to ensure personal care recipients have access to the providers they need to assist them in their daily living.

The issue of how to administer the personal care service program in Washington is also of broad public import. According to DSHS data, over 64,000 individuals receive personal care services from the Aging and Long-Term Support and Developmental Disabilities Administrations combined.¹ Unsurprisingly, individuals receiving personal care services most often choose to receive services from family members. According to DSHS, family caregivers serving as individual providers (IPs) are the “[l]argest [s]ector” of the paid Medicaid support providers, and the vast majority of paid in-home providers are related to the clients they serve.² Here, the issue in this case - whether certain DSHS’s rules are invalid because they require personal care workers to perform unpaid labor necessary to implement individual care plans and have a discriminatory effect on IPs who are related to their clients – not only affects the personal care workers, but also the thousands of individuals who use Medicaid funded personal care services as an alternative to more costly and restrictive facilities. Specifically, in addition to fundamental questions about labor rights, this case involves issues that are presently impacting

¹ See “Washington State DSHS Client Services All Ages State Fiscal Year 2017,” available online at <http://clientdata.rda.dshs.wa.gov/Home/ShowReport?reportMode=0> (last accessed July 29, 2019).

² Rector, B. (2017). “The Important Role of Family Caregivers in Washington State’s Long-Term Services and Supports System” at pp.17-18, available online at <https://www.milbank.org/wp-content/uploads/2017/12/Rector.pdf> (last accessed July 29, 2019).

thousands of people with disabilities and elders who urgently need a resolution in order to avoid harm of unnecessary institutionalization.

2. Inclusion and Independence of People with Disabilities are of Significant Public Importance.

a. *Inclusion, Integration, and Promotion of Autonomy Benefits People with Disabilities, Their Families and Society*

Washington’s own Department of Social Services (DSHS) states that the very purpose of Medicaid funded personal care services is to enable elderly people and/or people with disabilities to “remain at home.”³ The benefits of being supported in one’s home rather than institutional setting have been well-documented. In one longitudinal study of individuals who had been deinstitutionalized from a facility known as “Pennhurst,” researchers found the individuals who had moved out of the facility experienced significant gains in skills, personal happiness, family satisfaction, opportunities to participate in community activities, and other indicators of quality of life, concluding that the former Pennhurst residents were “better off.”⁴ The National Council on Disability also found that

³ “Services that help an adult remain at home.” Available online at <https://www.dshs.wa.gov/altsa/home-and-community-services/services-help-adult-remain-home> (last accessed July 22, 2019).

⁴ NAT’L COUNCIL ON DISABILITY, *OLMSTEAD: RECLAIMING INSTITUTIONALIZED LIVES* 12 (2003) (quoting James W. Conroy & Valerie J. Bradley, *The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis*, U.S. DEP’T HEALTH & HUMAN SERVS. 192 (1985) (hereinafter “NCD REPORT”); see also e.g., “The Effects of Community vs. Institutional Living on the Daily Living Skills of Persons with Developmental Disabilities?” Research reviewed and

generally, “the most integrated setting” to be “a place where the person exercises choice and control,” and a “home of one’s own shared with persons whom one has chosen to live with, or where one lives alone[.]”⁵

Washington recognizes that offering alternatives to institutional care serves important public policy objectives. For instance, Washington is among the first group of states to implement the Community First Choice program authorized under the Affordable Care Act to broaden the provision of Medicaid funded services, including personal care, in order to enable individuals who would otherwise need institutional care to receive personal care services in their homes.⁶ However, despite Washington’s early participation in the Community First Choice Option, it continues apply rules that restrict payments for personal care services delivered by the individuals who form the backbone of the in-home care workforce.

b. *Federal and State Law Recognize the Rights of People with Disabilities to Live and Fully Participate In the Community*

summarized by Charlie Lakin, Sheryl Larson, and Shannon Kim University of Minnesota, Institute on Community Integration (UCEDD)(2011) available online at https://www.aucd.org/docs/councils/core/Evidence-Based%20Policy%20Brief_1.pdf (finding “significantly better outcomes” for individuals with disabilities living in the community) (last accessed July 29, 2019).

⁵NCD Report, at 9.

⁶ Dear State Medicaid Director Letter, from Centers for Medicare and Medicaid Services (CMS), December 30, 2016, available online at <https://www.medicaid.gov/federal-policy-guidance/downloads/smd16011.pdf> (last accessed July 29, 2019); Community First Choice: Final Report to Congress As Required by the Patient Protection and Affordable Care Act of 2010 (P.L. 111-148) from the Dept. of Health and Human Services Office of the Secretary at p. 6, available online at <https://www.medicaid.gov/medicaid/hcbs/downloads/cfc-final-report-to-congress.pdf>.

Avoiding unnecessary institutionalization is an individual right that is fundamentally important for Washington to ensure. In 1990, Congress enacted the Americans with Disabilities Act (ADA), expanding upon Section 504 of the Rehabilitation Act, which prohibited disability-based discrimination by federally funded entities. Congress acknowledged prior to the ADA's passage that "then current laws were 'inadequate' to combat 'the pervasive problems of discrimination that people with disabilities are facing.'" *Helen L. v. DiDario*, 46 F.3d 325, 331 (3d Cir. 1995) (quoting Senate Report at 18; House Report (Part II) at 47). Forms of discrimination that concerned Congress included segregation of people with disabilities in institutions and their concomitant exclusion from the community and society at large.⁷ In response, Congress passed the ADA to serve as "a comprehensive piece of civil rights legislation which promises a new future: a future of inclusion and integration, and the end of exclusion and segregation." H.R. Rep. No. 101-485, pt. III at 26 (1990) (House Report (Part III)).

⁷ Senate Report at 5-6 ("One of the most debilitating forms of discrimination is segregation imposed by others."); House Report (Part II) at 29 ("Discrimination against people with disabilities includes segregation[] [and] exclusion . . ."); *See also* House Report (Part III) at 49-50 ("The purpose of [T]itle II is to continue to break down barriers to the integrated participation of people with disabilities in all aspects of community life."). Congress further found that "individuals with disabilities continually encounter various forms of discrimination, including . . . segregation." 42 U.S.C. § 12101(a)(5).

The ADA specified that discrimination against people with disabilities includes “segregation” and “institutionalization.” 42 U.S.C. § 12101(a)(3), (5). Pursuant to the ADA’s Title II requirement to issue regulations to implement the ADA’s bar against the exclusion, denial of benefits or services, and discrimination by “a public entity,” the Attorney General issued regulations providing, *inter alia*, that “[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 42 U.S.C. § 12132; 42 U.S.C. § 12134(a); 28 C.F.R. § 35.130(d) (“the integration mandate”). An integrated setting, according to the ADA regulations, is “a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.” 28 C.F.R. pt. 35, App. B. at 693 (2016). The U.S. Supreme Court held that Title II and its implementing regulations require that when a state provides services to people with disabilities, it must do so “in the most integrated setting appropriate to [their] needs.” *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 592 (1999), 28 C.F.R. § 35.130(d). The Court explicitly held that “[u]njustified isolation . . . is properly regarded as discrimination based on disability.” *Olmstead*, 527 U.S. at 597; *see also Disability Advocates, Inc. v. Paterson (DAI I)*, 598 F. Supp. 2d 289, 320 (E.D.N.Y. 2009) (concluding that “the proper interpretation of the regulations’

definition of ‘most integrated setting’ is set forth in the regulations themselves: whether a particular setting ‘enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible’”) (quoting 28 C.F.R. § 35.130(d), App. A).

A public entity violates Title II of the ADA when it segregates people with disabilities in public or private facilities or promotes the segregation of people with disabilities in such facilities through its planning, system design, funding choices, or service implementation. *See, e.g.*, 28 C.F.R. § 35.130(d); *Steimel v. Wernert*, 823 F.3d 902, 911 (7th Cir. 2016) (a state may “violate the integration mandate if it operates programs that segregate individuals with disabilities or through its planning, service system design, funding choices, or service implementation practices, promotes or relies upon the segregation of individuals with disabilities in private facilities or programs”) (internal quotation marks and alterations omitted); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1181-82 (10th Cir. 2003) (reversing grant of summary judgment where defendants’ restructuring of medication entitlements could place people at serious risk of unnecessary institutionalization in nursing facilities).

In addition, “[a] public entity may not, directly or through contractual or other arrangements, utilize criteria or methods of

administration: (i) That have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability,” including unnecessary institutionalization. 28 C.F.R. § 35.130(b)(3), (d); 28 C.F.R. § 41.51(b)(3), (d); 45 C.F.R. § 84.4(b)(2), (4). Courts have found ADA violations had been properly claimed for a variety of methods of administration that were resulting in unnecessary institutionalization of people with disabilities. *See e.g., Conn. Office of Prot. & Advocacy for Persons with Disabilities v. Conn.*, 706 F. Supp. 2d 266, 277-78 (D. Conn. 2010) (ADA violation to inadequately assess long-term needs and withhold information regarding alternatives to nursing facility care); *Dunakin v. Quigley*, 99 F. Supp. 3d 1297, 1319-20 (W.D. Wash. 2015) (ADA violation to deny evaluations for an alternative to nursing facility placement); *Kathleen S. v. Dep’t of Pub. Welfare of Pa.*, 10 F. Supp. 2d 460, 471 (E.D. Pa. 1998) (methods of administration at state institution caused eighty-eight people to be unnecessarily segregated in the hospital).

Specifically, in *Ball v. Rogers*, a federal district court found violations of the ADA where the state agency “failed to properly monitor” its home and community based services program and “repeatedly failed to provide the personal care services required in Plaintiffs’ case management plans” due to a “shortage of attendant care workers.” *Ball v. Rogers*, No. CV 00-67TUCEHC, 2009 WL 1395423, at *5 (D. Ariz. Apr. 24, 2009).

The Court found the agency was violating the ADA through its policy of allowing the service recipients to “assume the risk, by choosing to remain at home rather than being institutionalized, that services that they are dependent upon will not be delivered.” *Id.* The agency’s failure to “prevent unnecessary gaps in service” created a threat of institutionalization or actual institutionalization, which the district court found to constitute discrimination. *Id.* Hence, in the interest of avoiding discriminatory practices, it is crucial that Washington’s methods of administering its personal care program not include policies or practices that will result in unnecessary institutionalization or risk thereof.

c. *Washington’s Informal Support and Shared Benefit Rules contravenes the ADA and Section 504*

Washington’s implementation of its informal support and shared benefit rules place qualified individuals with disabilities at risk of unnecessary segregation and undermine the very intent and purpose of its own personal care program. These methods of administration of the personal care program violate Title II of the ADA and Section 504. DSHS recognizes the importance of respecting people with disabilities’ right to self-direction and choice in selecting a personal care provider, including

the ability to choose a family member.⁸ Individuals often prefer care by a well-known individual rather than strangers hired by an agency. However, DSHS's rules are impeding clients' ability to select the provider of their choice by making the choice to be a family or household home care worker an unaffordable one.

This is because DSHS assigns individual providers to perform personal care tasks in the care plans, while also reducing the amount of hours for which IPs can be paid to perform these tasks. Under WAC 388-106-0010, the definitions of "plan of care," "service summary," and "assessment details" state that a plan of care identifies the services the client is eligible for and the list of providers and what tasks they will provide. Similarly, WAC 388-71-0515(3) states that the "individual provider must provide the services as outlined on the client's plan of care...within the number of hours authorized." The informal support and shared benefit rules reduce paid hours for work performed on the grounds that such work results in a shared benefit or is provided informally, as volunteer time. *See* WAC 388-106-0010 (defining "shared benefit" to

⁸ "Medicaid and Long-Term Care Services for Adults," DSHS, available online at <https://www.dshs.wa.gov/sites/default/files/AL TSA/hcs/documents/22-619.pdf> (last accessed July 22, 2019) (Informing personal care recipients "[i]t is your choice who your caregiver(s) will be. You can find a caregiver yourself, called an Individual Provider (IP), get one through a home care agency, or a combination of both. If you want a family member to be your caregiver, he or she can only be hired as an IP.").

mean “(a) A client and their paid caregiver both share in the benefit of an IADL task **being performed**; or (b) Two or more clients in a multiclient household benefit from the same IADL task(s) **being performed.**”) (emphasis added); *id.* (defining “informal support” to mean “Assistance that **will be provided** without home and community based services funding...”) (emphasis added); WAC 388-106-0130 (department assigns a number of base hours of paid care based on need and then adjusts base hours down to account for informal supports and shared benefit); *see also* RF WSR 18-16-004 at 29-34 (DSHS May 2016 management bulletin directing that unrelated and non-household-member IPs cannot be a source of informal support because the FLSA requires they be paid for all hours worked but IPs related by family or household may provide such supports without pay). Thus, the amount of hours their care providers may be paid under DSHS’s shared benefit and informal support rules does not cover the number of hours they would have to work in order to perform all of the tasks listed in the client’s care plan.

Contrary to DSHS’s assertions that personal care recipients can select which tasks listed on their care plans that their IPs should perform, individuals with disabilities and elders who need assistance to complete basic daily living activities like preparing meals and bathing cannot simply elect to forgo necessary care like items on a "menu" without risking harm

to their health and well-being. *See* Resp. Br. at 12-13. A client who is assessed as needing assistance from an IP to cook or bathe will have a care plan identifying that IP as the person assisting the client with those tasks. WAC 388-106-0010 (definitions of “plan of care,” “service summary,” and “assessment details”). While DSHS suggests it is incumbent upon the client to prioritize among these types of vital assistance, the rules and the plans presume all tasks assigned to the provider are performed, even if the IP is not authorized to be paid pursuant the shared benefit and informal support rules. WAC 388-106-0010, -0130. *Id.*

Importantly, DSHS’s informal support and shared benefit rules have inequitable impacts on families that may have more limited resources. DSHS’s argument that a “family relationship” alleviates needs for paid care wrongly assumes that personal care recipients who would prefer their families to be their providers have family members who can afford to spend time staying at home to care for them without pay. Resp. Br. at 9. Hiring family should be a viable choice for all personal care recipients regardless of family income, although some personal care recipients may have even greater needs to hire family IPs for cultural or linguistic reasons. However, without compensation for all of the tasks assigned to them, individual providers who might otherwise be willing to support an individual to live at home may have no practical choice but to

decline work as a paid caregiver and instead engage in other employment that will compensate them for all of the time they spend working. As a result, personal care recipients whose families have the least resources will be most at risk of not having the ability to choose family IPs.

Because many people may not be able to afford to spend time doing uncompensated work, DSHS's rules create economic barriers for otherwise qualified individuals from entering or remaining in the caregiving workforce. Expecting home health agencies to serve as a substitute for IPs is not realistic or sustainable. The network of home health agency workers is already strained by the numerous existing workforce challenges, including the increasing turnover rates in the home health industry across the country and in rural areas.⁹ In fact, as Petitioner has pointed out, there is a growing labor shortage for caregivers to serve an expanding population of elderly and disabled individuals. *See* Petitioner's Statement of Grounds for Direct Review, at 11-12 (citing App. E, AARP, *Across the States, Profiles of Long-Term Services and Supports*

⁹ *See e.g.*, Robert Holly, *Home Care Industry Turnover Reaches All-Time High of 82%*, Home Health Care News, May 8, 2019, available online at <https://homehealthcarenews.com/2019/05/home-care-industry-turnover-reaches-all-time-high-of-82/> (last accessed July 29, 2019); Washington State Office of Rural Health, *There's No Place like Home: Rural Home Health and Hospice Care in Washington State, A Discussion of Challenges and Solutions*, January 2019, available at <https://www.doh.wa.gov/Portals/1/Documents/2900/609007.pdf> (discussing impact of home care workforce challenges in rural Washington counties).

(August 2018)). Yet, DSHS rules continue to make it impossible for many people to hire family members to be their IPs, which is only augmenting the demand for home care agencies and stretching an already untenably thin workforce.

Ultimately, these rules create more barriers to care than they remove. By making it financially impracticable for numerous people to serve as needed caregivers, DSHS rules place individuals who rely upon personal care services at serious risk of more costly and restrictive institutionalizations, in violation of the *Olmstead* mandate and to the severe detriment of Washington citizens. *See, e.g., V.L. v. Wagner*, 669 F.Supp.2d 1106 (N.D. Cal. 2009); *Marlo M. v. Cansler*, 679 F. Supp. 2d 635, 638 (E.D.N.C. 2010) (finding irreparable harm even if institutionalization were only temporary and recognizing the “regressive consequences” that such placements have on people); *Crabtree v. Goetz*, No. 08-0939, 2008 WL 5330506, at *25 (M.D. Tenn. Dec. 19, 2008) (finding that unnecessary institutionalization “would be detrimental to [plaintiffs’] care, causing, *inter alia*, mental depression, and for some Plaintiffs, a shorter life expectancy or death”); *Long v. Benson*, No. 08cv26, 2008 WL 4571903, at *2 (N.D. Fla. Oct. 14, 2008) (finding irreparable harm where person would be forced to leave his community placement and enter a nursing home and specifically recognizing the

“enormous psychological blow” that such placements would cause due to the “ very substantial difference in [plaintiff’s] perceived quality of life in the apartment as compared to the nursing home, each day he is required to live in the nursing home”); *Cota*, 688 F. Supp. 2d at 997-98 (irreparable harm where thousands of people were placed at risk of institutionalization as a result of changes in eligibility criteria for adult day healthcare due to state budget cuts); *Brantley v. Maxwell-Jolly*, 656 F. Supp. 2d 1161 (N.D. Cal. 2009) at 1176. Avoiding this risk of harm resulting from unnecessary institutionalizations is plainly an important public policy objective, warranting a swift resolution of the issues raised in this appeal.

V. CONCLUSION

In sum, this case presents an issue of broad public import because it will have a direct and substantial impact on the availability of in-home personal care services that thousands of individuals need to be able to access in order to continue benefitting from a life in the community. Amicus respectfully urges this Court to certify this appeal for direct review.

Respectfully submitted this 6th day of August, 2019.



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