MUI GUII LEWIS

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July 24, 2018

Honorable Tani Cantil-Sakauye, Chief Justice and Associate Justices Supreme Court of California 350 McAllister Street San Francisco, CA 94102

Re: Kerrie Reilly v. Marin Housing Authority

Supreme Court No. S249593

Amici Curiae in Support of Petition for Review

Your Honors:

Pursuant to rule 8.500(g) of the California Rules of Court, Autism Society of Los Angeles, Disability Rights California, National Disability Rights Network, Disability Voices United, Easter Seals Southern California, Inc., Fiesta Educativa, Inc., Robin Hansen, M.D., The Kelsey, Olivia Raynor, Ph.D., United Cerebral Palsy of Los Angeles, Ventura, and Santa Barbara Counties (UCPLA), and Larry Yin, M.D. (collectively, "amici") respectfully urge that review be granted.

I. INTRODUCTORY STATEMENT

Petitioner raises an important, unsettled issue of statewide significance and profound importance to thousands of Californians who are low-income and have developmentally disabilities: Does the developmental disability income exemption for Section 8's low-income federal housing benefits apply to payments made under the In-Home Supportive Services ("IHSS")

Program¹ to family members who care for developmentally disabled relatives?

The court of appeal decision below imposes onerous financial burdens on petitioner Kerrie Reilly and others situated like her, that is, those who care for developmentally disabled family members at home, thereby allowing them to stay at home and avoid institutionalization. Government assistance payments to caregiving family members encourage and promote these worthy goals.² Yet the court of appeal here held that such payments effectively reduce the Section 8 housing benefits that low-income families also require to have and maintain a home-environment for family members with developmental disabilities.

Counting IHSS payments as income for purposes of calculating housing subsidies—as the court of appeal decision requires—undermines the purposes of Section 8's developmental disability income exemption and of the IHSS program. The decision exposes families to the loss of housing benefits, rent increases they can ill afford, and jeopardizes their ability to keep disabled family members at home.

Ironically, the court of appeal holds that families that use government assistance payments to hire third-party-care providers for their disabled relatives do not have those payments counted toward housing benefit eligibility—those payments fall within the developmental disability income exemption. Ct. App. Slip Op.-13. But there is a serious shortage of third-party-care providers.³ Many family members must forego other employment

² IHSS is a "state and federally funded program developed to permit persons with disabilities to live safely in their own homes." *Calderon v. Anderson*, 45 Cal. App. 4th 607, 610 (1996).

The income exemption appears at 24 C.F.R. § 5.609(c)(16).

See Catherine Ho, Amid soaring Bay Area housing prices, a struggle to keep home aides, SAN FRANCISCO CHRONICLE (May 14, 2018 6:47 a.m.)https://www.sfchronicle.com/business/article/Amid-soaring-Bay-Area-housing-prices-a-struggle-12911410.php (noting that "some local providers have been forced to shut down home care services altogether").

and provide care themselves because they have no other realistic options. So the court of appeal decision leaves families caught between the difficulties they face in securing third-party care and the risks to their housing benefits that will now follow if—lacking realistic alternatives—they receive payments from the IHSS Program to provide care themselves. This "Catch-22" ought not escape review.

This Court should review the important issue presented by this case. It carries profound significance for many of our State's most vulnerable residents, as we explain in the following pages.

II. STATEMENT OF INTEREST OF AMICI CURIAE

Collectively, *amici* are deeply committed to serving people with disabilities and serving vulnerable populations. More specifically:

- 1. *Amicus* The Autism Society of Los Angeles empowers individuals with autism, their families, and professionals through advocacy, education, support, and community collaboration.
- 2. Amicus National Disability Rights Network is the non-profit membership organization for the federally mandated Protection and Advocacy (P&A) and Client Assistance Program (CAP) agencies for individuals with disabilities. The P&A and CAP agencies were established by Congress to protect the rights of people with disabilities and their families through legal support,

The article cites an executive director at a nonprofit provider as saying: "We've really been struggling to find enough caregivers to fulfill the needs of our clients." *Id. See also* Robyn I. Stone & Joshua M. Wiener, *Who Will Care For Us? Addressing The Long-Term Care Workforce Crisis*, U.S. DEPT. OF HEALTH AND HUMAN SERVICES, OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION, May 1, 2001, https://aspe.hhs.gov/basic-report/who-will-care-us-addressing-long-term-care-workforce-crisis ("Long-term care providers report unprecedented vacancies and turnover rates for paraprofessional workers...These shortages are likely to worsen over time as demand increases").

- advocacy, referral, and education. There are P&As and CAPs in all 50 states. Collectively, the P&A and CAP agencies are the largest provider of legally based advocacy services to people with disabilities in the United States.
- 3. *Amicus* Disability Voices United is a statewide organization directed by and for individuals with developmental disabilities of all ages and their families.
- 4. *Amicus* Easter Seals Southern California, Inc. serves people and families who face a wide range of disabilities, including physical emotional, intellectual, social and educational disabilities.
- 5. The mission of *amicus* Fiesta Educativa Inc. is to provide information and training to Latino families on how to obtain services for all persons with disabilities.
- 6. Amicus Robin Hansen, M.D., is a board certified developmental behavioral pediatrician who is a national leader in the field of developmental disability through her work establishing community partnerships, interdisciplinary training and research. She is the Director one of California's three federally funded University Centers for Excellence in Developmental Disabilities. Dr. Hansen works to improve the quality of life and ensure community inclusion for individuals with developmental disabilities through advocacy, community partnerships, interdisciplinary training and the translation of research into practical applications.
- 7. *Amicus* The Kelsey seeks to create mixed ability, mixed income housing communities where people of all abilities and backgrounds live, play, and serve together.
- 8. *Amicus* Olivia Raynor, Ph.D., is a licensed occupational therapist, with a master's degree in occupational therapy from the University of Southern California, and doctorate in educational psychology from the University of California Los Angeles. Dr.

> Raynor is the Director of one of California's three federally funded University Centers for Excellence in Developmental Disabilities. Dr. Raynor expertise includes systems change, community integration and the self-determination and inclusion of children, youth and adults with disabilities.

- 9. *Amicus* UCPLA's mission is to advance the independence, productivity and full citizenship of individuals with developmental and intellectual disabilities.
- 10. Amicus Larry Yin, M.D., MSPH, is a board certified Developmental & Behavioral Pediatrician and a General Pediatrician. Dr. Yin is a nationally recognized leader in developing and implementing quality services for infants, children, youth and adults with, or at risk for, behavioral, developmental, physical, and/or special health care needs and their families.

III. REVIEW IS NECESSARY TO ADDRESS AN IMPORTANT QUESTION OF LAW THAT AFFECTS COUNTLESS LOW-INCOME AND DEVELOPMENTALLY DISABLED INDIVIDUALS FACING HOMELESSNESS AND/OR INSTITUTIONALIZATION

The issue presented by this case affects thousands of lives. In California, more than 460,000 low-income people with disabilities qualify for the IHSS program.⁴ Of these, an estimated 42,000 people have developmental disabilities.⁵ For approximately 163,000 people, the IHSS

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Laurel Beck, *California's In-Home Support Program*, PUBLIC POLICY INSTITUTE OF CALIFORNIA (November 2015), http://www.ppic.org/publication/californias-in-home-support-program/.

Ginni Bella Navarre & Todd Bland, Considering the State Costs and Benefits: In-Home Supportive Services Program, CALIFORNIA LEGISLATIVE ANALYST OFFICE (LAO) 10 (January 10, 2010), http://www.lao.ca.gov/reports/2010/ssrv/ihss/ihss_012110.pdf.

provider is a family member who lives in the same house as the disabled person. By any measure, IHSS's impact on the Department of Housing and Urban Development's rent calculation rules affects a significant number of Californians. The developmental disability income exemption provides these caregivers with resources necessary to care for family members and maintain their housing. Thus, the court of appeal decision has profound and lasting ramifications for thousands of individuals and families.

A. The Court Of Appeal Decision Is Inconsistent With The Purposes Of The Law And Contrary To The Goal Of Protecting People With Disabilities

The court of appeal interpreted the DD income exemption so narrowly that it now undermines what the exemption was intended to accomplish. The court reasoned that it would be unfair and inequitable for parents caring for children with developmental disabilities to exempt caregiver payments, while parents of children with other types of disabilities do not enjoy a similar exemption. Ct. App. Slip Op.—13-14. The court of appeal's analogy is deeply flawed.

The developmental disability income exemption covers "[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." 24 C.F.R. §5.609(c)(16). The regulation addresses only homecare payments for an individual with a developmental disability. Section 5.609(c)(16)'s distinctive treatment of persons with developmental disabilities is justified by the historical discrimination and needless institutionalization such persons have long experienced. For years, only institutional care was available to persons with developmental disabilities.⁷ Institutionalized individuals were

⁶ *Id*.

⁷ C

Gretchen Engquist, Cyndy Johnson & William Courtland Johnson, *Trends* and Challenges in Publicly-Financed Care for Individuals with Intellectual and Developmental Disabilities, CENTER FOR HEALTH CARE

often subject to abuse and neglect, and even inhumane medical experiments and forced sterilization.⁸ Also, the cost of institutionalization far exceeds that of living-at-home costs.⁹ In 2009, California's average annual expenditures per patient in state institutions was \$255,864 compared to a mere \$22,809 for "Medicaid-funded home and community-based services."¹⁰

The latest version of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 was enacted to ensure that the disabled have access to community services and support. The Act includes a finding 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). Section 5.609(c)(16) should encourage—not punish—families striving to keep disabled family members at home.

The court of appeal drew a distinction between payments a family receives to hire a third-party caregiver (subject to income exemption) and payments a family member receives for his/her own caregiving (not subject to the exemption). Ct. App. Slip. Op.-13. But the practical reality is that third-

STRATEGIES, INC. 4 (Feb. 2013) https://www.chcs.org/media/IDD Service Delivery Systems 051313.pdf

⁸ 60 Minutes: A Dark Chapter in Medical History (CBS television broadcast Feb. 9, 2005); see also Buck v. Bell, 274 U.S. 200, 208 (1927) (upholding statute that permitted forced sterilization for being "feebleminded" without due process for the plaintiff and her mother).

NATIONAL COUNCIL ON DISABILITY, DEINSTITUTIONALIZATION TOOLKIT: COSTS IN DETAIL, 1 (2012) https://www.ncd.gov/publications/2012/DIToolkit/Costs/inDetail/.

Id. The Council's report suggests that the difference in cost is due to the fact that "community-based services include a diverse array of service types," while institutions traditionally employ a one-size fits all approach. Id. at 6-7. The institutions thus waste money by providing unnecessary, generalized services. Id.

party caregivers are hard to find and in dwindling supply.¹¹ Family members are often forced to provide care themselves because they are unable to engage third-party providers. Thus, the court of appeal decision effectively penalizes what is for many their only available method of keeping disabled family members at home, that is, by foregoing other employment and staying at home to provide care.

B. The Very Personal Stakes At Issue In This Case Support the Grant of Review

Rules of law often carry serious personal consequences. *Amici* illustrate the importance of this case with a few real-world examples of the difficulties and burdens the court of appeal decision presents for persons who have faced difficulties in navigating Section 8 benefits and the developmental disability income exemption.

Sariah

Sariah lives in a complex in San Leandro, CA that is subsidized by project-based Section 8. She 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 \$1600. As a result of this rental increase, she struggled to pay her rent in full and on time. She fell behind on rent and her housing provider told her that she would be evicted unless she could make all of her rental back payments. She sacrificed purchasing food and other necessities so she could

See supra note 3; accord Sarah Thomason & Annette Bernhardt, California's Homecare Crisis: Raising Wages Is Key to the Solution, UC BERKELEY LABOR CENTER 2 (November 7, 2017), http://laborcenter.berkeley.edu/pdf/2017/Californias-Homecare-Crisis.pdf ("The homecare industry has grown exponentially in recent decades and will continue to do so in the future.... Unless California's homecare crisis is addressed and workers' wages are increased, the elderly and people with disabilities will not get the care they require....").

keep her family housed. *Pro bono* counsel advocated for Sariah so that her income was appropriately excluded pursuant to Section 5.609(c)(16), reducing her rent down to \$800 and securing stable housing for her family.

Angi

Angi has a Section 8 voucher from the Orange County 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 Section 8 voucher was to be terminated in six months. Because the Housing Authority counted IHSS payments as income, Angi was responsible for the entire \$1325 rent. *Pro bono* counsel assisted her in having her IHSS payments correctly excluded under Section 5.609(c)(16). This reduced her rent from \$1325 to \$300, leaving her with remaining funds to pay for food, emergencies, and the many extraordinary needs related to her child's disability. Had she lost her voucher, she would have been homeless. Because her daughter's care needs are simply too great to manage in a shelter, this mother would have been forced to place her daughter in an institution if she had lost her Section 8 voucher and her apartment.

Walter

Walter and his wife have a Section 8 voucher from the Orange County 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 has a severe cognitive disability. The children receive 100 hours of nursing care and around 160 hours of IHSS. This IHSS is excluded by their housing authority based on Section 5.609(c)(16). This income has been excluded for the last six years. 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 housing authority counted the IHSS payment, it would at least double, or perhaps triple, the rental payment. If rent tripled, it would be impossible for the family to remain in their home.

They would inevitably face homelessness and would likely have to put their daughter in an institution.

Alexandria

Alexandria has a Section 8 voucher from the San Francisco Housing Authority. She receives IHSS to care for her 21-year-old daughter with severe developmental disabilities. Her daughter is non-ambulatory, confined 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 live beyond age seven. But Alexandria refused to place her daughter in a facility and 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 because her IHSS income was included when calculating her Section 8 benefits. Alexandria was days away from the sheriff coming to evict her and her family. *Pro bono* counsel was able to exempt Alexandria's IHSS income and have the Housing Authority recalculate her rent. As a result, Alexandria's rent dropped from \$1034 to \$245, and her housing was preserved. If the Housing Authority included this income again, Alexandria 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.

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This case presents an issue of extreme importance to California's low-income and developmentally disabled communities. Review is warranted.

Respectfully,

Thomas M. Peterson

Jum ne fetum

CERTIFICATE OF SERVICE

I declare that I am a resident of the State of California, County of San Francisco. 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 July 24, 2018, I caused the following document to be served:

AMICI CURIAE IN SUPPORT OF PETITION FOR REVIEW

via Electronic Mail, Rule 16(j). An attorney's registration with TrueFiling to participate in EFS constitutes consent to service or delivery of all documents by any other party in a case through the system. (California Rules of Court, rule 8.71.) This document generated by the Court will be served only through the EFS or by e-mailed notification to the following parties:

Randall Lee and Anne Gritzer Ilya Filmus

WFBM, LLP Marin Housing Authority

Frank Moore Deborah Gettleman and

Law Office of Frank S. Moore Benjamin Conway

Disability Rights California

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 July 24, 2018, at San Francisco, California.

By: Thomas M. Peterson