Appeal No. 09-17581

UNITED STATES COURT OF APPEALS FOR THE NINTH CIRCUIT

David Oster, et al., *Plaintiffs and Appellees,*

v.

John A. Wagner, et al., *Defendants and Appellants.*

ON APPEAL FROM THE UNITED STATES DISTRICT COURT
FOR THE NORTHERN DISTRICT OF CALIFORNIA
THE HONORABLE CLAUDIA WILKEN
CASE NO. CV 09-4668 CW

BRIEF OF *AMICI CURIAE* IN SUPPORT OF AN AFFIRMANCE

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I. Interest of Amici Curiae

Amici Curiae Communities Actively Living Independent & Free, California State organization of the National Alliance on Mental Illness, Disability Rights Education and Defense Fund, Inc., California Foundation of Independent Living Centers, The Judge David L. Bazelon Center for Mental Health Law, and The Arc of California (collectively "*amici*") are interested in this appeal because the State's planned terminations and reductions to In-Home Supportive Services ("IHSS") will harm many clients, members and communities that *amici* serve and represent.[1] Among these *amici* are many authorities on home- and community-based care, including organizations that help people with disabilities obtain the services and support they need to live independently. Many have considerable experience with IHSS. With this expertise and experience, *amici* can explain the benefits and importance of IHSS as a cost-effective program that helps many Californians with disabilities to live at home rather than in segregated settings such as institutions.

II. Introduction and Summary of Argument

The State of California designed and implemented the IHSS program in 1979 "to support the full integration of persons with disabilities in community

[1] A brief description of each *amicus* organization is attached hereto as Exh. 1.

life."[2] Now, after three decades of helping people with disabilities remain safely in their homes, the State proposes to terminate services for some and reduce them for others through implementing ABX4 4.[3] These cuts will affect over 130,000 IHSS beneficiaries,[4] more than the population of Berkeley (107,178) or Burbank (108,082).

Plaintiffs have explained why the planned cuts to IHSS violate the integration mandate of the Americans With Disabilities Act[5] ("ADA") under *Olmstead v. L.C.*[6] *Amici* wish to emphasize and support that argument by showing first, based on their experience and the relevant social science literature, that the ADA rejects discredited practices of providing long-term care only in segregated, institutional settings, and reflects a national commitment to autonomy, independence and quality of life for people with disabilities. Experts and government officials consistently endorse personal assistance programs like IHSS as fully embracing these values, and promoting better outcomes for recipients. According to noted researchers from the UCLA Center for Health Policy Research,

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[2] Supplemental Excerpts of Record ("SER") 196; Gov. Schwarzenegger Exec. Order S-10-08 (Sept. 24, 2008), *available at* http://gov.ca.gov/executive-order/10606.
[3] 2009 Cal. Legis. Serv. 4th Ex. Sess. Ch. 4 (A.B. 4) (West).
[4] Excerpts of Record ("ER") 168.
[5] 42 U.S.C. § 12132.
[6] 527 U.S. 581 (1999).

reducing and terminating IHSS, as the State proposes, will turn back the clock to the pre-ADA approach to providing long-term care services.[7]

Second, *amici* will show that other cuts to social services and healthcare in California have so frayed the safety net that IHSS recipients will have no viable alternatives if their IHSS benefits are reduced or eliminated. The State's proposed IHSS cuts will make it impossible for many seniors and people with disabilities to remain safely in their homes, indisputably the most integrated settings for them and also the environments most likely to promote their health and well-being. The loss of IHSS will lead inevitably to needless illness and injury, placement in segregated, institutional settings, and even preventable death. Evidence from social science and medical literature, empirical evidence concerning the lack of available care alternatives, and declarations of IHSS caregivers, recipients, and administrators all document the avoidable harm that will likely flow from the State's proposed terminations and reductions.

Finally, by showing that IHSS is a cost-effective method of care for those who need assistance to live safely in their homes, *amici* will rebut the State's claims that the IHSS cuts are necessary to save money.[8] The proposed

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[7] Steven P. Wallace et al., *Budget Proposals Turn Back Clock 30 Years in Long-Term Care Services for California Seniors*, UCLA CTR. FOR HEALTH POL'Y RES. (Feb. 2010) (Exh. 2) ["*Turn Back Clock*"].

[8] Appellants' Opening Brief ("AOB") 13-14; ER 1129-30.

terminations and reductions of IHSS would actually impose high costs. In the short term, these costs will likely include expensive visits to emergency rooms to treat injuries. In the long term, they will include the costs of care in institutions and other segregated settings.

III. Argument

A. Developments in medicine, social science, and law have established that community integration and freedom of choice provide people with disabilities with better quality of life than segregation in custodial institutions.

For more than 50 years, the overwhelming trend in care for people with disabilities has been toward community integration, in part through programs like IHSS, and away from institutional care. The benefits of integrated care and legal preference for that approach are now essentially undisputed.[9]

1. The shortcomings of treating persons with disabilities in large, segregated institutions became apparent by the middle of the 20th century.

From the beginning of the nineteenth century to the middle of the last century, states hid people with disabilities away in segregated, custodial institutions. According to a leading authority, these institutions were designed to prepare people with disabilities to live in integrated community settings, but

[9] *Olmstead*, 527 U.S. at 588.

ultimately proved unable to do so.[10] As a result, the focus for institutions shifted from training to providing lifelong custodial care. With this narrow mission, institutions were pressured to house as many people as possible at minimal cost.[11]

By the 1950s, lifelong custodial institutionalization had become the default model of care for people with disabilities.[12] In Disability at the Dawn of the 21st Century, Professor David Braddock offers a bleak picture of the typical mid-century institution:

> Living units were locked, windows barred, and the institutions became increasingly structured "like a hospital for the care of sick animals rather than as a place for the special education of human children and adults." Prolonged institutionalization exacted a price from residents by promoting excessive conformity to institutional culture at the expense of personal spontaneity, excessive fantasizing, fear of new situations, and excessive dependency on the institution.[13]

Families of institutional residents pressed for reforms and integration, with the momentum picking up in the 1960s. Through publicity and litigation, the institutional model became discredited. For example, Pennsylvania's Pennhurst

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[10] DISABILITY AT THE DAWN OF THE 21ST CENTURY 27 (David Braddock, ed. 2002) (Exh. 3).
[11] *Id*. at 31.
[12] *Id*.
[13] *Id*. (quoting Seymour B. Sarason & Thomas Gladwin, *Psychological and Cultural Problems in Mental Subnormality, in* MENTAL SUBNORMALITY: BIOLOGICAL, PSYCHOLOGICAL, AND CULTURAL FACTORS (Richard L. Masland et al., eds. 1958)).

State School and Hospital was the subject of a five-part 1968 report by NBC's Philadelphia affiliate called "Suffer the Little Children."[14] A decade later, in *Halderman v. Pennhurst State School and Hospital*, the district court concluded that the Pennhurst facility could not deliver proper care to most of its patients,[15] and ultimately issued an order that Pennsylvania close it down.[16] A report by the National Council on Disability, an independent federal agency, found that

> [A]s people moved from Pennhurst, they experienced significant gains in skills, personal happiness, family satisfaction, opportunities to participate in community activities, and other indicators of quality of life. In the community, the former Pennhurst residents were "better off."[17]

While the Pennhurst story was particularly dramatic, the basic narrative recurred throughout the country, including in California. Parallel concerns also developed

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[14] *See* Pennhurst Memorial & Preservation Alliance website, http://www.preservepennhurst.com/default.aspx?pg=26 (last visited Feb. 22, 2010) (video from NBC's 1968 report and links to archived news stories).

[15] 446 F. Supp. 1295, 1317-19 (E.D. Pa. 1978).

[16] *See* James W. Conroy, *The Hissom Outcomes Study: A Report on Six Years of Movement into Supported Living*, CTR. FOR OUTCOME ANALYSIS 36, 40, 45–46, 55 (Dec. 1995).

[17] NAT'L COUNCIL ON DISABILITY, *OLMSTEAD*: RECLAIMING INSTITUTIONALIZED LIVES 12 (2003) (Exh. 4) ["NCD REPORT"] (quoting James W. Conroy & Valerie J. Bradley, *The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis*, U.S. DEP'T HEALTH & HUMAN SERVS. 192 (1985) (Exh. 5)).

regarding conditions in nursing facilities that housed people with disabilities and the elderly, with reports that one in three nursing homes had been cited for abuse.[18]

2. The ADA and *Olmstead* provided a strong legal mandate for community integration.

The ADA's integration mandate required that people with disabilities receive care under most circumstances in the most integrated setting possible.[19] The ADA's legislative history makes clear that when Congress passed the law in 1990, the nation had moved from relying on large, custodial institutions to a new appreciation of the value of community-based care. One noted commentator observed:

> Such facilities have been judicially recognized as being among "the most isolated and restrictive" and "almost totally impersonal" settings in which a person can live. . . . [O]nce there, the residents lose "the basic rights that [persons without disabilities] take for granted, like choosing where they live, who they live with, what they eat, when to eat, [and] who their friends are . . . ."[20]

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[18] *See, e.g.*, Nat'l Ctr. on Elder Abuse website, http://www.ncea.aoa.gov/NCEAroot/Main_Site/FAQ/Nursing_Home_Abuse/News_Articles.aspx (last visited Mar. 1, 2010) (archiving news articles on nursing home abuse). *See also* US GEN. ACCT. OFFICE, NURSING HOMES: MORE CAN BE DONE TO PROTECT RESIDENTS FROM ABUSE (Mar. 2002) (Exh. 6); *Elder Justice: Protecting Seniors from Abuse and Neglect: Hearing Before the S. Comm. on Fin.*, 107th Cong. (June 18, 2002) (statement of Catherine Hawes, Prof., Tex. A&M U.: *Elder Abuse in Residential Long-Term Care Facilities: What Is Known About Prevalence, Causes, and Prevention*) (Exh. 7).

[19] Olmstead v. L.C., 527 U.S. 581, 597-602 (1999).

[20] Timothy Cook, *The Americans With Disabilities Act: The Move to Integration*,

Almost a decade after the passage of the ADA, the U.S. Supreme Court issued its landmark decision in *Olmstead.* Writing for the Court, Justice Ginsburg began by noting Congressional findings that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem."[21] The Court made clear that failure to implement the ADA's integration mandate when caring for people with disabilities amounted to unlawful discrimination.[22]

The *Olmstead* majority recognized two Congressional findings underlying the ADA, both supporting community integration of those with disabilities:

> First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.[23]

The ADA and the *Olmstead* decision together established the legal framework supporting community integration.

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64 TEMPLE L. REV. 393, 412 (1991).
[21] *Olmstead*, 527 U.S. at 588.
[22] *Id*. at 597-602.
[23] *Id*. at 600-01.

In response to *Olmstead* and subsequent federal guidance, California developed a state "*Olmstead* plan" in May 2003 under the auspices of the California Health and Human Services Agency, a cabinet-level agency encompassing all state departments that serve people with disabilities.[24] According to California's *Olmstead* Plan, "the (IHSS) program is an *essential* component of the State's effort to provide services to maintain individuals in their homes and communities."[25]

3. Research confirms that community integration for people with disabilities provides more personal autonomy and independence, and better quality of life, than institutional care.

Olmstead specifically held that, subject only to limited exceptions, people with disabilities have a right under the ADA to receive care in integrated home and community settings rather than in segregated custodial institutions.[26] The Court relied in part on federal regulations implementing the ADA that define the "most integrated setting" as "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.[27] The National Council on

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[24] CAL. HEALTH & HUMAN SERVS. AGENCY, CALIFORNIA OLMSTEAD PLAN (2003) (Exh. 8) (emphasis added); s*ee also*, CHSS *Olmstead* website, http://www.chhs.ca.gov/initiatives/Olmstead/Pages/OlmsteadPlan.aspx (last visited Mar. 1, 2010) .

[25] *Id*. at 32 (emphasis added).

[26] *Olmstead*, 527 U.S. at 597-602.

[27] *Id*. at 591-92; 28 C.F.R. § 35.130(d), app. A (2008); *see also* Ira Burnim &

Disability observed that "the most integrated setting" is generally (1) "a place where the person exercises choice and control," (2) a "home of one's own shared with persons whom one has chosen to live with, or where one lives alone," or (3) "living in the community with everyone else like everyone else."[28] This definition reflects contemporary research and understanding of the importance of personal choice, autonomy and quality of life for people with disabilities, including seniors. Significantly, this definition excludes more than just the historically-problematic large institutions; it also excludes smaller congregate-care facilities, which tend to restrict personal autonomy as well.

After years of studying the effects of integration, social scientists and healthcare researchers have consistently found that integration produces positive results when undertaken with individualized care planning and the full range of needed services.

> Integration dramatically improves the overall quality of life for persons with disabilities in a number of ways that are more impressionistic, yet still capable of evaluation. Researchers have measured, for example, a significantly more positive affect and appearance for persons with disabilities who have been integrated than for matched groups that were segregated. This is particularly important for children with disabilities. It is well-

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Jennifer Mathis, Bazelon Ctr. for Mental Health Law, *The Olmstead Decision at Ten: Directions for Future Advocacy*, CLEARINGHOUSE REV. J. OF POVERTY, LAW & POL'Y (2009) (Exh. 9).

[28] NCD REPORT (Exh. 3), *supra* note 17, at 9.

> accepted in our society that children should grow up in families. Children with disabilities suffer significant adverse effects when deprived of that opportunity through isolation in a segregated environment. Educators and disability researchers report integration produces improved appearance and responsiveness for persons with disabilities, even for those who previously had been largely unresponsive without contact with others without disabilities. Persons with disabilities living in the community are more likely to participate in the management of their activities, to make their own decisions and to be more involved in all decisions which affect their lives.[29]

Care in an integrated setting also helps to foster autonomy and independence, which in turn help improve medical outcomes and quality of life. As Justice (then Judge) Cardozo explained long ago, control over one's body and medical care is an essential freedom: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."[30] But such autonomy is not merely an abstract social good. The National Council on Disability points to multiple studies providing "evidence that being able to make personal choices regarding one's own life promotes health, well-being, and personal satisfaction."[31] Health care experts agree that providing personal, in-home assistance services like IHSS to people with disabilities is "pivotal to [their]

[29] Cook, *supra* note 20, at 455.
[30] 105 N.E. 92, 93 (N.Y. 1914)
[31] NCD REPORT (Exh. 3), *supra* note 17, at 47 (citing studies).

survival, productivity, and independence."[32] When people with disabilities select and manage their own service providers, as with IHSS, they report fewer unmet needs, better quality of life and more positive results.[33] Indeed, one expert has observed that "the most powerful assertion of . . . autonomy in health care today is the demand by many people with disabilities to control the circumstances in which they receive their long-term care and personal assistance services."[34] Programs like IHSS help people achieve personal autonomy,[35] whereas institutional care destroys it.

Integration also fosters active social relationships and connections with friends, neighbors, and communities, a dynamic that may reduce the risk of institutionalization by almost one-half.[36] Ultimately, integration and in-home

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[32] 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, 795 (1993).
[33] *See* A.E. Benjamin et al., *Comparing Consumer-Directed and Agency Models for Providing Supportive Services at Home*, 35 HEALTH SERVS. RES. 351, 352-53 (Apr. 2000) (Exh. 10); Jennie Chin Hansen, *Community and In-Home Models*, 44 J. SOC. WORK EDUC. 83, 86 (2008) (Exh. 11).
[34] Andrew I. Batavia, *The Growing Prominence of Independent Living and Consumer Direction as Principles in Long-Term Care: A Content Analysis and Implications for Elderly People With Disabilities*, 10 ELDER L.J. 263, 264-65 (2002) (citing studies).
[35] *See id*. at 265 ("Studies demonstrate that consumers tend to be highly satisfied with the assistance they receive under the independent living model" of "consumer-directed care" and "consumer-directed personal assistance services.").
[36] *See* Ulrike Steinbach, *Social Networks, Institutionalization, and Mortality Among Elderly People in the United States*, 44(4) J. GERONTOLOGY 183-90 (1992).

services are crucial because they allow people with disabilities to avoid institutions; this is significant because research shows that after entering an institution, even for a short time, it becomes difficult to return to community life.[37]

Social science and health care scholars are not alone in recognizing that integration produces a better quality of life for people with disabilities. Even Governor Schwarzenegger, who now advocates cutting IHSS, has recognized the benefits of community integration in general and the IHSS program in particular. In September 2008, the Governor declared:

> California has a demonstrated record of success in providing services that support the full integration of persons with disabilities in community life through such programs as In-Home Supportive Services. . . . [T]he opportunity to direct one's own affairs, live independently, and attain economic self-sufficiency is an essential component of developing self-worth and personal responsibility. Community-based care and services can . . . result in a higher quality of life that promotes the values of community participation, inclusiveness, and respect for diversity.[38]

As *amici* demonstrate in the following sections, the reductions and terminations of IHSS frustrate and undermine these requirements of the ADA and California's own *Olmstead* plan.

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[37] H. Stephen Kaye et al., *Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending?*, 28 HEALTH AFF. 262, 271 (2009) (Exh. 12).
[38] Exec. Order, *supra* note 2; SER 196.

B. IHSS recipients whose services will be reduced or terminated under ABX4 4 have no alternatives that will enable them to remain safely in their homes.

1. By definition, IHSS recipients cannot afford replacement services.

To qualify for IHSS, applicants must demonstrate that they have very low incomes.[39] Most IHSS recipients' eligibility is based on receipt of SSI (the federal Supplemental Security Insurance program), which provides $835 per month for an individual recipient.[40] As discussed in Section C, *infra*, even IHSS recipients whom the State labels "non-severely impaired" receive services costing an average of $705/month. This amount almost swallows the SSI stipend of $835/month. This demonstrates that IHSS recipients can not pay for personal care if their benefits are reduced or terminated.[41]

In addition, the State has cut its share of the SSI/SSP benefit three times in the past year alone, further affecting these vulnerable recipients. According to UCLA researchers, even apart from the reductions in IHSS, the cuts to SSI further

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[39] CAL. WELF. & INST. CODE § 12300(a); CAL. DEP'T OF SOC. SERVS., MANUAL OF POLICIES & PROCEDURES ["MPP"] 30-700.13-1, 30-755.1. *See also* ER 162-63, 2316, 2331, 2373; Appellee's Brief 13.

[40] MPP 30-755.111 (receipt of SSI to qualify for IHSS) (Exh. 13).

[41] *See Turn Back Clock* (Exh. 2), *supra* note 7, at 2; Steven P. Wallace, Susan E. Smith, *Half a Million Older Californians Living Alone Unable to Make Ends Meet*, UCLA HEALTH POL'Y RES. BRIEF (Feb. 2009) (Exh. 14).

"increase the pressure on older adults to abandon living independently and move into nonmedical, institutional care."[42]

2. Reducing or terminating IHSS puts current recipients at imminent risk of injury, disease, and even death if they stay at home.

As the District Court found, low-income people qualify for IHSS only if they cannot "perform the services themselves" and "safely remain in their homes . . . unless these services are provided."[43] To determine eligibility for particular services, county social workers conduct individualized in-person assessments of each applicant's need for IHSS based on these two statutory requirements.[44]

The UCLA Center for Health Policy Research has reported that "domestic services are in some respects the 'glue' that permits older people to stay in their homes . . . ."[45] This analysis finds confirmation in the real-life examples of IHSS recipients who would lose IHSS under ABX4 4. Such cases demonstrate the serious risks of injury, disease, and even death that would result from reduction or

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[42] *Turn Back Clock* (Exh. 2), *supra* note 7, at 2.
[43] ER 162-163; Appellee's Brief 13.
[44] CAL. WELF. & INST. CODE §§ 12300(a), 14132.95(a)(4)–(f), 14132.951; *see also* MPP 30-761.13, 30-763.112; ER 2373, 2378.
[45] Stephen P. Wallace et al., *Community-Based Long-Term Care: Potential Consequences of California's 2009 Budget Cuts*, UCLA CTR. FOR HEALTH POL'Y RES. 13 (Oct. 2009), http://www.healthpolicy.ucla.edu ["*Potential Consequences*"] (as quoted by the district court, ER 180); ER 960.

termination of IHSS. F.H., for example, sustained a serious brain injury in 1988 and has no family to help her.[46] She currently receives 56.7 hours of IHSS per month, for tasks like cleaning her apartment. Due to her disability, F.H. cannot perform these tasks herself. Her doctor has warned that if she inhales dust while sleeping, it may aggravate her sleep apnea and cause her to stop breathing. Without IHSS, no one will clean her apartment, and dust will accumulate, creating a potentially life-threatening hazard. Thus, a small amount of IHSS makes a big difference for F.H.

Joyce McHenry is a 59-year-old with severe depression and anxiety. Before she received IHSS, she was hospitalized for suicidal thoughts and because she deliberately took too much medication.[47] She now receives 41.7 hours of IHSS each month. Her caregiver reminds her to take her pills on time and helps her keep track of her daily medication. This and other services from her provider are critical for Ms. McHenry's continuation of her medication regimen and her ability to live at home. Ms. McHenry knows from experience that, without IHSS, she would have difficulty with medication, and might feel suicidal. Her IHSS provider's help has been vital to Ms. McHenry's ability to live safely in her home and avoid placement in a facility such as a psychiatric hospital.

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[46] ER 1715-16 (¶¶5, 12).
[47] ER 1692-93 (¶1-8).

3. Other programs that might assist IHSS recipients also face cuts and increased demand.

According to the State's estimates, approximately 130,000 people will lose some or all of their IHSS under ABX4 4.[48] These cuts should raise particular concern because there are few alternatives for IHSS recipients. Low-income adults with disabilities, including those who receive IHSS, "often rely on multiple programs to remain safely in their homes and out of hospitals and nursing homes. However, California's budget crisis has reduced state funding for a broad array of health and social service programs."[49] The State claims that "each individual's county social worker is responsible for determining *whether* there are other services available," an implicit acknowledgment that there may be none.[50] The State does not explain what will occur if the county social worker finds no available alternatives. Indeed, with differing eligibility requirements, long application processes, and limited capacity, other programs may not be readily available.

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[48] ER 591-92 (¶2, 9), 595-97.
[49] *Potential Consequences*, *supra* note 45, at 1 (ER 948).
[50] AOB 11 (emphasis added); ER 183, 1356, 752-56 (¶¶8-19, 21), 793-94 (¶7-9), 819-20 (¶¶3, 5), 839 (¶4, 6), 842-43 (¶¶4, 6-9), 856-57 (¶¶4, 7, 9), 1495-97 (¶¶23, 25, 31), 1500 (¶¶38-39), 1509-11 (¶¶12, 17, 20-21), 1533 (¶4), 1643 (¶18), 1656-57 (¶29, 31, 32), 1667-68 (¶18-19), 1670 (¶26), 1673 (¶5), 1712 (¶5), 1772 (¶6).

4. IHSS recipients cannot rely on the unpaid assistance of family members.

The State also makes an unwarranted assumption that family members will compensate for cuts to IHSS.[51] But the State has not based the IHSS cuts on the availability of family members, nor considered the family status of those affected by the cuts. A UCLA study found that of those 65 and older who were slated to lose all IHSS benefits, "more than half live alone and close to half do not have a family provider."[52] Even those with family caregivers will have to adjust to the abrupt loss of income from work as an IHSS provider. To replace that income, many family caregivers will need to find other employment, which may prevent them from providing further care. To the extent that these family members can continue to provide care without compensation from IHSS or income from employment, they will likely need some other form of government assistance, thus imposing another cost on the State.[53]

5. Institutionalization is a significant risk for persons with disabilities who lose their IHSS.

People who lose IHSS risk placement in segregated institutions, though many have stated with great passion that the last place they want to live is an

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[51] AOB 47.
[52] *See Potential Consequences*, *supra* note 45, at 13, 41 (ER 960, 988); ER 835 (¶2), 861 (¶6), 924 (¶31-32), 1497 (¶¶28, 31), 1536 (¶5), 1643 (¶19).
[53] *Id*.

institution.[54] As the district court concluded and Appellees argue persuasively, institutionalization of this kind would violate the ADA. Even temporary institutional placement would have destructive effects on individuals with disabilities. Persons with disabilities, especially mental disabilities, tend to experience atrophy of their community living skills when placed in custodial institutions.[55] As a result, many who enter institutions temporarily because they lose IHSS are unlikely to reenter the community.[56]

C. IHSS is cost-effective, and the proposed cuts will increase short-term and long-term costs.

The State's purported budgetary justifications for ABX4 4[57] fail because IHSS is the most cost-effective method of care for low-income Californians with disabilities. Since those who will lose IHSS services face a significant risk of institutionalization,[58] it is essential to compare the costs of IHSS to the costs of institutionalization.

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[54] ER 1481-82 (¶7), 1559-65 (¶28-45), 1686-88 (¶18-19), 1694-95 (¶¶7, 10-11), 1703 (¶6), 1710 (¶8-9), 1731 (¶12), 1746 (¶25), 1751 (¶16-17), 1763 (¶12), 1768 (¶13).
[55] Kaye (Exh. 11), *supra* note 37, at 271; *see also* ER 1668 (¶ 20); ER 1563-65 (¶39-45).
[56] *Id*.
[57] AOB 13-14.
[58] *See* Section B.5, *supra.*

When Congress enacted the ADA, it relied on widely accepted evidence that community-based care, like IHSS, is more cost-effective per capita than institutional care:

> Virtually all the relevant literature documents that segregating handicapped people in large, impersonal institutions is the most expensive means of care. Evidence suggests that alternative living arrangements allowing institutionalized residents to return to the community can save money. As a Federal court has noted, "Comparable facilities in the community are generally less expensive than large isolated state institutions."[59]

Studies conducted since the ADA's enactment validate Congress's conclusions about the cost benefits of community care, revealing "a consistent pattern across states and over time of better outcomes and lower costs in the community, consistent with US deinstitutionalization literature on outcomes, and cost comparison research showing US institutional services to be more costly than community services."[60]

California already benefits from its investment in IHSS and other home and community based long-term care programs, according to a recent report prepared

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[59] U.S. Comm'n on Civil Rights, *Accommodating the Spectrum of Individual Abilities*, CLEARINGHOUSE PUB. NO. 81 (Sep. 1983) at 78-79. This report was cited repeatedly in the Senate report accompanying the ADA.

[60] THE ECONOMICS OF DEINSTITUTIONALIZATION (Roger J. Stancliffe et al., eds. 2004) (internal citations omitted) (Exh. 15); *accord* SER 150; ER 1488 (¶¶4, 5), 1513-14 (¶¶3, 6); ER 1499-1500 (¶¶36, 40), 1510 (¶¶16-17), 1562 (¶38), 1657-58 (¶¶32, 34-35).

for California Community Choices.[61] After reviewing recent national studies of the relation between nursing facility and Home and Community-Based Services ("HCBS") cost trends, the report concluded that "[s]tates that had well-established HCBS programs had much less overall long-term care (LTC) spending growth than those with low HCBS spending, because these states were able to reduce institutional spending. . . . California was one of the states that expanded its HCBS program for non-MR/DD persons and [sic] resulted in lower long-term care spending for aged persons,"[62] including a lower than average rate of nursing facility usage. "If California had the same nursing facility usage as the national average, about 42,600 more persons would have their nursing facility stay paid for by Medi-Cal. At 2007 costs . . . the state would have spent an additional $1.4 billion per year."[63]

By cutting IHSS, California is going backwards not only in terms of care for those who need IHSS, but also in terms of cost management.[64]

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[61] ROBERT MOLLICA & LESLIE HENDRICKSON, HOME AND COMMUNITY−BASED LONG−TERM CARE: RECOMMENDATIONS TO IMPROVE ACCESS FOR CALIFORNIANS 189 (Nov. 2009) ["COMMUNITY CHOICES REPORT"] (Exh. 16).
[62] *Id*. at 159.
[63] *Id*. at 153.
[64] Far from proposing to cut IHSS, the State's Community Choices Report recommends a series of steps to make long term care more cost effective by expanding home based services. One recommendation is to "create rate incentives . . . to downsize nursing facilities, and the resulting savings can be used . . . to

1. Per capita, IHSS is the most cost-effective form of care for people with disabilities.

In 2009, the average cost of IHSS was approximately $912/month per recipient, or $10,947/year, or about $30/day.[65] IHSS costs for individuals the State labels "severely impaired" are higher than average—about $1,592/month in 2009, or $19,000/year ($52/day).[66] But IHSS costs for people assessed as "non-severely impaired" are lower than average—about $705/month in 2009, or $8,400/year ($23/day).[67] Many recipients can stay in their own homes with IHSS services costing less than $450/month.[68]

The reductions and terminations of IHSS imposed by ABX4 4 will fall predominantly on recipients at the lower end of this cost spectrum. Thus, the per-person cost savings from cutting these recipients will be relatively small. But the spread between the cost of IHSS for these people and the cost of institutional care will be much greater than for the average of all IHSS recipients. In short,

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expand affordable housing, adult day health care, and in-home services." *Id*. at 222.

[65] These amounts were calculated as averages of monthly data reported in 12 IHSS cost reports for 2009, published on the California Department of Social Services website, http://www.cdss.ca.gov/agedblinddisabled/PG1282.htm (last visited Mar. 1, 2010) ["CDSS REPORTS"] (Exh. 17); *see also* ER 1514 (¶6).

[66] *Id*. (last page of each monthly report is a summary of statewide IHSS costs for "severely impaired," "non-severely impaired," and average recipients).

[67] *Id*.

[68] ER 1658 (¶35).

removing these people from IHSS is likely to drive them into more expensive programs, a cost California taxpayers will ultimately bear.

Hospitals are the most expensive alternative, easily costing many times more than IHSS—about $1,230/day in 2004, compared to an average daily IHSS cost of $24 that year.[69] Thus, hospitalization for only seven days costs about as much as IHSS for the average recipient for a year. Nursing facilities had an average daily cost of about $161 dollars per patient in 2009, more than five times the average cost of IHSS per person in the same year.[70] Some large nursing facilities cost far more; Laguna Honda in San Francisco, a nursing facility with more than 780 beds, receives reimbursement of more than $400/day per person from local, state and federal funds.[71] Children with disabilities might be placed in a pediatric sub-acute facility if they cannot remain at home without IHSS, which can cost more than $600/day.[72]

For IHSS recipients with mental illness (who make up approximately 15% of adult IHSS recipients[73]), likely institutional placements include nursing facilities

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[69] Debi Waterstone et al., *California's In-Home Supportive Services Program: Who is Served?*, CAL. HEALTHCARE FOUND. 7 (Sept. 2004) (SER 150).
[70] *Id*. (2004 average daily rates for nursing homes was $118 compared to $24 per day for IHSS); ER 1513 (¶3), 1517.
[71] Complaint at ¶ 84, Chambers v. City & County of San Francisco (N.D. Cal. Oct. 12, 2006) (Exh. 18).
[72] CAL. CODE REGS. tit. 22, § 51511.6.
[73] ER 1907.

with specialized treatment programs (known as "Institutions for Mental Disease"), which cost $2000/year more than a regular nursing facility.[74] A Psychiatric Health Facility costs $585/day and an outpatient day treatment program, such as the one to which Plaintiff David Oster was sent last year,[75] costs $202/day.[76]

In sum, the alternatives for people whose IHSS is reduced or terminated are invariably more expensive than the IHSS program. In addition, to the extent existing facilities cannot handle the likely influx of persons displaced by the IHSS cuts, the State will find itself in the ironic position of needing to incur the enormous costs of reopening and operating closed institutions.

Finally, while some who lose or experience reductions in IHSS will have to seek out expensive long-term care alternatives, it is likely that many others will end up in emergency rooms due to injuries or illnesses that result from the loss of services. For example, recipients who need assistance bathing may fall in the tub if their IHSS provider is no longer available, or people with diabetes who need shopping and meal preparation assistance or help with medication may have difficulty managing without IHSS. Emergency room care for such individuals will come at a high price, in terms of avoidable injuries, monetary cost, and burdens on

[74] Cal. Dep't of Mental Health ("CDMH") Letter No. 03-04 (Oct. 2, 2003) (Exh. 19).
[75] ER 1772.
[76] CDMH Letter No. 09-12 (July 16, 2009) (Exh. 20).

county emergency resources and personnel. Emergency hospitalization for a single day can easily cost several hundred dollars, more than the cost of a full month of IHSS for many recipients.[77]

2. IHSS is cost-effective because service hours and wages are low compared to institutional care.

There are several reasons IHSS is more cost-effective than less integrated alternatives. First, there is a cap on IHSS benefits; no individual may receive more than 283 service hours per month.[78] This cap effectively limits monthly expenses well below the cost of institutions staffed around the clock, seven days a week.

Second, most IHSS recipients need only a few hours of assistance per day or per week. In 2009, the monthly statewide averages per IHSS recipient were 86.7 paid hours and $912.31/month.[79] About 60% of IHSS recipients receive fewer than 80 hours of services per month, and only about 6% are authorized to receive the maximum allowed hours.[80] For people who need only prompting for certain tasks, IHSS is particularly time-efficient because the IHSS provider may be able to

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[77] Waterstone (SER 164), *supra* note 69, at 21 ("Emergency hospitalizations due to accident, injury, or illness that result from loss of services cost the state at least $577 per day in 2002.").
[78] ER 2341 (MPP 30-757.1(4)).
[79] CDSS REPORTS, *supra* note 65; *see also* ER 1514 (¶6).
[80] CAL. LEG. ANALYST OFFICE, IN-HOME SUPPORTIVE SERVICES: BACKGROUND AND CASELOAD COMPONENTS 7 (Mar. 24, 2009) ["LAO MAR. 2009 REPORT"] (SER 21).

prompt tasks while performing other services.[81] In contrast, institutional settings are staffed to have care available all day, every day.

Third, the hourly wages paid to IHSS providers are relatively low. In 2009, the monthly statewide average wage was $10.52/hour.[82] These lower wage rates are possible, in part, because many IHSS services can be provided by persons with little formal training, and do not require licensed personnel, like nurses, who staff institutions.

Fourth, in-home services involve no facility overhead, and only minimal administrative overhead. IHSS recipients receive care in their own homes rather than in institutions or group residential settings, and recipients directly employ their care providers.[83]

This cost effectiveness of the program is apparent from the examples of Plaintiffs and others who will lose IHSS. Plaintiff Oster receives 63.2 hours of IHSS per month,[84] costing less than $700. Many others who face termination or reduction of IHSS also receive a relatively few IHSS hours. Such services are cost-effective, but critical to their ability to remain safely in their homes. For example, Gerald Aho, whose multiple disabilities prevent him from keeping his

[81] ER 1647 (¶10).
[82] CDSS REPORTS, *supra* note 65; *see also* ER 1514 (¶6).
[83] LAO MAR. 2009 REPORT (SER 16), *supra* note 80, at 2.
[84] ER 1771 (¶1).

apartment clean as required for him to remain in subsidized housing, receives 35 hours of IHSS per month,[85] costing less than $400. For Mr. Aho, those 35 hours make the difference between living in his own apartment and risking eviction and possibly returning to homelessness.[86] Larry Wilson, who has multiple disabilities and a Functional Index score of 1.75, receives 45 hours of IHSS per month, for less than $500.[87]

3. The Legislative Analyst Office's January 2010 report ignores quality of life concerns and under-counts the potential costs of cutting IHSS.

The State has asked the Court to take judicial notice[88] of a recent report issued by the Legislative Analyst Office **(**"LAO") that purports to show that cuts to IHSS may result in cost savings to the State and counties.[89] If this Court does take judicial notice, the report should receive little weight due to its limited scope and methodological flaws. First, the report explicitly acknowledges its limited scope, stating it considers only cost and not "the impact of the program on the quality of life of recipients."[90]

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[85] ER 1744-46 (¶¶6, 11, 15-23).
[86] *Id.*
[87] ER 1686 (¶¶13, 17).
[88] Appellants' Supplemental Request for Judicial Notice (Feb. 3, 2010).
[89] CAL. LEG. ANALYST OFFICE, CONSIDERING THE STATE COSTS AND BENEFITS: IN-HOME SUPPORTIVE SERVICES PROGRAM (Jan. 21, 2010).
[90] *Id.* at 17.

> [W]e recognize that one of the primary benefits of the IHSS program is that it may increase the quality of life for program recipients and their families. . . . [W]hether IHSS is cost-effective to state government should not be the sole basis for evaluating the merits of the program. Instead, the Legislature should consider both the cost-avoidance potential of IHSS and the enhanced quality of life for all recipients, including those who may be at minimal risk of [Skilled Nursing Facility] placement in the absence of the program."[91]

Nonetheless, the LAO's model assigns no value to the quality of life benefits that IHSS provides over institutional care.

Second, by focusing its cost analysis only on those whom it believes would enter skilled nursing facilities ("SNF"), the LAO significantly under-counts potential costs. This approach excludes the costs of care for people who enter facilities that do not provide a SNF level of care (*e.g.*, group homes). Additionally, the cost of "accidents" requiring hospitalization is included only if this "results in their placement in a SNF,"[92] but not if recipients experience costly hospitalizations yet never end up in a SNF.

The LAO's "fiscal model," which focuses on the oldest recipients with multiple needs, also under-counts costs by ignoring recipients with psychiatric disabilities, who may be younger and require fewer services. The LAO fails to

[91] *Id*. at 18, 22.
[92] *Id*. at 17.

consider the costs of their care in psychiatric hospitals as a result of setbacks they may suffer after losing IHSS services, or other costs if they become homeless.

The report also fails to consider other secondary costs of leaving vulnerable individuals without the assistance they need to live safely at home, even if they do not enter a SNF. These costs may include lost wages, increased absenteeism, and lower productivity for family members who may have to respond to repeated crises.[93] These effects also lead to lower tax revenues.

Still, despite under-counting potential costs of reductions in IHSS, the LAO concludes that "IHSS may well be cost-effective for the State General Fund,"[94] given the huge differential in relative costs that the LAO acknowledges—$12,000/year for IHSS versus $51,100 for a SNF.[95] Although the LAO does call for increased "targeting" of IHSS, its report provides no additional justification or support for the Functional Index as the means to this end, and instead suggests alternative reforms that do not rely on the FI rankings.[96] Its report offers no justification for the drastic reductions in IHSS in ABX4 4.

[93] *See id*. at 22-23.
[94] *Id*. at 21.
[95] *Id*. at 12.
[96] *Id*. at 24.

IV. **Conclusion**

For the foregoing reasons, and the reasons set forth in plaintiffs' briefs, the order of the district court should be affirmed.

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Pursuant to Federal Rule of Appellate Procedure 26.1, counsel represents that none of the *amicus curiae* on whose behalf this brief is filed, have parent, subsidiary, or affiliated corporations that have issued shares to the public.

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CERTIFICATE OF COMPLIANCE WITH CIRCUIT RULE 32

I certify that, pursuant to Fed. R. App. P. 32(a)(7)(C) and Ninth Circuit Rule 32-1, the attached amicus curiae brief uses a proportionally spaced, 14-point typeface, and consists of 6,660 words. This word count does not include the Table of Contents, the Table of Authorities, Corporate Disclosure Statement, this Certificate of Compliance, or the Certificate of Service. In preparing this certificate, I relied on the word count function of Microsoft Word 2003, used to prepare this brief.

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