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UNITED STATES DISTRICT COURT

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NORTHERN DISTRICT OF CALIFORNIA, SAN FRANCISCO DIVISION

10

11 STATE OF CALIFORNIA et al.,

12 Plaintiffs,

13 and

14 SERVICE EMPLOYEES  
INTERNATIONAL UNION LOCAL 503  
15 et al.,

16 Plaintiff-Intervenors,

17 v.

18 ALEX M. AZAR II et al.,

19 Defendants.

Case No. 3:19-cv-02552-VC

**BRIEF OF AMICI CURIAE  
DISABILITY RIGHTS  
ORGANIZATIONS,  
ORGANIZATIONS OF PERSONS  
WITH DISABILITIES AND SENIOR  
CITIZENS IN SUPPORT OF  
PLAINTIFFS AND PLAINTIFF-  
INTERVENORS**

Judge: Hon. Vince Chhabria

Date: Feb. 12, 2020

Time: 10:00 a.m.

Crtrm.: 4, 17th Floor

Complaint Filed: May 13, 2019

Trial Date: None Set

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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. This case involves personal assistance services provided pursuant to the model of consumer direction. Under that model, the individual consumer with a disability has the power to hire, fire, and supervise the person who provides her services, while the state has the power to set other key terms and conditions of employment. Consumer-directed personal assistance services help to implement the philosophy of independent living and the principle of consumer control for which the disability rights movement has fought very hard.

Plaintiffs challenge a Final Rule that would forbid the individuals who provide consumer-directed personal assistance services from agreeing to have union dues, health insurance, and other benefits deducted from their paychecks. *Amici* support Plaintiffs' challenge. *Amici* believe that the final rule, by weakening the unions that represent workers in consumer-directed systems, will harm disabled individuals by promoting turnover and instability in the personal-assistance workforce. *Amici* are listed and described in the appendix to this brief.

**ARGUMENT**

**I. 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.<sup>1</sup> As Ed Roberts, one of the early

<sup>1</sup> See Edward Berkowitz, *Disabled Policy: America's Programs for the Handicapped* 197-

1 leaders of the American disability rights movement, described that philosophy, the concept  
2 of “independent living”

3 meant active participation in society—working, having a home, raising a  
4 family, and generally sharing in the joys and responsibilities of community  
5 life. Independent living meant freedom from isolation and  
6 institutionalization; it meant the ability to choose where to live, how to live,  
7 and how to carry out the activities of daily living that most able-bodied  
8 people take for granted.<sup>2</sup>

9 The Americans with Disabilities Act explicitly embraces the philosophy of independent  
10 living. *See* 42 U.S.C. § 12101(a)(7) (finding that “the Nation’s proper goals regarding  
11 individuals with disabilities are to assure equality of opportunity, full participation,  
12 independent living, and economic self-sufficiency for such individuals”).

13 Personal assistance services, controlled by individuals with disabilities themselves,  
14 can be a crucial tool for making independent living a reality—if a stable workforce is  
15 available. *See* Andrew I. Batavia, “A Right to Personal Assistance Services: ‘Most  
16 Integrated Setting Appropriate’ Requirements and the Independent Living Model of Long-  
17 Term Care,” *27 Am. J. L. & Med.* 17, 20 (2001) (“Access to consumer-directed personal  
18 assistance services is also one of the foundational policy issues of the independent living  
19 movement, in which disability rights advocates have struggled for the past three decades to  
20 empower people with disabilities to live independently in their communities, rather than in  
21 institutions.”).<sup>3</sup> Many individuals with disabilities cannot physically carry out various  
22 tasks of daily life. But they are fully capable of deciding for themselves what tasks to

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23 207 (1987); James I. Charlton, *Nothing About Us Without Us: Disability Oppression And*  
24 *Empowerment* 130-32 (1998); Gerben DeJong, “Defining and Implementing the  
25 Independent Living Concept,” *in Independent Living For Physically Disabled People* 4, 8  
26 (Nancy M. Crewe & Irving Kenneth Zola, eds., 1983).

27 <sup>2</sup> Edward V. Roberts, “A History of the Independent Living Movement: A Founder’s  
28 Perspective,” *in Psychosocial Interventions With Physically Disabled Persons* 231, 237  
(Bruce W. Heller et al., eds., 1989).

<sup>3</sup> *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 personal assistance  
services to achieving the goals of independent living).

1 undertake and how to do so. The independent living philosophy posits that this sort of  
 2 *decisional* autonomy is the key aspect of independence. In the words of another leading  
 3 disability rights activist, “The Independent Living Movement argues that it is more  
 4 important for us to have full control over our lives than over our bodies. We will give up  
 5 doing some things for ourselves if we can determine when and how they are to be done.”<sup>4</sup>

6 Consumer-directed personal assistance gives individuals with disabilities this sort of  
 7 control. An individual with a disability hires and directs a “personal assistant” to perform  
 8 the tasks that the disabled person cannot physically perform herself. The personal assistant  
 9 acts “as an extension of the disabled person and follows the individual’s directions as to  
 10 how to meet his or her needs.” Andrew I. Batavia, Gerben DeJong & Louise Bouscaren  
 11 McKnew, “Toward a National Personal Assistance Program: The Independent Living  
 12 Model of Long-Term Care for Persons with Disabilities,” 16 *J. Health Pol., Pol’y & L.*  
 13 523, 529 (1991). Consumer-directed personal assistance “is based on the premise that  
 14 persons with disabilities should be empowered to live as independently as possible and that  
 15 physical (and even cognitive) limitations should not be barriers to expressing preferences  
 16 and making decisions about the services they receive and about how they conduct their  
 17 lives.” A.E. Benjamin, “Consumer-Directed Services at Home: A New Model for Persons  
 18 with Disabilities,” 20 *Health Aff.* 80, 82-83 (2001). Although the concept of consumer  
 19 direction originated in the disability rights movement, it has come to benefit older adults  
 20 with chronic conditions who need help with activities of daily living, who may not identify  
 21 as “persons with a disability” yet who welcome the option to make their own choices about  
 22 needed Medicaid home care services. See A.E. Benjamin & Ruth E. Matthias, “Age,  
 23 Consumer Direction, and Outcomes of Supportive Services at Home,” 41 *Gerontologist*  
 24

25 <sup>4</sup> Irving Kenneth Zola, “Developing New Self-Images and Interdependence,” in  
 26 *Independent Living For Physically Disabled People, supra*, at 49, 58; see also Adrienne  
 27 Asch, “Disability, Bioethics, and Human Rights,” in *Handbook Of Disability Studies* 297,  
 28 313 (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”).

1 632 (2001) (finding that older personal care users generally embrace consumer direction  
 2 and manage within it like younger users); AARP Public Policy Institute, *Consumer-*  
 3 *Directed Personal Care Services for Older People in the U.S.*, Issue Brief No. 64,  
 4 available at [https://assets.aarp.org/rgcenter/health/ib64\\_cd.pdf](https://assets.aarp.org/rgcenter/health/ib64_cd.pdf). (accessed Nov. 20, 2019).

5 In recent decades, states have vastly expanded the provision of consumer-directed  
 6 personal assistance services under their Medicaid programs. See Batavia, *supra*;  
 7 Benjamin, *supra*. California’s In-Home Supportive Systems program, for example,  
 8 employs “approximately 509,000 individuals” to “serve more than 540,000 IHSS  
 9 recipients.” Justice in Aging, *In-Home Supportive Services: A Guide for Advocates* 79  
 10 (June 2019), [https://www.justiceinaging.org/wp-content/uploads/2019/06/Final\\_IHSS-](https://www.justiceinaging.org/wp-content/uploads/2019/06/Final_IHSS-Adocate-Manual.pdf)  
 11 [Adocate-Manual.pdf](https://www.justiceinaging.org/wp-content/uploads/2019/06/Final_IHSS-Adocate-Manual.pdf) (accessed. Nov. 20, 2019)

12 States adopted and expanded these programs in response to the urgings of disability  
 13 rights activists.<sup>5</sup> Changes in Medicaid rules to encourage states to provide services and  
 14 supports outside of institutional settings have contributed to this development.<sup>6</sup> And the  
 15 Supreme Court’s decision in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), which  
 16 held that the ADA requires states to administer services in the most integrated setting  
 17 appropriate to individuals with disabilities, played a crucial role in spurring the expansion  
 18 of personal assistance services that promote community integration. See generally Brian J.  
 19 Stout, Kristofer J. Hagglund & Mary J. Clark, “The Challenge of Financing and Delivering  
 20 Personal Assistant Services,” 19 *J. Disability Pol’y Stud.* 44, 46-47 (2008) (describing how  
 21 the disability rights movement, the ADA and the *Olmstead* decision, and changes in  
 22 Medicaid have led to increased reliance on consumer-directed personal assistance).  
 23

24 <sup>5</sup> See A.E. Benjamin & Mary L. Fennell, “Putting the Consumer First: An Introduction and  
 25 Overview,” 42 *HSR: Health Services Res.* 353 (2007); Dennis L. Kodner, “Consumer-  
 26 Directed Services: Lessons and Implications for Integrated Systems of Care,” 3 *Int’l J.*  
 27 *Integrated Care* 1 (2003).

28 <sup>6</sup> 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).

1 Medicaid-funded, consumer-directed personal assistance ensures that people with  
 2 disabilities can achieve the goals of independent living. It does so by enabling people with  
 3 disabilities to make effective choices about how to live their own lives, on a day-to-day  
 4 and even minute-to-minute basis. It also frees people with disabilities of dependence on  
 5 the uncompensated assistance of parents, adult children, and other relatives. Reliance on  
 6 family members can undermine the independence and control that consumer-directed  
 7 personal assistance provides to individuals with disabilities.<sup>7</sup> Freeing disabled adults from  
 8 (perhaps well-meaning) restrictions on their choices has long been a key goal of the  
 9 disability rights movement.<sup>8</sup> The provision of consumer-directed services directly  
 10 advances that key goal by giving people with disabilities the opportunity to obtain  
 11 independence-promoting personal assistance from workers who are not their relatives. (It  
 12 also has the collateral effect of relieving family members of the burden of providing care.)  
 13 Although many individuals with disabilities have chosen to continue to receive assistance

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 16 <sup>7</sup> See Batavia, *supra*, at 21 (reliance on family members as personal assistants places  
 17 “stress” on “their caregivers and their relationships with these individuals” and requires  
 18 many consumers to “subvert their care preferences to the wills and schedules of their  
 19 caregivers”); Batavia, DeJong & McKnew, *supra*, at 527 (reliance on family members can  
 20 result in “an unhealthy dependency on family members, which diminishes opportunities  
 21 for personal growth and independence”); Benjamin, *supra*, at 88 (noting “the argument  
 22 from some disability advocates that family members should be the last choice in hiring,  
 23 since familial ties complicate what should be an employer-employee relationship between  
 24 consumers and workers”); A.E. Benjamin, Ruth Matthias & Todd M. Franke, “Comparing  
 25 Consumer-Directed and Agency Models for Providing Supportive Services at Home,” 35  
 26 *HSR: Health Services Res.* 351, 362 (2000) (“Many advocates for younger adults with  
 27 disabilities oppose the hiring of family members in service roles, because family ties are  
 28 seen as constraints on the autonomy of consumers in selecting and directing their service  
 workers.”); Brian R. Grossman, 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”).

<sup>8</sup> See, e.g., Samuel R. Bagenstos & Margo Schlanger, “Hedonic Damages, Hedonic  
 Adaptation, and Disability,” 60 *Vand. L. Rev.* 745, 795 (2007).

1 from relatives,<sup>9</sup> many others do not have family members who can provide assistance—  
 2 and still others have made the choice to hire their assistants on the open market. A  
 3 Medicaid program that promotes the availability of a robust personal-assistance workforce  
 4 gives individuals with disabilities this important choice, increases the likelihood that  
 5 diverse individuals will find the right provider match, and enhances independence.

6 **II. THE FINAL RULE WILL HARM DISABLED INDIVIDUALS BY**  
 7 **CREATING INSTABILITY AND TURNOVER IN THE PERSONAL-**  
 8 **ASSISTANCE WORKFORCE**

9 Consumer-directed personal assistance can thus play a key role in promoting  
 10 independence among people with disabilities and helping them avoid institutionalization.  
 11 But there is an obstacle to the success of consumer-directed programs: high turnover and  
 12 instability in the labor market for personal-assistance workers. By weakening the unions  
 13 that represent these workers, the Final Rule will create even more turnover and instability.

14 Consumers “consistently report difficulty in recruiting and retaining personal  
 15 assistants.” Stout *et al.*, *supra*, at 45 (citation omitted). Many commentators have noted  
 16 the “unacceptably high rates of vacancies and turnover” among personal assistants. Nari  
 17 Rhee & Carol Zabin, “The Social Benefits of Unionization in the Long-Term Care Sector,”  
 18 *in Academics on Employee Free Choice: Multidisciplinary Approaches to Labor Law*  
 19 *Reform* 83, 84 (John Logan, ed., 2009).<sup>10</sup>

20 As a result, many individuals with disabilities have been unable to obtain the  
 21 services and supports that will promote their independence. Not only have individual  
 22 consumers been unable to find personal assistants available for hire,<sup>11</sup> but turnover among

23 <sup>9</sup> Cf. Benjamin & Matthias, *supra*, at 636 (reporting that older users of consumer-directed  
 24 services are more likely to choose to hire a relative).

25 <sup>10</sup> See *id.* at 84-85 (noting that “[t]urnover rates range from 41 percent per year to over 71  
 26 percent per year in community settings,” and “80 to 90 percent of home-health aides leave  
 27 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.”).

28 <sup>11</sup> 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).



1 providers has also had “a profoundly negative effect on consumers’ ability to achieve full  
 2 community integration.” Stout *et al.*, *supra*, at 45. Turnover among personal assistants  
 3 increases the risk that individuals with disabilities will be reinstitutionalized. See  
 4 Peggie R. Smith, “The Publicization of Home-Based Care Work in State Labor Law,” 92  
 5 *Minn. L. Rev.* 1390, 1395 (2008). Even in the best case, turnover requires consumers to  
 6 bear the burden of continually training new personal assistants. See Charlene Harrington,  
 7 Terence Ng, Stephen H. Kaye & Robert Newcomer, *Home and Community-Based*  
 8 *Services: Public Policies to Improve Access, Costs, And Quality* (2009).<sup>12</sup>

9 Unionization of personal-assistance workers helps to address these problems. The  
 10 high rate of turnover among personal assistants stems largely from low wages and benefits  
 11 (including inadequate health insurance coverage).<sup>13</sup> But it is the state, not individual  
 12 consumers, that has control over these aspects of the employment relationship. When  
 13 personal assistants can bargain collectively over those terms and conditions of  
 14

15 <sup>12</sup> See also Robyn I. Stone, “The Direct Care Worker: The Third Rail of Home Care  
 16 Policy,” 25 *Ann. Rev. Pub. Health* 521, 525 (2004) (noting that “problems with attracting  
 17 and retaining direct care workers may translate into poorer quality and/or unsafe care,  
 18 major disruptions in the continuity of care, and reduced access to care” and that “reduced  
 19 availability and frequent churning of home care workers may affect clients’ physical and  
 20 mental functioning”).

21 <sup>13</sup> See Rhee & Zabin, *supra*, at 84; Alison Ashley, Sandra S. Butler & Nancy Fishwick,  
 22 “Home Care Aides’ Voices from the Field: Job Experiences of Personal Support  
 23 Specialists—the Maine Home Care Worker Retention Study,” 7 *Home Healthcare Nurse*  
 24 399 (2010); see also Rivas, *supra*, at 3 (“One of the most intractable problems was the  
 25 level of compensation received by personal attendants which, until the recent collaboration  
 26 with the Service Employees International Union (SEIU), was rarely higher than minimum  
 27 wage. While the low wages created hardship for the workers, consumers also found it  
 28 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 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”).

1 employment, they obtain leverage to improve their wages and benefits, resulting in  
 2 decreased turnover—with the ultimate consequence of advancing the independence of  
 3 disabled individuals who use assistance services. The evidence suggests that is exactly  
 4 what has happened. When California, Washington, Massachusetts, Illinois, and Oregon  
 5 allowed personal assistants to unionize, the result was “substantial gains in wages and  
 6 benefits.”<sup>14</sup> And “available research indicates that wage and benefit increases due to  
 7 collective bargaining have led to significantly lower worker turnover, greater availability  
 8 of qualified workers, and shorter gaps in services for consumers.”<sup>15</sup>

9 The Final Rule will undermine unionization and collective bargaining among  
 10 personal-assistance workers. Indeed, Plaintiffs make a forceful argument that the very  
 11 point of the Rule is to achieve that result. The Final Rule will prohibit personal assistants  
 12 from agreeing to have their union dues automatically deducted from their paychecks. It  
 13 will thus invalidate a key term that commonly appears in the collective bargaining  
 14 agreements of workers in public programs. *See, e.g.*, Kenneth Bullock, “Official Time as a  
 15 Form of Union Security in Federal Sector Labor-Management Relations,” 59 *A.F. L. Rev.*  
 16 153, 160–61 (2007) (noting ubiquity of dues check-off provisions in collective bargaining  
 17 agreements in the public and private sectors). In so doing, the Final Rule will deprive  
 18 unions of the resources they need to be effective bargaining agents—resources that

19 \_\_\_\_\_  
 20 <sup>14</sup> Rhee & Zabin, *supra*, at 87; *see* Smith, *supra*, at 1413 (describing significant wage and  
 21 benefits gains for personal assistants following adoption of these arrangements in Illinois,  
 22 Oregon, and Washington State); Benjamin I. Sachs, “Labor Law Renewal,” 1 *Harv. L. &*  
*Pol’y Rev.* 375, 387 (2007) (describing significant wage gains for personal assistants  
 following adoption of these arrangements in Illinois, California, and Oregon).

23 <sup>15</sup> Rhee & Zabin, *supra*, at 91; *see* Candace Howes, “Upgrading California’s Home Care  
 24 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  
 25 assistants in California (under an arrangement similar to Illinois’s) led to improvements in  
 26 wages and benefits and reduction in turnover); Nancy Folbre, “Demanding Quality:  
 27 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  
 28 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).

1 personal-assistance workers have agreed to provide in exchange for representation. *See*,  
2 *e.g.*, Ann C. Hodges, “Maintaining Union Resources in an Era of Public-Sector Bargaining  
3 Retrenchment,” 16 *Emp. Rts. & Emp. Pol’y J.* 599, 605–06 (2012) (noting importance of  
4 dues check-off provisions in maintaining union resources).

5 By weakening the unions that represent personal-assistance workers, the Final Rule  
6 will deprive them of needed leverage to negotiate for increased wages and benefits. The  
7 consequence will be to exacerbate the instability and turnover in the job market for  
8 personal assistants, and ultimately to deprive individuals with disabilities of the supports  
9 they need to promote independence and avoid institutionalization. It may also drive the  
10 workforce to find employment at home care agencies, which are not covered by the Final  
11 Rule—and which do not provide disabled individuals the same sort of independence and  
12 control as do consumer-directed services. The Final Rule thus threatens to undermine the  
13 interests of people with disabilities.

14 **CONCLUSION**

15 This Court should invalidate the Final Rule.

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17 DATED: November 22, 2019

Respectfully submitted,

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ROSEN BIEN GALVAN & GRUNFELD LLP

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By: /s/ Ernest Galvan

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Ernest Galvan

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Attorneys for *Amici Curiae*

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1 **APPENDIX**

2 *Identification of Amici Curiae*

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

10 **Justice in Aging** is a non-profit organization with the mission of improving the  
11 lives of low-income older adults living in the United States. For 47 years, Justice in Aging  
12 has used the power of law to fight senior poverty by securing access to affordable health  
13 care, economic security, and the courts for older adults with limited resources. Justice in  
14 Aging works to secure the opportunity for older adults to live with dignity, regardless of  
15 financial circumstances—free from the worry, harm, and injustice caused by lack of health  
16 care, food, or a safe place to sleep.

17 **The Disability Law Center** is the designated protection and advocacy system for  
18 people with disabilities in Massachusetts and is mandated pursuant to federal law to  
19 protect and advocate for the rights of individuals who have disabilities. See 42 U.S.C. §  
20 10805 (persons with mental illness); 42 U.S.C. § 15043 (persons with developmental  
21 disabilities), 29 U.S.C. § 794e (persons with other disabilities, including physical  
22 disabilities); 42 U.S.C. § 300d-53 (persons with traumatic brain injury). DLC's mission  
23 includes promoting the right of all people with disabilities to have the opportunity to  
24 participate fully and equally in every aspect of society. Accordingly, DLC is dedicated to  
25 the principle of self-determination for persons with disabilities and to ensuring that access  
26 and accommodations are readily available throughout the Commonwealth.

27 **Disability Rights California** (formerly known as Protection and Advocacy, Inc.),  
28 is a nonprofit agency established under federal law to protect, advocate for and advance

1 the human, legal and service rights of Californians with disabilities. Disability Rights  
2 California works in partnership with people with disabilities, striving towards a society  
3 that values all people and supports their rights to dignity, freedom, choice, and quality of  
4 life. Since 1978, Disability Rights California has provided essential legal services to  
5 people with disabilities. In the last year, Disability Rights California provided legal  
6 assistance on nearly 26,000 matters to individuals with disabilities, including impact  
7 litigation and direct representation. Disability Rights California has extensive policy and  
8 litigation experience securing the rights of people with disabilities to public benefits.

9       **The California Long-Term Care Education Center** provides educational  
10 opportunities as tools of empowerment for long-term care workers to build better lives,  
11 provide quality care and meet and invest in, the critical needs of the long-term care  
12 workforce. It offers evidence-informed training for IHSS home care providers and the  
13 seniors and persons with disabilities to whom they provide services.

14       **Access Living** is a Center for Independent Living for people with disabilities  
15 established pursuant to the Rehabilitation Act, 29 U.S.C. § 796f. Access Living is  
16 governed and staffed by a majority of people with disabilities, including both physical and  
17 mental disabilities. Access Living’s statutorily mandated mission includes ensuring that  
18 people with disabilities have equal access to and participation in services, programs,  
19 activities, resources and facilities, whether public or private. See *id.* § 796f-4(b)(1)(D).  
20 Located in Chicago, Access Living is the largest Center for Independent Living in Illinois  
21 and one of the nation’s first and largest. One of its central aims is to ensure people with  
22 disabilities have the opportunity to integrate fully into the communities of their choosing.  
23 To that end, Access Living has historically provided services, supports, and advocacy to  
24 enable people with disabilities to live in integrated communities.

25       **Equip for Equality** (“EFE”), founded in 1985, is an independent, non-profit  
26 organization that administers the federally-mandated protection and advocacy system in  
27 Illinois. EFE’s mission is to advance the human and civil rights of people with disabilities  
28 in Illinois. A primary focus of EFE is to advocate through individual advocacy and

1 systemic litigation for people with disabilities to live in the most integrated setting. EFE  
2 has promoted the full inclusion of people with disabilities by advocating for increased  
3 community-based services, including adequate wages for community service workers.  
4 Most recently, in *Ligas v. Eagleson*, No. 05-cv-4331 (N.D. Ill.), a community integration  
5 class action, EFE brought a Motion to Enforce the Consent Decree and successfully argued  
6 that inadequate wages for disability service professionals were adversely impacting the  
7 rights of class members to fully participate in their community. Because of EFE's expertise  
8 in working with people with disabilities who depend on adequately funded personal  
9 assistance, it has critical information and an important perspective to provide to this Court.

10       The **National Disability Rights Network** (NDRN) is the non-profit membership  
11 organization for the federally mandated Protection and Advocacy (P&A) and Client  
12 Assistance Program (CAP) agencies for individuals with disabilities. The P&A and CAP  
13 agencies were established by the United States Congress to protect the rights of people  
14 with disabilities and their families through legal support, advocacy, referral, and education.  
15 There are P&As and CAPs in all 50 states, the District of Columbia, Puerto Rico, and the  
16 U.S. Territories (American Samoa, Guam, Northern Mariana Islands, and the US Virgin  
17 Islands), and there is a P&A and CAP affiliated with the Native American Consortium  
18 which includes the Hopi, Navajo and San Juan Southern Paiute Nations in the Four  
19 Corners region of the Southwest. Collectively, the P&A and CAP agencies are the largest  
20 provider of legally based advocacy services to people with disabilities in the United States.

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