IN THE SUPREME COURT OF THE STATE OF CALIFORNIA

KERRIE REILLY, Petitioner and Appellant,

٧.

MARIN HOUSING AUTHORITY, Defendant and Respondent.

After a Decision of the California Court of Appeal First Appellate District, Division Two, Case No. A149918 Affirming a Judgment of the Superior Court of Marin County Case No. CIV 1503896, Honorable Paul M. Haakenson, Judge

APPLICATION FOR LEAVE TO FILE AMICI CURIAE BRIEF and AMICI CURIAE BRIEF IN SUPPORT OF PETITIONER

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California Rule of Court 8.520(f)(4)	8
Other Authorities	
24 C.F.R. § 8	11, 15 11, 16, 23 11

A.E. Coy et al, Moderated mediation path analysis of Mexican traumatic brain injury patient social functioning, family functioning, and caregiver mental health, Archives of Physical Medicine and Rehabilitation, Vol. 94(2), Aug. 2012	26
Amy Hewitt, Raising Expectations: The Direct Support Professional Workforce, The Arc National Conference, Aug. 4, 2013 https://www.thearc.org/doent.doc?id=4338	
The Arc, National Family Caregiver Support Program, https://www.thearc.org/sslpage.aspx?pid=3378	22
Brian R. Grossman, Introduction to the Special Issue: Family Support of Persons with Disabilities Across the Life Course, Journal of Family Social Work, Vol. 19, 4, Sep. 2016	19
Cal. Dep't Soc. Serv.'s Manual of Policies and Procedures § 30-757.173(a)16, 2	21
California Department of Social Services, https://www.cdss.ca.gov/inforesources/IHSS (last visited Dec. 13, 2018)	10
California Legislative Analyst Office, Considering the State Costs and Benefits: In-Home Supportive Services Program, Jan. 10, 2010, p. 10, http://www.lao.ca.gov/reports/2010/ssrv/ihss/ihss_012110.pdf	10
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Combined Income and Rent, 60 Fed. Reg. 17388, 17391-17393 (April 5, 1995)	14
David A. Ervin et al, Healthcare for persons with intellectual and developmental disability in the community, Frontiers in public health, Vol. 2(83), Jul. 2014	18
Eugenio Cerosimo & Nicolas Musi, <i>Improving treatment in Hispanic/Latino</i> patients, The American Journal of Medicine, Vol. 124(1), 2011	25
Harder & Company Community Research, A Blind Spot in the System: Health Care for People with Developmental Disabilities, Sept. 2008	17
Jodi Robledo & Anne M. Donnellan, Supportive Relationships in Autism Spectrum Disorder: Perspective of Individuals with ASD and Supporters, Behavioral Sciences (Basel, Switzerland), Vol. 6(4), 23, Nov. 2016	23

Spectrum Disorder: Perspective of Individuals with ASD and Supporters, Behavioral Sciences (Basel, Switzerland), Vol. 6(4), 23, Nov. 2016	24
Lynda L. Anderson et al, <i>The State of the Science of Health and Wellness for Adults with Intellectual and Developmental Disabilities</i> , Intellect Dev. Disabil. Vol. 51(5), Oct. 2013	19
M.C. Zea et al, Latino Cultural Values: Their Role in Adjustment to Disability, Journal of Social Behavior and Personality, Vol. 9, No. 5, 1994	26
Marlo Sollitto, 13 Secrets that Make Caregiving Easier, https://www.agingcare.com/articles/make-caregiving-easier-141826.htm	23
60 Minutes: A Dark Chapter in Medical History (CBS television broadcast, Feb. 9 2005)	20
National Core Indicators, 2016 Staff Stability Survey Report, Jan. 2018	17, 18
Norah C. Keating et al, A taxonomy of the economic costs of family care to adults, The Journal of the Economics of Ageing, Vol. 2014; 3	14, 22
Trust, Oxford English Dictionary. (3rd ed. 2015)	24
Public Policy Institute of California, California's In-Home Support Program, Nov. 2015, http://www.ppic.org/publication/californias-in-home-support-program/	10
S.R. Cohen et al, Receiving or believing in family support? Contributors to the life quality of Latino and non-Latino families of children with intellectual disability, Journal of Intellectual Disability Research, Vol. 58(4), 2016.	25
Susan H. McDaniel & Anthony R. Pisani, Family Dynamics and Caregiving for People with Disabilities (last visited Dec. 13, 2018)	22
United Healthcare Community & State, Family Caregiving in the United States, August 2017	22
United States Census Bureau, https://www.census.gov/quickfacts/ca (last visited on December 7, 2018)	25
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APPLICATION FOR LEAVE TO FILE AMICI CURIAE BRIEF

Amici Curiae, identified below, apply for permission to file the attached Amici Curiae Brief pursuant to California Rule of Court 8.520(f). Collectively, Amici are deeply committed to serving people with disabilities and vulnerable populations. Given this, they seek leave to participate in this case via the attached brief.

The individual *Amici* and their interest are more specifically described as follows:

Association of Regional Center Agencies (ARCA) promotes, supports, and advances regional centers in achieving the intent and mandate of the Lanterman Developmental Disabilities Services Act in providing community-based services that enable individuals with developmental disabilities to achieve their full potential and highest level of self-sufficiency. The Association functions as a leader and advocate in promoting the continuing entitlement of individuals with developmental disabilities to all services that enable full community inclusion. The Association also participates in the development of public legislative policy and serves as a focal point for communication, education, training, and prevention services.

The Autism Society of Los Angeles is a non-profit organization that empowers individuals with autism, their families, and professionals through advocacy, education, support, and community collaboration.

CASHPCR was organized about four decades ago when parents from the different State Hospitals came together to work on issues affecting their children.

CASHPCR membership has changed as some Developmental Centers have closed. Other family groups have decided to pursue advocacy outside of the CASHPCR organization.

CASHPCR currently represents and speaks directly on behalf of Fairview Families and Friends, from Fairview Developmental Center; and the Porterville Parent Group, from Porterville Developmental Center.

Disability Voices United is a statewide organization directed by, and for, individuals with developmental disabilities of all ages and their families. It advocates for choice and control over the lives of individuals with developmental disabilities.

Fairview Families and Friends is a support and advocacy group for the residents of Fairview Developmental Center. It helps enrich Fairview residents to live materially, emotionally, and spiritually by extending to the residents' additional benefits that may be beyond Fairview's budget.

Housing Choices' mission is to enhance the lives of people with developmental and other disabilities and their families by creating and supporting quality, affordable housing opportunities. Housing Choices works to ensure that all people enjoy rewarding lives in affordable homes of their choosing.

Jewish Los Angeles Special Needs Trust (JLA Trust) acts to ensure that children and adults with disabilities are able to obtain the highest possible quality of life by leveraging the power of the community to assist with financial security.

National Disability Rights Network is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and the Client Assistance Programs (CAP) for individuals with disabilities. P&As and CAPs work to improve the lives of people with disabilities by guarding against abuse; advocating for basic rights; and ensuring accountability in health care, education, employment, housing,

transportation, and within the juvenile and criminal justice systems. Collectively, the Network is the largest provider of legally based advocacy services to people with disabilities in the United States.

Professor Alison Morantz is the James and Nancy Kelso Professor of Law at Stanford University's Intellectual and Developmental Disabilities Law and Public Policy Project.

Public Counsel was founded in 1970, Public Counsel strives to achieve three main goals: protecting the legal rights of disadvantaged children; representing immigrants who have been the victims of torture, persecution, domestic violence, trafficking, and other crimes; and fostering economic justice by providing individuals and institutions in underserved communities with access to quality legal representation.

Amici's Position. Counsel for Amici have carefully reviewed the briefing before this Court and the Court of Appeal, and thus are familiar with the arguments raised by the parties. This brief does not repeat the parties' submissions, but presents Amici's own perspectives on the case. The attached brief will assist the Court in deciding the issues by providing a broader legal and factual context within which to analyze and develop a decision in this case.

Amici Disclosure Statement. Pursuant to Rule 8.520(f)(4), Amici state that no party or counsel for a party has authored the proposed Amici brief in whole or in part. Further, no party or counsel for a party has made any monetary contribution to fund the preparation or submission of this proposed amici brief.

Accordingly, *Amici* respectfully ask that the Court consider their views in evaluating the arguments raised in this action by accepting the attached brief.

Dated: December 19, 2018

Respectfully submitted,

MORGAN, LEWIS & BOCKIUS LLP

By:

Thomas M. Peterson

Counsel for Amici

Association of Regional Center Agencies, Autism Society of Los Angeles, CASHPCR, Disability Voices United, Fairview Families and Friends, Inc., Housing Choices, Jewish Los Angeles Special Needs Trust (JLA Trust), National Disability Rights Network, Professor Alison Morantz and Public Counsel

AMICI CURIAE BRIEF IN SUPPORT OF PETITIONER INTRODUCTION AND SUMMARY OF ARGUMENT

Petitioner raises an important issue of statewide significance and profound importance to thousands of low-income and developmentally disabled Californians:

Does the developmental disability state payments exclusion for Section 8, low-income federal housing benefits apply to payments made under the In-Home Supportive Services ("IHSS") program to families who care for their developmentally disabled family members?

The issue presented affects thousands of lives. In California, more than 460,000 low-income people with disabilities qualify for the IHSS program, which provides inhome assistance to eligible aged, blind and disabled individuals as an alternative to out-of-home care. Of these, an estimated 42,000 people have developmental disabilities. For approximately 163,000 people, the IHSS provider is a family member who lives in the same house as the disabled person. By any measure, a significant number of California families and individuals are affected by disabilities and rely on support under the IHSS program. Yet many of these families also rely on housing assistance from the

¹ Public Policy Institute of California, *California's In-Home Support Program*, Nov. 2015, http://www.ppic.org/ publication/californias-in-home-support-program/.

² California Department of Social Services, https://www.cdss.ca.gov/inforesources/IHSS (last visited Dec. 13, 2018)

³ California Legislative Analyst Office, Considering the State Costs and Benefits: In-Home Supportive Services Program, Jan. 10, 2010, p. 10, http://www.lao.ca.gov/reports/2010/ssrv/ihss/ihss_012110.pdf.

⁴ Ibid.

government and must therefore navigate the interplay between the IHSS program and the U.S. Department of Housing and Urban Development's ("HUD") rent calculation rules.

Local public housing authorities, like defendant Marin Housing Authority, receive funding from HUD to administer the Housing Choice Voucher program (commonly referred to as "Section 8"). 24 C.F.R. § 982.1(a). The program supports qualifying lowincome families whose "annual income" is below a certain level by subsidizing a percentage of their rental payments.⁵ The size of the subsidy varies depending on the family's income. 24 C.F.R. § 982.1(a)(3). HUD regulations define those amounts to be included in a family's "annual income" for purposes of calculating their rental payments. 24 C.F.R. § 5.609. Importantly, "[a]mounts paid by a State agency to a family with a member who has a developmental disability and is living at home to offset the cost of services and equipment needed to keep the developmentally disabled family member at home" are excluded from the definition of "annual income." 24 C.F.R. § 5.609(c)(16). We refer to this provision as "the developmental disability state payments exclusion." The developmental disability state payments exclusion provides families with resources necessary to care for disabled family members, while also allowing them to maintain their housing.

Yet the Court of Appeal for the First Appellate District held that IHSS payments to families who *themselves* care for disabled family members are to be included in the

⁵ A family's eligibility to receive a housing voucher under the 'Section 8' HUD regulation is based on the family's size and total annual gross income. To be eligible, the family's income may not exceed 50% of the median income for the county in which the family lives.

family's "annual income" for purpose of calculating their Section 8, low-income housing benefits. *Reilly v. Marin Hous. Auth.*, A149918, Slip Opinion at 15 (Cal. Ct. App. April 25, 2018) ("*Reilly*"). In reaching this conclusion, the court of appeal differentiated between families providing care themselves and those that hire third-party caregivers.

Such a distinction ignores the tremendous sacrifices families endure to ensure that disabled family members avoid institutionalization and remain, safely, at home. This distinction exposes families to the loss of housing benefits and rent increases they can ill afford, and undermines the purposes of the developmental disability state payments exclusion and of the IHSS program. Notably, the court of appeal decision jeopardizes the ability of families to keep disabled family members at home, and avoid institutionalization. This undesirable result cannot be reconciled with the purposes of these government assistance programs.

There are at least five reasons that strongly favor the conclusion that IHSS payments to families that provide care themselves should *not* be included in their "annual income" for purposes of calculating their Section 8, low-income housing benefits. These reasons, set out below, are interspersed with actual examples to illustrate the *real-world* importance of the issue presented and the serious difficulties caused by the court of appeal decision. First, families make the sacrifices associated with providing care to avoid institutionalizing disabled family members. These sacrifices should be encouraged, not punished. Second, families provide "supportive services" and "protective supervision" because third-party caregivers are often not readily available to provide immediate and constant care and support. Third, caregiving has evolved over time from

remain at home. This evolution in both legislative policy and social acceptance of developmentally disabled individuals is necessary to promote the inclusion and integration of disabled individuals within the community. Fourth, families provide higher quality of care and support because they have already developed personal, intimate relationships built on trust. Fifth, for some communities, their *culture* requires that families provide the "supportive services" and "protective supervision" themselves. These communities are very family-oriented, and demand family involvement in all aspects of the care and support process.

The court of appeal decision has profound and harmful ramifications for thousands of individuals and families across California. This Court should reverse.

LEGAL ARGUMENT

I. Families Who Avoid Institutionalization And Keep Their Developmentally Disabled Family Member At Home Should Be Encouraged, Not Punished.

The court of appeal decision improperly limits the developmental disability state payments exclusion so as to undermine what it was designed to achieve. The California Legislature enacted the IHSS program to "help incapacitated persons avoid institutionalization" and "permit persons with disabilities to live safely in their own homes." Welf. & Inst. Code, § 12300(a); *Calderon v. Anderson* (1996) 45 Cal. App. 4th 607, 610. In doing so, the Legislature authorized payments for severely impaired Californians to receive up to 65 hours per week in supportive services, including domestic services, personal care services, and protective supervision. Welf. & Inst.

Code, § 12300(b); see also Norasingh v. Lightbourne (2014) 229 Cal.App.4th 740, 745 ("Protective supervision" is monitoring of the behavior of a mentally impaired or mentally ill recipient to safeguard him or her from injury or accident."). The developmental disability state payments exclusion was included to "provide families with homecare payments... to offset the cost of services and equipment needed to keep a developmentally disabled family member at home, rather than placing the family member in an institution. Since families that strive to avoid institutionalization should be encouraged, not punished, the Department is adding this additional exclusion to income." Combined Income and Rent, 60 Fed. Reg. 17388, 17391-17393 (April 5, 1995). HUD added this exclusion to allow families receiving "homecare payments" (such as California's In-Home Supportive Services payments) to receive the full "encouragement" intended by the homecare payment program, and not to experience the corresponding "punishment" of a rent increase (as is inevitable when such payments are included in the calculation of the family's "annual income").6

But rather than *encouraging* families to avoid institutionalization, the court of appeal decision effectively *punishes* families who endure tremendous sacrifices to ensure that family members may remain, safely, at home. We draw this Court's attention to two real world examples, which are also described in the *amicus* letter many of these *amici* joined in support of review, dated and filed July 24, 2018.

⁶ Norah C. Keating et al, *A taxonomy of the economic costs of family care to adults*, The Journal of the Economics of Ageing, Vol. 2014; 3, 11, 12-13.

Walter and his wife have a Section 8 voucher from the Orange County Housing Authority ("OC Housing Authority"). Walter's wife is the primary caretaker for their two children with disabilities—a 4-year-old son with autism and a 10-year-old daughter with cerebral palsy. Walter's daughter is quadriplegic, non-verbal, tube fed, and with a diminished intellectual capacity. The children receive 100 hours of nursing care and around 160 hours of IHSS. This IHSS income has been excluded by their housing authority for the last six years based on 24 C.F.R. § 5.609. Walter does not know what his family would do if that income was included in their rent and their rent increased significantly. Their rent is now \$350. If the OC Housing Authority counted the IHSS payment, it would at least double, or perhaps triple, the rental payment, making it impossible to remain in their home. They would inevitably face homelessness and likely have to put their daughter in an institution.

Similarly, Sariah lives at a complex in San Leandro, CA that is subsidized by project-based Section 8. Sariah cares for her six-year-old son who has significant developmental disabilities. Her son was approved for IHSS protective supervision in May 2017. When Sariah notified her housing provider of this additional income, her rent nearly doubled from \$800 to around \$1,600. As a result of this rental increase, Sariah struggled to pay her rent in full and on time. She fell behind on rent and her housing provider talked to her about how she would not be able to remain in her home unless she could make all of her rental back payments. Sariah sacrificed purchasing food and other necessities so she could keep her family housed. *Pro bono* counsel advocated for Sariah

so that her income was appropriately excluded under 24 C.F.R. § 5.609(c)(16), reducing her rent down to \$800 and securing stable housing for her family.

These examples help illustrate the serious consequences associated with the court of appeal's failure to recognize that HUD added an "additional exclusion to income" because "families that strive to avoid institutionalization should be encouraged, not punished." Rules of law often carry serious personal consequences. Discharge of the judicial function must not lose sight of this fact. An increase in rent can undermine the purposes of homecare payments to such families – especially low-income families; when such payments are excluded from family income, the public policy goals behind those payments are advanced.

II. Families Must Provide Care To Their Developmentally Disabled Family Members Because Third-Party Caregivers Are Not Always Readily Available.

The court of appeal discusses at length the need to reach a "reasonable outcome" by "treat[ing] comparably two families with a developmentally disabled family member: one family in which a third party cares for the disabled person, and the other in which a parent does." *Reilly* at 13. But the outcome it reaches is anything but "reasonable." The court determined that IHSS payments to families who themselves provide care are included in their "annual income." *Reilly* at 15. Such a decision ignores the very real situation many families face. The "supportive services" and "protective supervision" required to permit the developmentally disabled individual to remain, safely, at home often requires 24-hour care and oversight. Cal. Dep't Soc. Serv.'s Manual of Policies and Procedures § 30-757.173(a). Yet the practical reality is that the third-party caregivers

qualified to provide such services are not always readily available;⁷ they are hard to find and are in dwindling supply,⁸ especially when one considers the low rate of compensation attributable to the provision of such services.⁹ These are limits on the services third-party caregivers may provide, necessitating family assistance with other needs like buying clothing, cultivating a social life, getting exercise and the like.

Thus, family members are often required to step in and provide care themselves because they cannot find third-party caregivers. Such families are faced with the decision of whether to institutionalize disabled family members, or provide services themselves. The first option undermines the purposes for which the HUD regulation and the IHSS program were designed. But choosing the second option would, under the court of appeal decision, *punish* families by reducing their Section 8, low-income housing benefits and likely lead to homelessness and the resulting institutionalization of the disabled individual. Thus, the court of appeal decision effectively penalizes families for what is their only available method of keeping their family together and at home.

⁷ Harder & Company Community Research, *A Blind Spot in the System: Health Care for People with Developmental Disabilities*, Sept. 2008, p. 4. https://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf docs/A%20 Blind%20Spot%20in%20the%20System.pdf.

⁸ Amy Hewitt, *Raising Expectations: The Direct Support Professional Workforce*, The Arc National Conference, Aug. 4, 2013, p. 10, https://www.thearc.org/doent.doc?id=4338.

⁹ National Core Indicators, 2016 Staff Stability Survey Report, Jan. 2018, p.31. The study found that third-party caregivers assisting people with intellectual and developmental disabilities received a median hourly wage of \$11.41.

III. Caregiving Has Evolved Over Time From Institutionalizing Individuals To Providing Homecare.

The court of appeal decision ignores the evolution of caregiving that has shifted from institutionalizing individuals with cognitive disabilities and medical issues to supporting them to live in homes and communities. Until the mid-twentieth century, people with developmental disabilities could only receive care and treatment services in institutions. They were viewed as being "sick" and were committed to institutions more commonly operating as "centers of custodial care." As a result, people with developmental disabilities "lived far shorter life spans and experienced far greater health disparities and inequities."

But there has been a sea change in society and policy, that now encourages the integration of individuals with disabilities into the general community. For example, the federal Developmental Disabilities Assistance and Bill of Rights Act provides that "access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life..." 42 U.S.C. § 15001(b). This evolution of view has been influenced by the fact that "individuals with developmental disabilities are at greater risk than the general population of abuse, neglect, financial and sexual exploitation, and the violation of their legal and human rights." 42 U.S.C. § 15001(a)(5).

¹⁰ Ibid.

¹¹ David A. Ervin et al, *Healthcare for persons with intellectual and developmental disability in the community*, Frontiers in public health, Vol. 2(83), Jul. 2014, p. 2.

¹² Ibid.

Congress' findings and policy decisions recognize the value in homecare and the importance of family involvement in the provision of care, treatment and supportive services.¹³

Yet the court of appeal ignores this evolution in both legislative policy¹⁴ and social acceptance of developmentally disabled individuals. Its decision fails to appreciate that these are vulnerable people requiring immediate and constant supervision to prevent injury or accident. The ramifications of the court's decision point backward, to now-disfavored institutionalization.¹⁵

Once again, it is important to consider these matters from the perspective of those affected. Angi has a Section 8 voucher from the OC Housing Authority. She receives IHSS protective supervision funds to care for her adult daughter with severe developmental disabilities. Her daughter has Rett Syndrome and is completely dependent on others for care, including bathing, feeding, toileting, eating, getting in and out of her wheelchair, and traveling to and from locations. In July 2016, Angi was notified that her

¹³ Brian R. Grossman, *Introduction to the Special Issue: Family Support of Persons with Disabilities Across the Life Course*, Journal of Family Social Work, Vol. 19, 4, Sep. 2016, p. 237-238.

¹⁴ For example, the Affordable Care Act of 2010 improved access and decreased health care inequities for people with disabilities by introducing provisions that prohibit insurance denials based on preexisting conditions, prohibit annual and lifetime coverage limits, making essential the coverage of rehabilitation and habilitation and mental health services, and assuring that dental care is also deemed essential. More importantly people with developmental disabilities are identified as a priority population, meaning that specific training programs will be enacted for both primary care and dentistry. See also Lynda L. Anderson et al, The State of the Science of Health and Wellness for Adults with Intellectual and Developmental Disabilities, Intellect Dev. Disabil. Vol. 51(5), Oct. 2013, 385, 395-396.

¹⁵ Catherine Thornberry & Karin Olson, *The abuse of individuals with developmental disabilities*, Developmental Disabilities Bulletin, Vol. 33, No. 1 & 2, 1, 3.

Section 8 voucher was to be terminated in six months. Because the OC Housing Authority counted IHSS payments as income, Angi was responsible for the entire \$1,325 rent. *Pro bono* assisted her in having her IHSS payments correctly excluded under developmental disability state payments exclusion. This reduced her rent from \$1,325 to \$300, leaving her with remaining funds to pay for food, emergencies, and the many extraordinary needs related to her child's disability. Had this income been counted, she would have lost her voucher and become homeless. Because her daughter's care needs are simply too great to manage in a shelter, Angi would have been forced to place her daughter in an institution if she had lost her Section 8 voucher and her apartment.

Such a result is obviously unwanted, but is the very real outcome for many families under the court of appeal decision. It is a result irreconcilable with Congress' efforts to prevent the "abuse and neglect, and even inhumane medical experiments and forced sterilization" institutionalized individuals were subjected to. But that is precisely what the court of appeal decision does to these disabled individuals; it makes it incredibly difficult for low-income families, like petitioner and Angi and thousands of others similarly effected in California, to provide for their disabled family members, to keep them out of institutions, and to "promote self-determination, independence, productivity, and integration and inclusion in all facets of community life..."

¹⁶ 60 Minutes: A Dark Chapter in Medical History (CBS television broadcast, Feb. 9 2005); see also Catherine Thornberry & Karin Olson, The abuse of individuals with developmental disabilities, Developmental Disabilities Bulletin, Vol. 33, No. 1 & 2, 1, 5.

IV. Families Provide Higher Quality Services To Disabled Family Members Because The Services Required Are Of A Personal Nature And Embody A High Degree Of Trust.

The court of appeal decision fails to take into account the quality of services families provide to their family members with disabilities. The IHSS program is designed to pay for only a portion of the home care that a developmentally disabled individual requires. The precise number of hours of services a particular individual may receive is based on California Department of Social Services' hourly task guidelines. See Welf. & Inst. Code § 12301.2. The total is capped at 283 hours per month in attendant care. Welf. & Inst. Code §§ 12303.4(b), 14132.95(g). Persons often require "protective supervision," which is only available if "a need exists for twenty-four-hours-a-day of supervision," meaning 720 hours in a thirty-day month. Cal. Dep't Soc. Serv.'s Manual of Policies and Procedures § 30-757.173(a). As such, it is clear that IHSS program participants needing round-the-clock "supportive services" and "protective supervision" are left with a large shortfall of unmet need. But despite this tremendous gap, the nature of the caregiving services must be of the *highest quality* to ensure that developmentally disabled individuals are supervised, kept safe, and supported to allow integration, selfdetermination and inclusion within the community.

Yet the court of appeal's decision fails to recognize the tension between the quality of services required and the quality of support actually authorized under the IHSS program. Further, it ignores that (i) the provision of "supportive services" and "protective supervision" are very personal in nature, and (ii) these services embody a high degree of trust.

First, this Court must ask itself: who is best placed to provide round-the-clock care and support services that are of a very personal nature? A person who has already developed an intimate relationship with the individual; a relationship of love and devotion, ¹⁷ built on the desire to sacrifice to provide for the disabled family member? Or a hired worker that is compensated to provide only a small fraction of the care actually required? Petitioner, and many similarly situated Californians, forego full-time employment and sacrifice their own time, freedom and energy to care for family members. 18 Family "caregiving requires time, money, and social capital" and the "opportunity costs are equally great." 19 Yet there are approximately 2.9 million family caregivers of individuals with intellectual and/or developmental disabilities in the United States, ²⁰ including Alexandria. Alexandria has a Section 8 voucher from the San Francisco Housing Authority ("SF Housing Authority"). She receives IHSS to care for her 21-year-old daughter with severe developmental disabilities. Her daughter is nonambulatory, relegated to a bed, non-verbal, uses a feeding tube, has seizures, and has cerebral palsy. When Alexandria's daughter was two and her disabilities were diagnosed, her doctors recommended that she be placed in a facility and stated she was unlikely to

¹⁷ Susan H. McDaniel & Anthony R. Pisani, *Family Dynamics and Caregiving for People with Disabilities*, p. 24 (last visited Dec. 13, 2018) ("Providing care for a disabled family member is often a labor of love.").

¹⁸ Norah C. Keating et al, *A taxonomy of the economic costs of family care to adults*, The Journal of the Economics of Ageing, Vol. 2014;3, 11, 12-13.

¹⁹ *Ibid*.

²⁰ United Healthcare Community & State, *Family Caregiving in the United States*, August 2017, p. 3 *citing* The Arc, National Family Caregiver Support Program, https://www.thearc.org/sslpage.aspx?pid=3378.

live beyond age seven. But Alexandria refused to place her daughter in a facility and has cared for her for years. In 2017, Alexandria fell behind on rent due to medical expenses not covered by Medi-Cal and an inflated rent resulting from including her IHSS income. She was days away from the sheriff coming to evict her and her family. *Pro bono* counsel was able to rely on 24 C.F.R. § 5.609(c)(16) regulation to exempt her income and have the SF Housing Authority recalculate her rent due. As a result, her rent dropped from \$1,034 to \$245, and her housing was preserved. If the SF Housing Authority included this income again, she would return to extreme housing instability, have a difficult time buying food, and lose the ability to transport her disabled daughter out of the home.

Second, the importance of trust in the caregiving relationship cannot be overstated. The caregiver must trust that the disabled individual will be receptive to their involvement in the caregiving process, and, more importantly, the disabled individual must trust that the caregiver has both the ability and the individual's best intentions at heart when providing services.²¹ Trust is "the foundation for building unified supportive relationships" because trusting someone to be responsible for your life requires "a huge leap of faith."²²

²¹ Marlo Sollitto, *13 Secrets that Make Caregiving Easier*, https://www.agingcare.com/articles/make-caregiving-easier-141826.htm (last visited Dec. 13, 2018).

²² Jodi Robledo & Anne M. Donnellan, *Supportive Relationships in Autism Spectrum Disorder: Perspective of Individuals with ASD and Supporters*, Behavioral Sciences (Basel, Switzerland), Vol. 6(4), 23, Nov. 2016, 3, 10-11.

And so it becomes clear that the court of appeal erred when it failed to incorporate the disabled individual's perspective into its decision. The presence of trust facilitates and fosters a strong bond between the caregiver and the recipient, which in turn ensures that the provision of care and support is more warmly received. It is most easily developed when the recipient of the care has a "firm belief in the reliability, truth, or ability" of the caregiver.²³ Yet the court ignored the very real factors that make up a successful caregiving relationship, one that is built on trust. The court failed to appreciate that "[t]rust usually develops naturally over time,"²⁴ but *already* exists within a family, who share intimate, personal relationships with the developmentally disabled family member. Because trust is the foundation of the caregiving relationship, the court of appeal's failure to appreciate the importance of family care undermines the purpose of the IHSS program and unfairly burdens families who provide "supportive services" and "protective supervision," all to the detriment of the developmentally disabled individual.

V. Families Provide Care And Supportive Services For Cultural Reasons, Which Become Undermined By The Court Of Appeal's Decision.

It is important for this Court to understand the differences in cultural beliefs across communities. Families may be *unwilling* to relinquish caregiving services to a third-party caregiver because they believe it is their *cultural responsibility* to provide these

²³ Trust, Oxford English Dictionary. (3rd ed. 2015).

²⁴ Jodi Robledo & Anne M. Donnellan, *Supportive Relationships in Autism Spectrum Disorder: Perspective of Individuals with ASD and Supporters*, Behavioral Sciences (Basel, Switzerland), Vol. 6(4), 23, Nov. 2016, 3, 10-11.

services themselves. For families who rely on Section 8, low-income housing benefits, they are denied the right to practice their cultural traditions and beliefs.

For example, the tension created by the court of appeal decision is likely to affect Latino families that have as part of their culture strong family traditions. The Latino community makes up approximately 39% of the population in California. It is a culture "rich in traditions, beliefs, practices, and attitudes" and centers on a strong loyalty to family. The Latino culture embraces "attitudinal familism," which refers to the belief that family members should be emotionally close, spend time together, provide assistance to each other and take on responsibility for the well-being of the entire family." This belief "influence[s] perceptions and understanding of the disease processes and treatment" because "Latinos have [been] shown to place significant value on the well-being of their family. As a result, the caregiver structures of Latino families tend to embody a more collectivist and family approach, and have been shown to be larger than

²⁵ United States Census Bureau, https://www.census.gov/quickfacts/ca (last visited on December 7, 2018).

²⁶ Eugenio Cerosimo & Nicolas Musi, *Improving treatment in Hispanic/Latino patients*, The American Journal of Medicine, Vol. 124(1), 2011, p. S18.

²⁷ S.R. Cohen et al, *Receiving or believing in family support? Contributors to the life quality of Latino and non-Latino families of children with intellectual disability*, Journal of Intellectual Disability Research, Vol. 58(4), 2016, p. 3.

²⁸ Eugenio Cerosimo & Nicolas Musi, *Improving treatment in Hispanic/Latino patients*, The American Journal of Medicine, Vol. 124(1), 2011, p. S18.

that of white families in the U.S."²⁹ In fact, "support may be expected from the family more than from the [] professional."³⁰

For Latino families with such strong cultural beliefs, it is not so much a decision to sacrifice everything to provide for their disabled family member as it is their *duty* to uphold their cultural obligations. They forego opportunities to earn valuable income, which, according to the United States Census Bureau, is an incredible sacrifice given that Latino families are amongst the lowest income-earning families in the United States.³¹

The court of appeal decision takes no account of this reality. The decision in this case should accommodate cultural diversity.

CONCLUSION

Amici respectfully ask this Court to hold that the developmental disability state payments exclusion for Section 8, low-income federal housing benefits applies to IHSS payments made to families who care for their developmentally disabled family members.

²⁹ A.E. Coy et al, *Moderated mediation path analysis of Mexican traumatic brain injury patient social functioning, family functioning, and caregiver mental health*, Archives of Physical Medicine and Rehabilitation, Vol. 94(2), Aug. 2012, p. 366.

³⁰ M.C. Zea et al, *Latino Cultural Values: Their Role in Adjustment to Disability*, Journal of Social Behavior and Personality, Vol. 9, No. 5, 1994, 185, 191.

³¹ United States Census Bureau, *Income and Poverty in the United States: 2015*, p. 5, figure 1.

Dated: December 19, 2018

Respectfully submitted,

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Association of Regional Center Agencies, Autism Society of Los Angeles, CASHPCR, Disability Voices United, Fairview Families and Friends, Inc., Housing Choices, Jewish Los Angeles Special Needs Trust (JLA Trust), National Disability Rights Network, Professor Alison Morantz and Public Counsel

CERTIFICATE OF WORD COUNT

(Cal. Rules of Court, Rule 8.204(c)(1))

I hereby certify that pursuant to California Rules of Court, Rule 8.204(c)(1), the attached brief, including footnotes, but excluding the caption page and this certification, contains 5,225 words, as counted by the Word 2016 word-processing program used to generate the brief.

Dated: December 19, 2018

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CERTIFICATE OF SERVICE

I, Davace Chin, declare that I am a resident of the State of California. I am over the age of eighteen years and not a party to the within action; my business address is Morgan, Lewis & Bockius LLP, One Market Street, Spear Tower, San Francisco, California 94105.

On December 19, 2018, I caused the following document to be served:

APPLICATION FOR LEAVE TO FILE *AMICI CURIAE* BRIEF and *AMICI CURIAE* BRIEF IN SUPPORT OF PETITIONER

via U.S. Postal Service – by placing the document listed above in a sealed envelope with postage thereon fully prepaid, in the United States mail at San Francisco, California addressed as set forth below:

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I declare under penalty of perjury, under the laws of the United States of America and the State of California, that the above is true and correct. Executed on December 19, 2018, at San Francisco, California.

By: Navace Chin

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