

No. 11-681

In The
Supreme Court of the United States

—◆—
PAMELA HARRIS, et al.,

Petitioners,

v.

PAT QUINN, GOVERNOR OF ILLINOIS, et al.,

Respondents.

—◆—
**On Writ Of Certiorari To The
United States Court Of Appeals
For The Seventh Circuit**

—◆—
**BRIEF OF THE AMERICAN ASSOCIATION OF
PEOPLE WITH DISABILITIES, THE DISABILITY
RIGHTS EDUCATION AND DEFENSE FUND,
THE JUDGE DAVID L. BAZELON CENTER
FOR MENTAL HEALTH LAW, THE NATIONAL
COUNCIL ON AGING, AND OTHER DISABILITY
AND SENIOR ORGANIZATIONS AS *AMICI
CURIAE* IN SUPPORT OF RESPONDENTS**

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INTEREST OF THE *AMICI*

Amici are disability rights organizations and organizations of people with disabilities and senior citizens who use personal assistance services to promote independence, integration, and freedom from institutionalization.¹ This case presents a constitutional challenge to the arrangements a number of states have adopted to provide representation and collective bargaining rights to the workers who provide personal assistance. Those arrangements have typically resulted from a process in which people with disabilities have actively participated and asserted their interests. The structure of those arrangements, in which state law provides that the employer's role is shared by the individual consumer with a disability (who has the power to hire, fire, and supervise the person who provides her services) and the state (which has the power to set other key terms and conditions of employment), serves to implement the philosophy of independent living and the principle of consumer control for which the disability rights movement has fought very hard. *Amici*, many of which are located in states that have adopted these collective-bargaining arrangements, are concerned that a ruling invalidating them will undermine the

¹ Counsel for the parties have filed with the Clerk blanket consents to the filing of *amicus* briefs in this matter. No counsel for a party authored this brief in whole or in part, and no person or entity other than *amici* and their counsel made a monetary contribution to the preparation or submission of this brief.

interests and independence of individuals with disabilities. *Amici* are listed and described in the appendix to this brief.



SUMMARY OF ARGUMENT

Petitioners argue that personal assistants who provide in-home services to persons with disabilities under Illinois’s Medicaid program are not “true public employees,” because the individual consumers retain the power to hire, fire, and supervise the assistants who provide services to them personally. That argument misconstrues the relationship between personal assistants, individuals with disabilities, and the state under the Illinois Medicaid program. Under that program, the state and the individual consumer share the responsibilities of an employer. The consumer has the power to choose the individual who will provide her services and to supervise that individual on a day-to-day basis, while the state retains the power to set workforce-wide terms and conditions of employment.

This sharing of responsibilities directly responds to the concerns of people with disabilities. The American disability rights movement is based on a philosophy of independent living. That philosophy supports policies that ensure that people with disabilities have the opportunity to participate fully in society and control the day-to-day and minute-to-minute aspects of their lives. Consumer-controlled personal assistance

services, in which individuals with disabilities hire, fire, and direct the individuals who provide services to them, are a key means of making the philosophy of independent living a reality and preventing unnecessary institutionalization. Responding to the urgings of disability rights activists, changes in federal funding rules, and this Court's decision in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), states have increasingly provided for consumer-controlled personal assistance services under their Medicaid programs.

Although disability rights activists urged states to provide consumer-controlled personal assistance services – services that granted to individuals with disabilities key aspects of the employer role – they recognized that there are certain aspects of the employment relationship that individual consumers are unlikely to be in a position to manage. States like Illinois have accordingly retained authority over those systemic terms and conditions of employment, and they have appropriately authorized personal assistants to bargain collectively with the state itself over them. Collective bargaining over those systemic terms and conditions of employment has served the interests and independence of individuals with disabilities by helping to promote a stable personal assistant workforce. A ruling that declared Illinois's arrangement unconstitutional would disserve individuals with disabilities and undermine efforts to achieve the goals of independent living.



ARGUMENT

Petitioners argue that personal assistants who provide in-home services to people with disabilities under Illinois’s Medicaid program are not “true public employees.” Pet. Br. 15. They contend that those personal assistants “are not managed or supervised by the State, but by the person with disabilities who employs them.” *Id.* at 39. These arguments fundamentally misconstrue the relationship between personal assistants, individuals with disabilities, and the state under Illinois’s Medicaid program. Under that program, the state and the individual with a disability share the responsibilities of an employer. The sharing of responsibilities directly achieves the goal of providing stable and – crucially – truly consumer-directed services.

Central to this arrangement is the opportunity for personal assistants to collectively bargain with the state over key terms and conditions of employment – including wages and employment-related benefits that only the state, and not an individual consumer, is in a position to provide – while ensuring that they are subject to the day-to-day supervision, and hiring and firing authority, of the individuals with disabilities to whom they provide services. Because the state directly controls substantial aspects of the terms and conditions of a personal assistant’s employment, and the state has determined that personal assistants may choose to bargain collectively over those terms and conditions, the bargaining agent they select may properly collect an agency fee from

those on whose behalf it must act. See, e.g., *Locke v. Karass*, 555 U.S. 207, 213 (2009).

A contrary conclusion would severely undermine the interests and independence of the individuals with disabilities who receive personal assistance through Illinois's program. If the state chose to continue providing the program's workers with effective collective bargaining rights, it would be forced to abandon the principle of consumer control over hiring, firing, and day-to-day supervision. But people with disabilities, acting through the disability rights and independent living movements, fought long and hard for state laws granting them the right to control these aspects of the assistance they receive. Alternatively, the state could abandon collective bargaining and simply treat personal-assistance workers for all purposes as employees of the individual consumers they serve. But that would deprive the workers of the opportunity to bargain over those terms and conditions of employment that individual consumers are often in no position to set – including wages and benefits. Collective bargaining over those terms and conditions of employment has led in many states to significant improvements in wages and benefits, and – most important for people with disabilities – to increased stability and reduced turnover in the market for personal assistants. This Court should not jeopardize those developments. It should instead affirm the judgment of the Seventh Circuit.

A. Consumer-Directed Personal Assistance and the Independent Living Philosophy

Over the past several decades, people with disabilities have urged states to provide them supportive services in their own homes, so that they need not enter nursing homes or other institutions. These demands have stemmed from a philosophy of independent living, indigenous to the disability rights movement, which supports policies that ensure that people with disabilities have the opportunity to participate fully in society and control the day-to-day and minute-to-minute aspects of their lives.² As Ed Roberts, one of the early leaders of the American disability rights movement, described that philosophy, the concept of “independent living”

meant active participation in society – working, having a home, raising a family, and generally sharing in the joys and responsibilities of community life. Independent living meant freedom from isolation and institutionalization; it meant the ability to choose where to live, how to live, and how to carry

² See Edward Berkowitz, *Disabled Policy: America's Programs for the Handicapped 197-207* (1987); James I. Charlton, *Nothing About Us Without Us: Disability Oppression and Empowerment* 130-32 (1998); Gerben DeJong, *Defining and Implementing the Independent Living Concept*, in *Independent Living for Physically Disabled People* 4, 8 (Nancy M. Crewe & Irving Kenneth Zola, eds., 1983).

out the activities of daily living that most able-bodied people take for granted.³

The Americans with Disabilities Act explicitly embraces the philosophy of independent living. See 42 U.S.C. § 12101(a)(7) (finding that “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”).

Personal assistance services, controlled by individuals with disabilities themselves, can be a crucial tool for making independent living a reality – if a stable workforce is available. See Andrew I. Batavia, *A Right to Personal Assistance Services: “Most Integrated Setting Appropriate” Requirements and the Independent Living Model of Long-Term Care*, 27 Am. J. L. & Med. 17, 20 (2001) (“Access to consumer-directed personal assistance services is also one of the foundational policy issues of the independent living movement, in which disability rights advocates have struggled for the past three decades to empower people with disabilities to live independently in their communities, rather than in institutions.”).⁴ Many

³ Edward V. Roberts, *A History of the Independent Living Movement: A Founder’s Perspective*, in *Psychosocial Interventions With Physically Disabled Persons* 231, 237 (Bruce W. Heller et al., eds., 1989).

⁴ See also Lynn May Rivas, *A Significant Alliance: The Independent Living Movement, the Service Employees International Union, and the Establishment of the First Public Authorities in California* 2-3 (2005) (describing the importance of
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individuals with disabilities cannot physically carry out various tasks of daily life. But they are fully capable of deciding for themselves what tasks to undertake and how to do so. The independent living philosophy posits that this sort of *decisional* autonomy is the key aspect of independence. In the words of another leading disability rights activist, “The Independent Living Movement argues that it is more important for us to have full control over our lives than over our bodies. We will give up doing some things for ourselves if we can determine when and how they are to be done.”⁵

Consumer-directed personal assistance gives individuals with disabilities this sort of control. An individual with a disability hires and directs a “personal assistant” to perform the tasks that the disabled person cannot physically perform herself. The personal assistant acts “as an extension of the disabled person and follows the individual’s directions as to how to meet his or her needs.” Andrew I. Batavia,

personal assistance services to achieving the goals of independent living).

⁵ Irving Kenneth Zola, *Developing New Self-Images and Interdependence*, in *Independent Living for Physically Disabled People*, *supra*, at 49, 58. See also Adrienne Asch, *Disability, Bioethics, and Human Rights*, in *Handbook of Disability Studies* 297, 313 (Gary L. Albrecht et al., eds., 2001) (arguing that “independence need not be viewed in physical terms” but that instead “self-direction, self-determination, and participation in decision making about one’s life are more genuine and authentic measures of desirable independence”).

Gerben DeJong & Louise Bouscaren McKnew, *Toward a National Personal Assistance Program: The Independent Living Model of Long-Term Care for Persons with Disabilities*, 16 J. Health Pol., Pol'y & L. 523, 529 (1991). Consumer-directed personal assistance “is based on the premise that persons with disabilities should be empowered to live as independently as possible and that physical (and even cognitive) limitations should not be barriers to expressing preferences and making decisions about the services they receive and about how they conduct their lives.” A.E. Benjamin, *Consumer-Directed Services at Home: A New Model for Persons with Disabilities*, 20 Health Aff. 80, 82-83 (2001). Although the concept of consumer direction originated in the disability rights movement, it has come to benefit older adults with chronic conditions who need help with activities of daily living, who may not identify as “persons with a disability” yet who welcome the option to make their own choices about needed Medicaid home care services. See A.E. Benjamin & Ruth E. Matthias, *Age, Consumer Direction, and Outcomes of Supportive Services at Home*, 41 Gerontologist 632 (2001) (finding that older personal care users generally embrace consumer direction and manage within it like younger users); AARP Public Policy Institute, *Consumer-Directed Personal Care Services for Older People in the U.S.*, Issue Brief No. 64, available at <http://goo.gl/B9q54C>.

In recent decades, states have vastly expanded the provision of consumer-directed personal assistance services under their Medicaid programs. See Batavia, *supra*; Benjamin, *supra*. In doing so, they have responded to the urgings of disability rights activists.⁶ Changes in Medicaid rules to encourage states to provide services and supports outside of institutional settings have contributed to this development.⁷ And this Court's own decision in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), which held that the ADA requires states to administer services in the most integrated setting appropriate to individuals with disabilities, played a crucial role in spurring the expansion of personal assistance services that promote community integration. See generally Brian J. Stout, Kristofer J. Hagglund & Mary J. Clark, *The Challenge of Financing and Delivering Personal Assistant Services*, 19 J. Disability Pol'y Stud. 44, 46-47 (2008) (describing how the disability rights movement, the ADA and the *Olmstead* decision, and

⁶ See A.E. Benjamin & Mary L. Fennell, *Putting the Consumer First: An Introduction and Overview*, 42 HSR: Health Services Res. 353 (2007); Dennis L. Kodner, *Consumer-Directed Services: Lessons and Implications for Integrated Systems of Care*, 3 Int'l J. Integrated Care 1 (2003).

⁷ The most important change was Congress's creation of the Home and Community-Based Services waiver program by adding Section 1915(c) to the Medicaid Act, now codified at 42 U.S.C. § 1396n(c), in 1983. Other crucial changes came in Medicaid Act provisions that authorized payment for home and community-based services as part of a state's Medicaid plan, see 42 U.S.C. § 1396n(i), (j), (k).

changes in Medicaid have led to increased reliance on consumer-directed personal assistance).

Medicaid-funded, consumer-directed personal assistance ensures that people with disabilities can achieve the goals of independent living. It does so by enabling people with disabilities to make effective choices about how to live their own lives, on a day-to-day and even minute-to-minute basis. It also frees people with disabilities of dependence on the uncompensated assistance of parents and other relatives. Reliance on parents – who are understandably paternalistic toward their (disabled *or* nondisabled) adult children – can undermine the independence and control that consumer-directed personal assistance provides to individuals with disabilities.⁸ Freeing

⁸ See Batavia, *supra*, at 21 (reliance on family members as personal assistants places “stress” on “their caregivers and their relationships with these individuals” and requires many consumers to “subvert their care preferences to the wills and schedules of their caregivers”); Batavia, DeJong & McKnew, *supra*, at 527 (reliance on family members can result in “an unhealthy dependency on family members, which diminishes opportunities for personal growth and independence”); Benjamin, *supra*, at 88 (noting “the argument from some disability advocates that family members should be the last choice in hiring, since familial ties complicate what should be an employer-employee relationship between consumers and workers”); A.E. Benjamin, Ruth Matthias & Todd M. Franke, *Comparing Consumer-Directed and Agency Models for Providing Supportive Services at Home*, 35 HSR: Health Services Res. 351, 362 (2000) (“Many advocates for younger adults with disabilities oppose the hiring of family members in service roles, because family ties are seen as constraints on the autonomy of consumers in selecting and directing their service workers.”); Brian R. Grossman,

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disabled adults from paternalistic restrictions on their choices has long been a key goal of the disability rights movement.⁹ The provision of consumer-directed services directly advances that key goal by giving people with disabilities the opportunity to obtain independence-promoting personal assistance from workers who are not their relatives. Although many individuals with disabilities have chosen to continue to receive assistance from relatives,¹⁰ many others do not have relatives who can provide assistance – and still others have made the choice to hire their assistants on the open market. A Medicaid program that promotes the availability of a robust personal-assistance workforce gives individuals with disabilities this important choice, increases the likelihood

Martin Kitchener, Joseph T. Mullan & Charlene Harrington, *Paid Personal Assistance Services: An Exploratory Study of Working-Age Consumers' Perspectives*, 19 *J. Aging & Social Pol'y* 27, 38 (2007) (“Although some respondents had access to informal care, they often did not want to rely on these individuals.”); Margaret A. Nosek & Carol A. Howland, *Personal Assistance Services: The Hub of the Policy Wheel for Community Integration of People with Severe Physical Disabilities*, 21 *Pol'y Stud. J.* 789, 791 (1993) (stating that reliance on family members as personal assistants “may cause role overload or a mixing of roles that can strain relationships to the breaking point” and that it is therefore “not safe to assume that family will always provide the best assistance”).

⁹ See, e.g., Samuel R. Bagenstos & Margo Schlanger, *Hedonic Damages, Hedonic Adaptation, and Disability*, 60 *Vand. L. Rev.* 745, 795 (2007).

¹⁰ Cf. Benjamin & Matthias, *supra*, at 636 (reporting that older users of consumer-directed services are more likely to choose to hire a relative).

that diverse individuals will find the right provider match, and enhances independence.

B. Sharing the Role of Employer Serves the Goals of Independent Living

Illinois's Medicaid program provides for personal assistance services "to prevent unnecessary institutionalization" and to "enabl[e]" eligible individuals with disabilities "to remain in their own homes or other living arrangements." 20 ILCS § 2405/3(f). Adopting a relationship that is common in the staffing-services and other industries, Illinois law allocates different aspects of the employer's role to the state and to the individual consumer. In keeping with the principles of independent living, Illinois law provides that the individual consumer with a disability has the power "to hire and fire" his or her own personal assistant, as well as to direct the tasks performed by that assistant on a day-to-day and minute-to-minute basis. *Id.*¹¹ But the law also provides that personal assistants shall be entitled to select a bargaining representative who engages in collective bargaining with the state concerning other "terms and conditions of employment that are within the State's control." *Id.*

Illinois's arrangement is similar to arrangements a number of other states have adopted for personal

¹¹ The personal assistant must meet certain state-imposed standards to be eligible for hire or continued employment. See 89 Ill. Admin. Code §§ 677.40, 686.10.

assistants hired under their Medicaid programs.¹² In Illinois as in these other states, the arrangement resulted from negotiations and discussions between the state, workers' advocates, organizations representing consumers with disabilities, and other stakeholders.¹³ The sharing of the employer role serves a key function in ensuring that Medicaid-funded personal assistance services in fact advance the goals of independent living.

These arrangements provide that, although the state pays the personal assistant's wages and controls

¹² See Cal. Welf. & Inst. Code § 12301.6; Conn. Gen. Stat. § 17b-706 *et seq.*; Md. Health-Gen. Code § 15-901 *et seq.*; 118E Mass. Gen. L. § 70 *et seq.*; Minn. Stat. § 179A.50 *et seq.*; Mo. Rev. Stat. § 208.856 *et seq.*; Or. Const. Art. XV, § 11; Or. Rev. Stat. § 410.595 *et seq.*; 21 Vt. Stat. Ann. § 1631 *et seq.*; Rev. Code Wash. § 74.39A.220 *et seq.*

¹³ See Eileen Boris & Jennifer Klein, *Caring for America: Home Health Workers in the Shadow of the Welfare State* 195-196, 215 (2012); Nari Rhee & Carol Zabin, *The Social Benefits of Unionization in the Long-Term Care Sector*, in *Academics on Employee Free Choice: Multidisciplinary Approaches to Labor Law Reform* 83, 85 (John Logan, ed., 2009). See also Patrice M. Mareschal, *Innovation and Adaptation: Contrasting Efforts to Organize Home Care Workers in Four States*, *Lab. Stud. J.*, Mar. 2006 at 25, 28-29 (describing how California's arrangement resulted from a coalition between the Service Employees International Union and "major senior and disability IHSS consumer groups, namely the California Foundation of Independent Living Centers and the California Senior Legislature"); Linda Delp & Katie Quan, *Homecare Worker Organizing in California: An Analysis of a Successful Strategy*, *Lab. Stud. J.*, Mar. 2002 at 1, 11-14 (same); Rivas, *supra* (same).

other terms and conditions of employment, the individual consumer with a disability has the power to hire, fire, and supervise the person who provides assistance to her. See Benjamin I. Sachs, *Labor Law Renewal*, 1 Harv. L. & Pol’y Rev. 375, 386 (2007) (“Reflective of the nature of the services provided by home care workers * * * , decisions regarding the hiring, firing, and supervision of workers are often reserved [under these bargaining arrangements] for the consumers of home care services * * * . Thus, such decisions may not be the subject of collective bargaining between workers and the public authorities.”). Some consumers choose to provide their own training to assistants to ensure that the services fit the individual consumer’s unique needs and preferences. Some programs, although not Illinois’s, offer eligible consumers the option to take responsibility for payments to providers to maximize flexibility in managing their own services.¹⁴ For purposes of those key aspects of the employment relationship – which directly advance the goals of independent living – the consumer is properly regarded as an employer of the personal assistant.

But there are other key terms and conditions of employment that many individual consumers – whether or not they had disabilities – would be unlikely to be able to provide themselves. In Illinois,

¹⁴ See, e.g., Cal. Welf. & Inst. Code § 12304 (giving eligible individuals with disabilities the option of advance cash payments for in-home services).

the state has retained the power to set workforce-wide terms and conditions like these, including: the setting of wages; the provision of benefits (such as health insurance and paid time off), which cannot be easily managed on a one-on-one basis; and the creation and management of systems for identifying prospective personal assistants, matching them with consumers willing to hire them, and administering payroll and tax matters. As one study found, “although [personal assistance services] recipients want to self-direct their supportive services, they generally report that the numerous employer-related fiscal/administrative tasks are onerous.” Teresa Scherzer, Alice Wong & Robert Newcomer, *Financial Management Services in Consumer-Directed Programs*, 26 *Home Health Care Services Q.* 29, 32 (2007). And many consumers report difficulties in soliciting, screening, and sorting applications for personal assistant positions. See Grossman et al., *supra*, at 37.

Because those aspects of the employment relationship cannot easily be managed by an individual consumer, the personal assistant workforce has proven unstable. “Consumers of PAS consistently report difficulty in recruiting and retaining personal assistants.” Stout et al., *supra*, at 45 (citation omitted). Many commentators have noted the “unacceptably

high rates of vacancies and turnover” among personal assistants. Rhee & Zabin, *supra*, at 84.¹⁵

As a result, many individuals with disabilities have been unable to obtain the services and supports that will promote their independence. Not only have individual consumers been unable to find personal assistants available for hire,¹⁶ turnover among providers has also had “a profoundly negative effect on consumers’ ability to achieve full community integration.” Stout et al., *supra*, at 45. Turnover among personal assistants increases the risk that individuals with disabilities will be reinstitutionalized. See Peggie R. Smith, *The Publicization of Home-Based Care Work in State Labor Law*, 92 Minn. L. Rev. 1390, 1395 (2008). Even in the best case, turnover requires consumers to bear the burden of continually training new personal assistants. See Charlene Harrington, Terence Ng, Stephen H. Kaye & Robert Newcomer,

¹⁵ See *id.* at 84-85 (noting that “[t]urnover rates range from 41 percent per year to over 71 percent per year in community settings,” and “80 to 90 percent of home-health aides leave their jobs within the first two years; 40 to 60 percent leave after less than one year”); Grossman et al., *supra*, at 36 (“Most respondents [to a survey of consumers] pointed out the problems in obtaining [personal assistance] providers because of the shortage of workers.”).

¹⁶ See RTZ Associates, Inc., *Impact of Health Benefits on Retention of Homecare Workers: A Two-Year Study of the IHSS Health Benefits Program in Los Angeles County* 13 (2004).

Home and Community-Based Services: Public Policies to Improve Access, Costs, and Quality (2009).¹⁷

The arrangements adopted by Illinois and other states represent an effort to solve this problem. Under these arrangements, the state controls the more systematic aspects of the employment relationship, which many individual consumers will have difficulty managing for themselves. When a representative selected by personal assistants negotiates with the state over those terms and conditions of employment, it is not engaged in “lobbying.” Cf. Pet. Br. 40. Rather, it is engaged in activity at the core of collective bargaining – negotiating a contract with the entity that controls key terms and conditions of employment. See *Knox v. SEIU, Local 1000*, 132 S. Ct. 2277, 2294 (2012) (reaffirming “the important difference between a union’s authority to engage in collective bargaining and related activities on behalf of nonmember employees in a bargaining unit and the union’s use of nonmembers’ money ‘to support candidates for public office’ or ‘to support political causes which [they] oppos[e].’”) (quoting *International Ass’n of Machinists v. Street*, 367 U.S. 740, 768

¹⁷ See also Robyn I. Stone, *The Direct Care Worker: The Third Rail of Home Care Policy*, 25 Ann. Rev. Pub. Health 521, 525 (2004) (noting that “problems with attracting and retaining direct care workers may translate into poorer quality and/or unsafe care, major disruptions in the continuity of care, and reduced access to care” and that “reduced availability and frequent churning of home care workers may affect clients’ physical and mental functioning”).

(1961); alterations in *Knox*). This collective bargaining takes place with the state, which is the employer that has authority over such core terms and conditions of employment as wages and benefits, while state law gives individual consumers the authority of employer for purposes of the decisions to hire, fire, and supervise the individuals who personally provide them services.

Adoption of this shared employment relationship promotes the goal of consumer control while helping to ensure that a stable and fairly compensated workforce of personal assistants will exist. Indeed, the sharing of the employer role responds directly to concerns expressed by disability rights activists. In California, for example, major organizations of people with disabilities insisted on provisions that retained consumer control in significant respects, by reserving for consumers the power of hiring, firing, and supervision, and by requiring that consumers represent a majority of the members of the board of each public authority (the agency that is the employer of record for collective-bargaining purposes).¹⁸ As we have

¹⁸ See Cal. Welf. & Inst. Code § 12301.6(c); Rivas, *supra*, at 6-9. See also Rhee & Zabin, *supra*, at 86 (noting that these reforms “preserved consumer choice in hiring and firing their own support workers”); Mareschal, *supra*, at 29 (explaining that under the California arrangement “consumers retained their right to hire, supervise, and fire their home care aides” and also “gained a voice in the administration of the IHSS program”).

shown, Illinois and other states similarly promote consumer control.¹⁹

But disability rights activists also recognized that much of the instability in the personal assistant workforce related to terms and conditions that individual consumers were unlikely to be able to affect. And they understood that collective bargaining between the workers and the state, which controlled *those* terms and conditions, could aid consumers. For example, many observers attribute the high degree of turnover among personal assistants to low wages and benefits (including inadequate health insurance coverage).²⁰ But it is the state, not individual consumers,

¹⁹ See 20 ILCS § 2405/3(f). See also Conn. Gen. Stat. § 17b-706a(e)(2)(A); Md. Health-Gen. Code § 15-907(b); 118E Mass. Gen. L. § 73(a); Minn. Stat. § 179A.54, Subd. 4; Mo. Rev. Stat. § 208.862.1; Or. Const. Art. XV, § 11(3)(c); 21 Vt. Stat. Ann. § 1640(a); Rev. Code Wash. § 74.39A.270(4).

²⁰ See Rhee & Zabin, *supra*, at 84; Alison Ashley, Sandra S. Butler & Nancy Fishwick, *Home Care Aides' Voices from the Field: Job Experiences of Personal Support Specialists – the Maine Home Care Worker Retention Study*, 7 Home Healthcare Nurse 399 (2010). See also Rivas, *supra*, at 3 (“One of the most intractable problems was the level of compensation received by personal attendants which, until the recent collaboration with the Service Employees International Union (SEIU), was rarely higher than minimum wage. While the low wages created hardship for the workers, consumers also found it difficult to attract and retain attendants with such low wages.”) (footnotes omitted); Kristin Smith & Reagan Baughman, *Caring for America's Aging Population: A Profile of the Direct-Care Workforce*, Monthly Lab. Rev., Sept. 2007, at 20 (describing the personal-assistant workforce as “a low-wage workforce with correspondingly low levels of health insurance coverage and

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that has control over these aspects of the employment relationship. Allowing personal assistants to bargain collectively with the state over those terms and conditions of employment could be expected to lead to increased wages and benefits, and decreased turnover – with the result of promoting the independence of individuals with disabilities who use assistance services. The evidence suggests that is exactly what has happened. Illinois’s arrangement and similar ones in California, Washington, Massachusetts, and Oregon have led to “substantial gains in wages and benefits” for personal assistants.²¹ And “available research indicates that wage and benefit increases due to collective bargaining have led to significantly lower worker turnover, greater availability of qualified

high levels of turnover”); Grossman et al., *supra*, at 37 (consumers surveyed “attributed the shortage of workers and the high turnover rates to inadequate wages (ranging from \$7-\$10 per hour) and benefits paid by public [personal assistance services] programs”); H. Stephen Kaye, Susan Chapman, Robert J. Newcomer & Charlene Harrington, *The Personal Assistance Workforce: Trends in Supply and Demand*, 25 Health Aff. 1113, 1114 (2006) (noting that “low wages, scarce health benefits, and irregular work schedules” for personal assistants “make it problematic to attract and retain qualified workers”); Stone, *supra*, at 522 (arguing that “low” wages and “inadequate” benefits “contribute to high vacancy and turnover rates among direct care workers”).

²¹ Rhee & Zabin, *supra*, at 87. See Smith, *supra*, at 1413 (describing significant wage and benefits gains for personal assistants following adoption of these arrangements in Illinois, Oregon, and Washington State); Sachs, *supra*, at 387 (describing significant wage gains for personal assistants following adoption of these arrangements in Illinois, California, and Oregon).

workers, and shorter gaps in services for consumers.”²²

But it is not just wages and benefits for which personal assistants may have an interest in bargaining collectively. As noted above, many consumers find it difficult to solicit, sort, and select applicants for personal assistance jobs. Personal-assistance workers share an interest in identifying consumers who will hire them. Workers in California, Oregon, and Washington have used their collective bargaining rights to negotiate over the design of referral registries, which facilitate matching between workers and consumers. As one study of the attitudes of personal assistance consumers found, many (though not necessarily all) consumers welcome the implementation of registries like these, because they make it easier for consumers to find and hire assistants who fit their needs and

²² Rhee & Zabin, *supra*, at 91. See Candace Howes, *Upgrading California’s Home Care Workforce: The Impact of Political Action and Unionization*, in *The State of California Labor, 2004* at 71 (Ruth Milkman, ed., 2004) (finding that unionization of personal assistants in California (under an arrangement similar to Illinois’s) led to improvements in wages and benefits and reduction in turnover); Nancy Folbre, *Demanding Quality: Worker/Consumer Coalitions and “High Road” Strategies in the Care Sector*, 34 *Pol. & Society* 1, 14 (2006) (noting that unionization of personal assistants in California and Oregon (under arrangements similar to the Illinois arrangement challenged here) “clearly improved wages and benefits, and also gave clients greater choice of caregivers”); RTZ Associates, Inc., *supra* (finding that the adoption of health care benefits for personal assistants pursuant to a collective bargaining arrangement like the one at issue here reduced worker turnover).

desires.²³ Both consumers and workers can also benefit from the creation of intermediaries that can manage some of the fiscal/administrative tasks that many (though not all) individual consumers find difficult to handle for themselves. See Harrington et al., *supra*. Because no individual consumer could set up a registry or intermediary, personal assistants must bargain with the state if they are to have a voice over these aspects of their employment. And collective bargaining, by promoting the creation of these entities, can serve the interest of both workers and consumers.

Finally, and perhaps most importantly, collective bargaining channels disputes over the terms and conditions of personal-assistance employment into the peaceful forum of a negotiating table. Consumers with disabilities and the workers who provide personal assistance do not agree on all issues relating to the terms and conditions of employment, but they do share an interest in providing a mechanism for peaceful resolution of disputes. Particularly given the essential contribution of personal assistance to the independence, integration, and freedom from institutionalization of people with disabilities, labor strife

²³ See Grossman et al., at 37 (“A number of respondents suggested that a registry of available [personal assistance services] providers should be created and managed by either the state or a local program. A registry could make the search for providers less work intensive and less costly (i.e., not having to place advertisements in local newspapers), especially in rural communities.”).

among the personal-assistant workforce could have profoundly negative consequences for consumers. It is notable in this regard that consumers have insisted, in a number of the collective bargaining regimes in this context, that personal assistants not be entitled to strike to obtain a bargaining advantage. See Rivas, *supra*, at 6-9; Sachs, *supra*, at 386.²⁴ By acceding to that insistence, the states have ensured that disputes over the terms and conditions of personal assistants' employment will not be disruptive of the lives and independence of people with disabilities. The state's interests in "maintaining peaceful labor relations," which this Court has held sufficient to justify an agency-fee regime, *Locke*, 555 U.S. at 213, take on heightened importance in this context.

The sharing of the employer role under Illinois's collective-bargaining arrangement for personal assistants thus directly serves the goals of independent living and consumer control for which disability rights activists have fought. Whether or not the arrangements set up by Illinois and other states would make the state an employer for purposes of the common law or federal statutes – an issue that is not presented in this case – those arrangements properly authorize

²⁴ See Md. Health-Gen. Code § 15-906; 118E Mass. Gen. L. § 73(d); Mo. Rev. Stat. § 208.862.6; Or. Const. Art. XV, § 11(3)(f); 21 Vt. Stat. Ann. § 1637(c)(4), (d); Rev. Code Wash. § 74.39A.270(2)(d). The collective bargaining agreement for Illinois personal assistants, available at <http://goo.gl/twJDGP>, contains a no-strike clause (Art. XII § 5).

personal assistants to engage in collective bargaining with the state over the terms and conditions of employment that the state manages, while empowering individual consumers to choose their own assistants and direct them on a day-to-day basis. Because the workers under this arrangement bargain collectively with the state over terms and conditions of employment, an agency-fee regime is constitutional under this Court's First Amendment cases. See *id.*

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CONCLUSION

The judgment of the court of appeals should be affirmed.

Respectfully submitted,

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Alphabetical List of *Amici*

Access Living is a Center for Independent Living in Chicago, Illinois, that serves and represents persons with disabilities. A cross-disability organization governed and staffed by a majority of people with disabilities, Access Living traces its roots to the independent living movement that began in the early 1970s. The independent living movement has as its fundamental principle that people with disabilities are entitled to the same civil rights, options and control over choices in their own lives as people without disabilities. Access Living provides personal assistant training and instruction and empowers consumers to hire, fire, and supervise the daily work of their personal assistants. Many of Access Living's clients directly benefit from consumer-directed services and the advantages of collective bargaining. Given its role, Access Living has a significant interest in the outcome of this litigation.

The mission of the **AIDS Foundation of Chicago (AFC)** is to lead the fight against HIV/AIDS and improve the lives of people affected by the epidemic. Founded in 1985 by community activists and physicians, AFC is a local and national leader in the fight against HIV/AIDS. AFC collaborates with community organizations to develop and improve HIV/AIDS services; fund and coordinate prevention, care, and advocacy projects; and champion effective, compassionate HIV/AIDS policy. The **AIDS Legal Council of Chicago (ALCC)** exists to preserve, promote and protect the legal rights of men, women and children

in the metropolitan Chicago area impacted by HIV. The Council provides direct legal services to people in need, educates the public about HIV-related legal issues, and advocates for social policies that ensure fair treatment for all people affected by HIV/AIDS. For the past two decades, AFC has administered the AIDS waiver on behalf of the Illinois Department of Rehabilitative Services (DRS). The AIDS waiver is a home and community-based waiver program that offers additional services to those living with symptomatic HIV or AIDS, in order to provide an alternative to hospitalization or institutional care. Today the AIDS waiver assists nearly 1,000 severely ill individuals and prevents institutionalization with the delivery of essential AIDS specialty community-based services. Personal assistants are an essential component to the effective coordination and operation of the program. A well-educated and trained personal assistant workforce assist clients in striving toward care and treatment adherence, self-management, and full independence.

The **American Association of People with Disabilities (AAPD)**, founded in 1995 and headquartered in Washington, D.C., is the largest national nonprofit disability rights organization in the United States. AAPD promotes equal opportunity, economic power, independent living, and political participation for people with disabilities. Its members, including people with disabilities and family, friends, and supporters, represent a powerful force for change. AAPD advocates for federal policy that expands

access to Medicaid funded home and community-based services, which includes incentives for states to expand access to these critical community living services. Advocating and promoting the adoption of joint-employer model by states which allow individuals to direct their Medicaid personal assistance services advances the independent living interest of people with disabilities. AAPD and its members benefit from a stable and appropriately compensated workforce who provide Medicaid personal assistance services and thus have a direct interest in the outcome of this litigation.

The **Boston Center for Independent Living (BCIL)**, founded in 1974, annually provides services to approximately 4,000 people with disabilities, assisting individuals to secure affordable housing, obtain benefits, get jobs, and address health care needs, among many things. As a Personal Care Management agency funded by the Massachusetts Medicaid program, BCIL assists over a thousand individuals to receive and manage their personal care attendant (PCA) services. This program has often been called “the most important independent living program there is” for people with disabilities needing assistance with activities of daily living. BCIL also advocates on issues of concern to the state’s disability community, giving top priority to issues surrounding the PCA program. Critical to sound operation of a program now serving over 27,400 consumers state-wide is a stable, adequately compensated workforce.

This is inextricably tied to the care and independence of those on the PCA program.

The **California Alliance for Retired Americans (CARA)** is California's largest, grassroots senior advocacy organization, representing over 950,000 seniors through our 250 affiliated organizations. CARA works on issues to improve the quality of life for seniors and their families, and is the state affiliate of the 4 million member national organization, the Alliance for Retired Americans. CARA advocates for the creation of a rational system for providing long-term services and supports so people can remain living safely in their home and in the community. This system must provide quality care for consumers of long-term services and quality jobs for the people who provide those services. In order to create quality jobs including health benefits, screening, and registry services, CARA supports a joint consumer-employer model for providing long-term services and supports and has a direct interest in the outcome of this litigation.

The **Center for Medicare Advocacy, Inc.**, provides information, education, and representation to older people and people with disabilities regarding fair access to Medicare and health care. The Center's work involves responding to over 7,000 calls and e-mails annually, producing educational materials, pursuing Medicare coverage for beneficiaries, and engaging in litigation of national significance – with a particular emphasis on issues of import to people with low incomes and long-term conditions. The

Center has a substantial interest and expertise in ensuring that due process and access to necessary, quality care are available to people with Medicare, Medicaid, and disabilities.

The **Congress of California Seniors (CCS)**, founded in 1977 and headquartered in Sacramento, California, is the most active senior advocacy and outreach organization in the state and one of the largest in the nation. CCS promotes public and private efforts to ensure that seniors and people with disabilities live in security and dignity and in the least restrictive environment of their choice. CCS encourages equal opportunity, economic power, independent living, and active public participation for seniors and people with disabilities. Over many years, CCS's members and affiliates, including seniors and their families, friends, providers, and supporters, have become a respected and powerful force for positive change. CCS advocates for state and federal budgets, laws, and policies that expand access to home and community-based services, which includes incentives for states to expand access to these critical community living services. The Congress of California Seniors and its members benefit from a stable and appropriately compensated workforce who provide Medicaid (Medi-Cal) personal assistance services and CCS, therefore, has a direct interest in the outcome of this litigation.

The **Disability Law Center (DLC)** is a statewide private nonprofit organization and the designated Protection and Advocacy ("P&A") system for the

Commonwealth of Massachusetts. As such, it operates under a federal mandate to protect and advocate for the rights of individuals with disabilities and to assist in educating policymakers. The mission of DLC is to provide legal advocacy on disability issues to promote the rights of people with disabilities to participate fully and equally in the social and economic life of Massachusetts. In pursuit of its mission, DLC has worked to expand and strengthen home and community-based services needed to allow individuals with disabilities to live and work independently in the community. Personal care attendant (“PCA”) services are often critical for DLC clients to have meaningful lives and avoid unnecessary segregation and institutionalization. To prevent any interruption of PCA services, which may jeopardize jobs, family relationships and independent living, DLC has worked to promote an organized, more stable and higher paid PCA workforce for its constituents. DLC has participated in policy advocacy related to the working conditions and oversight of the PCA program, which now includes union representation of 32,000 Massachusetts PCAs.

The **Disability Policy Consortium (DPC)** is the largest cross-disability advocacy organization in Massachusetts. DPC’s mission is to advocate for the full equality of and inclusion of people with disabilities into all aspects of our society. Many of its members are users of Personal Care Attendant services and have a profound interest and stake in the outcome of this case. Prior to Massachusetts’s creation of

a collective-bargaining regime for Personal Care Attendants, wages were low and the hiring of qualified attendants was difficult. Because of low wages, DPC members were competing with fast food franchises and retailers for providers of care. Because of the intimate and personal nature of the work, finding reputable, caring and sensitive employees is critical. This need combined with the low wage often put people with disabilities in untenable situations. Since unionization, wages have risen by more than 28% to \$12.98 per hour. This change has resulted in improved care for people living in the least restrictive environment, thus realizing the vision articulated in the *Olmstead* decision.

The **Disability Rights Education & Defense Fund (DREDF)**, based in Berkeley, California, is a national nonprofit law and policy center dedicated to advancing and protecting the civil rights of people with disabilities. Founded in 1979 by people with disabilities and parents of children with disabilities, DREDF remains board- and staff-led by members of the community it represents. Recognized for its expertise in the interpretation of federal and California disability civil rights laws, DREDF pursues its mission through education, advocacy and law reform efforts.

Disability Rights Oregon (DRO) is the Protection and Advocacy organization for Oregon. In this capacity, DRO advocates for safe, high quality community-based services for Oregonians with disabilities. These are services that are not only desired by DRO's clients

but also respect their rights under the Americans with Disabilities Act to receive publically funded services in the most integrated, appropriate settings. Oregon has a system like that in Illinois for the screening, certification, training and compensation of personal assistants who are hired, fired and directed by the recipients of those services. This structure has been in place for over ten years and has resulted in a more stable and competent workforce. A decision in this case that upsets Oregon's system would hurt the ability of DRO's clients to remain in their homes and communities with safe and competent assistance.

Easter Seals Massachusetts is a statewide, community-based organization that takes pride in its nearly 70 year history of assisting people of all ages to live full, independent and enriched lives. Easter Seals Massachusetts believes in the philosophy of independent living. Its mission is to provide services to ensure that children and adults with disabilities have equal opportunities to live, learn, work and play. Since its founding in 1944, Easter Seals has sustained an unwavering presence and maintained a resolute focus on its vision – that people with disabilities are empowered to reach their full potential. Easter Seals Massachusetts is governed by a locally-elected Board of Directors whose membership includes people with disabilities as well as parents of children with disabilities. Easter Seals Massachusetts advocated for the Massachusetts law, similar to the Illinois law under challenge here, that creates a collective bargaining arrangement for the individuals

who provide consumer-directed personal assistance services.

Equip for Equality (EFE), founded in 1985, is an independent, not-for-profit organization that administers the federally mandated protection and advocacy services in Illinois. EFE's mission is to advance the human and civil rights of children and adults with physical and mental disabilities in Illinois. One of the statutory mandates under which EFE operates is the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15001 *et seq.* A primary goal of the Act is to "provid[e] individuals with developmental disabilities with the information, skills, opportunities, and support to . . . live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens." 42 U.S.C. § 15001(16). Over the years, EFE has worked to effectuate this goal in Illinois by handling hundreds of cases on behalf of people with developmental disabilities seeking to live in the most integrated setting. EFE also is lead counsel in *Ligas v. Hamos*, a class action on behalf of thousands of people with disabilities living in institutions, or at risk of institutionalization, who are seeking community services. EFE also works to promote safe and effective community services through its public policy advocacy and its statutorily mandated monitoring activities, and supports efforts to increase resources for community-based services, including higher wages for community service providers. Because of EFE's expertise in working with people with developmental

disabilities, it has critical information and an important perspective to provide to the Court.

The **Health and Medicine Policy Research Group (HMPRG)** is a 30-year-old research and advocacy institute with a focus on Illinois public health and care for the poor and underserved. Through its Center for Long-Term Care Reform, HMPRG has played a leadership role in the balancing of long-term care services in support of culturally competent, high quality, and predominantly home-based long-term care for seniors and people with disabilities. HMPRG has built relationships with consumers, advocates for seniors and people with disabilities, policy makers, and labor organizations to pursue policies that enhance access to quality services, independent living, consumer direction, and a stable, fairly-compensated workforce in Illinois's long-term care system.

The **Illinois Network of Centers for Independent Living (INCIL)** is the statewide association whose members are the 22 Centers for Independent Living (CILs) in Illinois. INCIL advocates for full civil rights for people with disabilities, including the right to live in the community rather than in institutions, and to receive necessary supports and services in their homes. The services provided by home and community-based personal assistants (PAs) in Illinois are crucial to each consumer's ability to remain independent. Under Illinois law, consumers are entitled to hire, train, supervise and, if necessary, fire personal assistants of their choice, empowering them

to exercise full control over their supports and services. The state is the employer of record, managing payroll and taxes for PAs employed by consumers. This also allows PAs to organize for the purpose of collective bargaining, which has brought about reasonable wages and related benefits such as health care coverage. This in turn has developed a workforce of reliable and committed personal assistants who provide the quality of services so essential to independence. INCIL has a direct interest in maintaining the right of home and community-based personal assistants to have representation for collective bargaining so that this exemplary program will remain high quality and continue to assure the civil rights of people with disabilities.

The **Independent Living Center of the North Shore and Cape Ann, Inc. (ILCNSCA)** is the service and advocacy agency run by and for people with disabilities of all types and of all ages who live and work in the 25 municipalities from Melrose to Rockport, Massachusetts. ILCNSCA has consistently been successful in guiding many to live more independently, and for the community to be more inclusive of all, especially of those of us living with significant disabilities. ILCNSCA has assisted many individuals to leave skilled nursing facilities and live more independently with their chosen services and supports in their community. Many use consumer-directed Personal Care Attendant services. ILCNSCA is very concerned that without a trained, dynamic, competent and expanding workforce, PCA workers

will not be available to those of us who do not want to be in skilled nursing facilities. As advocates for independent living, choice, consumer control, and dignity of risk, ILCNSCA sees that the model developed in Massachusetts with a PCA Work Force Council consisting of consumer/employers, state government (funders), and a union is necessary for those of us who use PCA services to maintain our freedom.

The **Judge David L. Bazelon Center for Mental Health Law** is a national nonprofit advocacy organization that provides legal assistance to individuals with mental disabilities. The Center was founded in 1972 as the Mental Health Law Project. Through litigation, policy advocacy, training and education, the Center promotes the rights of individuals with mental disabilities to participate equally in all aspects of society, including housing, employment, education, health care, community living and other areas. The Center has devoted much of its resources to ensuring that individuals with disabilities have opportunities to live in their own homes with the services necessary to succeed. It has litigated numerous cases to enforce the ADA's integration mandate and the Olmstead decision, has engaged in policy advocacy to promote the availability of services that enable individuals with disabilities to live in their own homes, and has served as a resource for lawyers and advocates addressing these issues across the country.

The **National Consumer Voice for Quality Long Term Care** (formerly NCCNHR) was formed in 1975

to advocate for quality for people with long-term care needs. The Consumer Voice advocates for public policies that support quality care and quality of life responsive to consumers' needs in all long-term care settings; empowers and educates consumers and families with the knowledge and tools they need for self-advocacy; trains and supports individuals and groups that empower and advocate for long-term care consumers; and promote the critical role of direct care workers and best practices in quality care delivery. The Consumer Voice has long held that a strong, stable, well-trained workforce is critical for quality of care and quality of life for individuals receiving long-term services and supports.

The **National Council on Aging (NCOA)** is the nation's leading nonprofit service and advocacy organization representing older adults and the community organizations that serve them. Its goal is to improve the health, independence, and economic security of 10 million older adults by 2020. For more than 60 years, NCOA has been a trusted voice and innovative problem-solver helping seniors navigate the challenges of aging in America. NCOA works with local and national partners to give older adults tools and information to stay healthy and secure, and it advocates for programs and policies to improve the lives of all seniors and people with disabilities, especially the most vulnerable. NCOA works closely with disability organizations and organizations representing direct care workers. It leads a collaborative of 38 national aging and disability organizations working

together to advance long-term services and supports policy. NCOA strongly supports options for self-direction, access to home and community-based services, and the availability of an adequate direct care workforce to meet current and future needs for long-term services and supports as our population ages.

The **National Senior Citizens Law Center (NSCLC)** is a nonprofit organization that advocates for the independence and well-being of low-income older persons and people with disabilities. For more than 40 years, NSCLC has served these populations through litigation, administrative advocacy, legislative advocacy, and assistance to legal aid attorneys and other local advocates. Our goal is to strengthen the public benefits programs that allow low-income older adults to live with dignity and independence. NSCLC has participated as class counsel in numerous lawsuits to preserve or expand older adults and persons with disabilities' access to Medicaid, including representing self-directing consumers of personal care services in California, where provider wages and benefits are subject to collective bargaining.

For more than a quarter century, **Puget Sound Advocates for Retirement Action (PSARA)** has been active in fighting for older Americans, their children and their families. PSARA's efforts are based on the belief that seniors, our children and grandchildren need and deserve a lifelong, adequate, dependable income; comprehensive, affordable health care, including prescription drug coverage; taxes and

utility bills we can handle; access to affordable housing, transportation, and social services; support for our family caregiving responsibilities; and quality time to relax and enjoy life with family and friends. Tens of thousands of Washington's seniors depend on Washington's Medicaid home care program to live independently and with dignity in their homes and communities. PSARA members benefit from a well-trained, well-compensated and stable workforce to provide this vital service and therefore have a direct interest in this case.

The **Sargent Shriver National Center on Poverty Law (Shriver Center)** is a proponent of anti-poverty measures and focuses on policy and legal matters in housing, health care, employment, public benefits, criminal justice, and education. Advocating for efforts to increase and maintain access to quality health care is critical to the Shriver Center's multi-pronged approach to decrease poverty and its impact on communities. As part of these efforts, the Shriver Center supports collective bargaining, which results in a more stable personal assistant workforce for Medicaid recipients, particularly for persons with disabilities. These resources increase opportunities for individuals facing economic challenges to make better lives for themselves and their families. The Shriver Center supports Respondent's arguments and has a compelling interest in the outcome of this case.

Stavros Center for Independent Living, Inc., serves more than 6,000 persons with disabilities each

year in the western Massachusetts counties of Franklin, Hampden, and Hampshire. Founded in 1974, Stavros was the third independent living center to be established in the United States. Central to its work – through the provision of personal care attendant services (3,800 people), nursing home transition services (about 40 each year), ramp construction (about 50 each year), and the refurbishing and recycling of durable medical equipment (about 500 pieces of equipment each year) – is helping people live in their own homes. Stavros has learned from experience that for many, many disabled individuals real freedom depends on the availability of personal care attendants, and that this, in turn, depends on a well-compensated and well-trained workforce. For the disability community, the availability of good and reliable attendants promotes access to jobs, education, and participation in all aspects of life, as well as health and safety.

United Spinal Association is the largest disability-led nonprofit organization serving and representing the interests of more than a million Americans living with spinal cord injuries and disorders (SCI/D). Founded in 1946 by paralyzed veterans, it has approximately 40,000 members in all 50 states and reaches out to these individuals through 42 chapters and 200 support groups. Throughout its history, United Spinal Association has dedicated its energy and programs to improving the quality of life for these Americans of all ages and advancing their independence. Many of United Spinal Association's

members rely on quality personal assistant services to participate fully in their communities and live in the settings they choose.

The **Washington Association of Area Agencies on Aging (W4A)** is a membership organization made up of 13 Area Agencies on Aging (AAA) in Washington State. The organization seeks to enhance the effectiveness of each AAA through a strong agenda of information, debate, advocacy and education. The Area Agencies on Aging directly provide services and supports to elders and adults with disabilities including case management, information and assistance, community living connections, and family caregiver supports and services. The AAAs also contract with a wide range of community agencies and organization providing services to the elderly and younger people with disabilities. W4A members work directly with Washington's home care aides to provide quality in-home services to seniors and people with disabilities. W4A has a direct interest in this case because of the potential impact on Washington's successful home and community-based long-term care system.

The mission of the **World Institute on Disability (WID)** in communities and nations worldwide is to eliminate barriers to full social integration and increase employment, economic security and health care for persons with disabilities. WID creates innovative programs and tools; conducts research, training, public education and advocacy campaigns; and provides technical assistance. An internationally recognized public policy center founded in 1983 by

three leaders of the Independent Living Movement – Ed Roberts, Judy Heumann, and Joan Leon – WID’s program work focuses on issues and problems that directly affect people’s ability to live full and independent lives. A majority of WID’s board and staff are persons with disabilities.
