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NO. 97216-8

SUPREME COURT OF THE STATE OF WASHINGTON

SEIU 775,

Petitioner,

v.

STATE OF WASHINGTON, WASHINGTON STATE DEPARTMENT
OF SOCIAL AND HEALTH SERVICES,

Respondent.

**BRIEF OF AMICUS CURIAE NORTHWEST JUSTICE PROJECT
IN SUPPORT OF PETITIONER'S REQUEST FOR DIRECT
REVIEW**

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I. INTRODUCTION

Amicus curiae respectfully requests that the Court grant direct review of Petitioner SEIU 775's appeal arguing that Washington's demographic crisis supports direct review by this Court. Statement of Grounds for Direct Review at 11. The Washington State Legislature has similarly recognized the coming crisis while also acknowledging the importance of seniors and people with disabilities remaining in their homes or community settings if they so choose. *See* Laws of 2019, ch. 363, § 1. As explained more fully below, however, the Department of Social and Health Services' (Department) history of cutting the Medicaid personal care services program and the problems inherent in the informal support and shared benefit rules challenged in this case make it difficult to meet the coming need. Direct review is therefore warranted.

II. INTEREST OF AMICUS CURIAE

Northwest Justice Project (NJP) is the largest statewide nonprofit law firm providing free civil legal aid to low-income people in Washington State. We serve hundreds of clients every year who receive Medicaid personal care services, and we are actively involved in litigation addressing systemic issues that arise from the Department's management of the program. Our interests are fully set out in our motion to participate as amicus curiae.

III. NATURE OF CASE AND DECISION; ISSUES PRESENTED FOR REVIEW

Amicus agrees with Petitioner's Nature of Case and Decision and Issues Presented for Review.

IV. ARGUMENT

A. Direct Review is Warranted to Address Significant Issues of Public Importance Related to Low-Income People with Disabilities and Their Care Providers

1. Washington's History of Repeated Cuts to Medicaid Personal Care Services Raises Troubling Concerns about the State's Failure to Take Beneficiaries' Actual Needs into Account in Establishing Care Hours

As noted by all parties and amici curiae, the purpose of Medicaid-funded personal care services is to support elderly people and people with disabilities to "remain at home."¹ Personal care services are defined as "physical or verbal assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs)" for which a person needs help due to functional limitations. WAC 388-106-0010. The care provided is essential because it allows Medicaid beneficiaries to pursue a meaningful life, with the freedom to be integrated in the community instead of being institutionalized.

¹ See Pet'r's Statement of Grounds for Direct Review at 1; Answer to Statement of Grounds for Direct Review at 5-6 (describing the range of non-institutional, community-based settings in Washington); *see also* Br. of Amicus Curiae Disability Rights Wash. at 1.

The Department, however, has a history of cutting essential personal care services hours, with no regard to beneficiaries' actual needs. These reductions have been fiscally driven, and have resulted in extensive litigation in which this Court has played an important role in ensuring compliance with the law.

a. The Troubling History of Cuts to the Neediest People

An examination of how many personal care services hours, or base hours, are assigned to the neediest of beneficiaries—the E High group, or those beneficiaries who require exceptional care—is illustrative. Base hours are the minimum number of paid hours a beneficiary is authorized to receive before the Department applies various downward adjustments to them, of which the challenged rules constitute the lion's share. WAC 388-106-0125, 388-106-0130.

The Department first develops a plan of care and assigns base hours using the Comprehensive Assessment Reporting Evaluation (CARE) tool, an instrument used to determine the nature and scope of care a beneficiary needs. Medicaid beneficiaries receive personal care assistance with their ADLs, such as bathing, bed mobility, dressing, eating, medication management, and mobility. Personal care hours also assist with IADLs, such as meal preparation, shopping, ordinary housework, traveling to

medical services, and wood supply. WAC 388-106-0010. Both ADLs and IADLs are essential for everyday life. While ADLs are geared toward physical assistance, IADLs are activities that assist beneficiaries around their home or in the community. *See id.*

CARE also considers other factors, such as cognitive performance and behaviors. WAC 388-106-0085, 388-106-0100. However, the CARE assessment does not determine authorized hours based on the number of times the same assistance must be provided to the beneficiary, or the length of time it takes to perform any ADLs. *See Answer to Statement of Grounds for Direct Review at 3* (“The Department never asks how much time it takes to provide care for the client.”).

Once a beneficiary is assessed, the Department places the beneficiary into one of seventeen classifications. WAC 388-106-0080. Each classification has been assigned a number of base personal care hours per month. The E Group, for example, is the classification group for people who require exceptional care; they are the neediest and most vulnerable beneficiaries. *See WAC 388-106-0110*. Beneficiaries are only placed in the E group if they have ADL scores greater than 22 and meet at least one of two profiles. WAC 388-106-0110(1). The first profile requires the beneficiary to have a turning/repositioning program, active or passive range of motion assistance, and at least one of the following: a catheter program,

a bowel program, ostomy care or total assistance for toileting. *Id.* The second profile requires a turning/repositioning program; active or passive range of motion assistance; nutrition support through a tube; and dialysis or ventilator/respirator support. *Id.* People who require exceptional care with high needs (i.e. the E High Group) are those who have an ADL score of 26-28, which means that they are totally dependent on their caregiver for completing most or all of their ADLs. *See* WAC 388-106-0010; 388-106-0125(1)(a).

In 2005, the Department enacted final rules implementing the CARE tool. Wash. St. Reg. 05-11-082 (June 14, 2005). At that time, Group E High was assigned 420 base hours. *Id.*

In 2009, the Washington State Legislature passed an operating budget that directed the Department to reduce base hours. Laws of 2009, ch. 564, § 206(5) (“Amounts appropriated in this section reflect a reduction to funds appropriated for in-home care. The department shall reduce the number of in-home hours authorized.”). The Department issued an emergency rule cutting Group E High beneficiaries from 420 hours of paid care per month to 416 hours. Wash. St. Reg. 09-14-046 (July 1, 2009).² All

² The E Group is used for illustrative purposes, but the 2009 reductions in base hours applied to each of the seventeen classification groups. In other words, the base hours for each classification group were reduced and have not been restored.

seventeen classification groups had their hours cut to varying degrees and by as much as nine hours per month. *Id.* This reduction of hours persisted through a series of emergency rules and unrelated litigation challenging the Department's inclusion of children and youth under the age of twenty-one in the mandatory reductions, and finally became permanent in May 2010. Wash. St. Reg. 10-11-050 (June 12, 2010).

Medicaid beneficiaries in Group E High received a respite in 2010 when the Legislature restored base hours by way of supplemental funding, with the goal of making them permanent. Laws of 2010, ch. 37, § 206(6)(b) (“[A]ppropriations are provided solely for the department to partially restore the reduction to in home care”); Wash. St. Reg. 10-14-055 (July 1, 2010), 10-22-066 (Oct. 29, 2010), 10-22-123 (filed Nov. 3, 2010). This respite was short-lived because Governor Gregoire issued an Executive Order on September 13, 2010, to reduce state spending. An emergency rule was adopted on January 1, 2011, cutting base hours again. Wash. St. Reg. 11-02-041 (Jan. 1, 2011); *see also* Wash. St. Reg. 12-13-068 (July 19, 2012) (permanent rules).³ Group E High plummeted to 393 base hours. The Department also reduced base hours for all of the other classification groups

³ This reduction was the subject of extensive litigation. *See M.R. v. Dreyfus*, 697 F.3d 706 (9th Cir. 2012) (reversing denial of injunction challenging the mandatory reduction of personal care hours as a result of the Executive Order).

substantially lower than they had been during the 2009 cuts. Wash. St. Reg. 11-02-041, 12-13-068. Today, Group E High remains at 393 base hours, and all other classification groups remain at their 2011 levels. WAC 388-106-0125(1)(a). Each classification group's base hours were reduced by the Executive Order. These across-the-board cuts were never restored after the economy improved. *Id.*

b. Extensive History of Other Cuts Struck Down by This Court

Additionally, the Department promulgated a series of rules that further reduced base hours in certain circumstances, including when the client lived with his or her individual provider (i.e. the Shared Living Rule) and based upon the child's age and whether the child lives with a parent (i.e. the Children's Assessment Rule). The Shared Living Rule involved an automatic reduction in personal care services of fifteen percent if a beneficiary lived with his or her caregiver. *See Jenkins v. Washington State Dep't of Soc. & Health Servs.*, 160 Wn.2d 287, 290, 157 P.3d 388, 389 (2007). The Northwest Justice Project represented the plaintiffs in *Jenkins* because of the dire impact on our clients, in contravention of federal law.

The Children's Assessment Rule also involved automatic reductions of personal care hours but based solely upon a child's age, the child's presumed developmental needs, and the assumption that a child's needs

were met or partially met when that child lived with his or her parent. *See Samantha A. v. Dep't of Soc. Servs. & Health Servs.*, 171 Wn.2d 623, 630, 256 P.3d 1138, 1141 (2011).

The Washington State Supreme Court struck down each of these rules in turn. *Samantha A.*, 171 Wn.2d at 637 (Children's Assessment Rule); *Jenkins*, 160 Wn.2d at 300 (Shared Living Rule). In subsequent litigation, the individual providers (IP, or caregiver) received a \$57 million jury award against the Department for hours worked but unpaid by application of the Shared Living Rule. *Rekhter, et al. v. State, Dep't of Social and Health Servs.*, 180 Wn.2d 102, 323 P.3d 1036 (2014).

Worse still, even after the Shared Living Rule and Children's Assessment Rules were struck down, the "shared benefit"⁴ and "informal support"⁵ rules further eroded the base hours that were already reduced by

⁴ Shared benefit is defined in WAC 388-106-0010 to mean:

- (a) A client and their paid caregiver both share in the benefit of an IADL task being performed; or
- (b) Two or more clients in a multiclient household benefit from the same IADL task(s) being performed.

⁵ The "informal support" rule refers to that portion of WAC 388-106-0010 that allows a paid caregiver to be considered a source of informal support. The Department first promulgated that rule in 2015, Wash. St. Reg. 15-20-054 (Oct. 31, 2015), and amended it in 2018, Wash. St. Reg. 18-16-004 (Aug. 19, 2018), to only apply the informal support rule based on individual providers as a source of informal support where the paid provider is related by family or household to the client. Currently, informal support is defined in WAC 388-106-0010 to mean:

- (a) Assistance that will be provided without home and community based services funding. The person providing the informal support must be age 18 or older. Sources of informal support include but are not limited to: family members, friends,

the Department's various budgetary cuts to the program. If, for example, the Department determines that the individual provider shares the benefit of an IADL service such as housework or shopping, or is related to the beneficiary and willing to volunteer for some otherwise paid time, then the Medicaid beneficiary's base hours are reduced based on a formula set forth in regulations. *See* WAC 388-106-0130.

This Court has instructed the Department to allocate personal care hours based on an individual determination and in response to individual need. *See Jenkins*, 160 Wn.2d at 300. *Jenkins* did not stand for the proposition that caregivers should work for free. Rather, any deduction in authorized hours must be based on some factor that actually reduces a client's need for paid care. Whether or not an IP derives some benefit from a task does not change the client's need to have the task performed. A paid provider may only be considered a source of informal support to the extent those hours are outside the employment relationship; those are the only hours that reduce the need for paid care.

housemates/roommates, neighbors, school, childcare, after school activities, church, and community programs. The department will not consider an individual provider to be a source of informal support unless the individual provider is also a family member or a household member who had a relationship with the client that existed before the individual provider entered into a contract with the department;

(b) Adult day health is coded in the assessment as a source of informal support, regardless of funding source;

(c) Informal support does not include shared benefit or age appropriate functioning.

Consequently, as SEIU 775 argues, the Department cannot lawfully reduce paid caregiver hours by application of the informal support and shared benefit rules because both require the IP to perform tasks within the employment relationship without compensation in legal tender. Statement of Grounds for Direct Review at 8-9. As illustrated by the following two hypothetical scenarios, these rules make it impossible for the Department to engage in the required person-centered approach to determining beneficiaries' needs and to allocate essential personal care hours. They cause significant harm to the very people the Medicaid personal care services program is designed to help.

2. NJP's Extensive Advocacy Experience Demonstrates the Problems Posed by the Shared Benefit and Informal Support Rules

Northwest Justice Project has advised or represented 406 clients in the last three years in cases involving home and community-based care, Medicaid, long-term care health facilities, developmental disability services, and disability rights. Of these cases, a number involve the impact of the informal support and shared benefit limits on clients. The following hypothetical scenarios are based on our extensive experience representing numerous clients whose base hours have been reduced by operation of the

challenged rules. These scenarios demonstrate the impact of these rules on our clients, illustrating the issues of public interest in this case.⁶

a. The Shared Benefit Rule Requires Caregivers to Whom the Rule Applies to Work for Free

Mr. Jones, an 85-year-old man, is cared for by his adult granddaughter, Susan, in order to stay safely at home, avoiding institutionalization. His disabilities include emphysema with shortness of breath, incontinence of bowel and bladder, diabetes, risk of inhaling food into his lungs when he swallows, and rheumatoid arthritis with pain daily. He is unable to make decisions for himself.

Mr. Jones is totally dependent on Susan for nearly all of his ADLs, including dressing every day, personal hygiene (brushing his teeth, washing his hands and face), toileting, taking his medicine, bathing, mobility in his home and community, eating, and transferring from place to place (e.g., from a couch or bed to a wheelchair). Mr. Jones requires a turning and repositioning program and range of motion exercises. He needs extensive assistance in all remaining ADLs.

He requires significant assistance in virtually all IADLs, as well. He cannot prepare his own meals. As a diabetic, he requires meals and snacks

⁶ To be clear, the following scenarios are hypotheticals based on NJP's extensive experience in representing clients in in-home care cases; they do not include information about actual clients.

throughout the day that must be suitable for a diabetic. Those meals and snacks mean Susan, who is not diabetic, must fix meals and clean up solely for his benefit. His incontinence results in bed-wetting and accidents, requiring Susan to change his bedding frequently, help him change clothes, and do many more separate loads of laundry.

Mr. Jones is awarded 393 base caregiver hours per month. *See* WAC 388-106-0125(1)(a). This allocation of hours fails to take into account Mr. Jones' need for extra laundry due to his incontinence or his extra diabetic-specific meals and meal cleanup.

When Mr. Jones first started receiving Medicaid funded personal care, Susan lived nearby. When his condition deteriorated, she moved in with him and Mr. Jones was reassessed. Because Susan now lives with him, the Department reduces his hours of care by operation of the shared benefit rule, which assumes that performing Mr. Jones' IADLs also benefits his caregiver. The meals Susan prepares for Mr. Jones, the work she does cleaning up after those meals, and the multiple loads of daily laundry she must complete do not benefit her in any way. Mr. Jones' needs far exceed any benefit Susan might receive from living with him. Paradoxically, even though Mr. Jones requires extraordinary assistance in IADLs, the shared benefit rule results in a reduction of 48 hours per month with the IADLs of

meal preparation, shopping and ordinary housework calculated as shared benefit, $\frac{1}{4}$ to $\frac{1}{2}$ of the time. *See* WAC 388-106-0130(2)(a).

Mr. Jones' situation demonstrates the disturbing impact of the shared benefit rule on very needy beneficiaries. This is because the effect of the rule's fractional reductions to base hours is greater for beneficiaries with higher base hours. But this rule also affects beneficiaries in every one of the CARE classifications. The shared benefit rule is a perfect example of the cliché "No Good Deed Goes Unpunished." In Mr. Jones' case, the punishment (reduced hours) is magnified by his neediness.

The next scenario illustrates the negative impact of the informal support rule where a paid caregiver is the source of informal support.

**b. The Informal Support Rule
Results in the Caregivers to Whom
the Rule Applies Performing Work
for Free**

Ms. Smith is a 25-year-old woman diagnosed with post-traumatic stress disorder, an intellectual/cognitive disability, severe anxiety, and schizophrenia. As a result of her disabilities, she requires assistance with the ADLs of personal hygiene, dressing, and mobility outside her home. Ms. Smith wants to live in her own home and not be institutionalized. She often throws items at her caregiver, is assaultive and combative during care,

tries to leave home without her caregiver, and refuses to leave home when severely anxious.

Ms. Smith's CARE assessment found that, as a result of her mental health, intellectual/cognitive disabilities, and challenging behaviors, she is unable to go shopping for herself, do any of her own housework, prepare her own meals, or drive anywhere, including to medical appointments. It also found that her decision-making capacity is severely impaired. She is placed in classification group B High and awarded 129 base hours per month, before the informal support reductions are applied. WAC 388-106-0125.

Ms. Smith used to live far from family but she recently moved within walking distance of her brother, John, who becomes her paid caregiver. During the CARE assessment, John tells the case manager that his sister's needs are important and he is not going to let her suffer when she needs help because there is no one else to help her. John does not want to spend his personal time taking care of his sister, but feels that he has no choice. John does not know the impact of the informal support rule.

If John provided exactly 129 hours of care, his sister's base hours would not be reduced. When Ms. Smith lived far from her brother and had an unrelated caregiver, her base hours were not reduced. However, because John is related to Ms. Smith and he disclosed during the CARE assessment

that he provides more care than 129 hours per month, her base hours *decreased*.

Like the shared benefit rule, the informal support rule is a fine example of the “No Good Deed Goes Unpunished” cliché. The more John works above 129 hours per month to provide the help his sister needs with her IADLs, the harsher the impact of the informal support rule. If John stopped being Ms. Smith’s paid caregiver and were replaced by an unrelated caregiver who did exactly as John does (i.e., provided more care than 129 hours per month), Ms. Smith’s base hours would not be reduced. *See* WAC 388-106-0130. When John goes above and beyond Ms. Smith’s 129 base hours that extra work is treated as informal support because John is a family paid caregiver. *See* WAC 388-106-0010 (the Department considers informal support only if the caregiver is family member or had a relationship with the client before becoming a caregiver).

3. The Shared Benefit and Informal Support Rules Exploit Caregivers

The CARE tool does not consider the length of time it takes a caregiver to perform caregiving tasks, nor does it provide additional hours for the number of times a caregiver must perform a specific activity. For example, the CARE tool does not authorize more hours for someone who needs to be lifted from bed to a wheelchair three times in a week from

someone who needs to be lifted thirty times in a week. But the challenged rules do count the number of times caregivers go above and beyond a beneficiary's base hours to reduce those same base hours of care regardless of the beneficiary's need for care. The more generous the caregiver is, the harsher the reduction.

As SEIU 775 points out, not paying caregivers for work they perform within the scope of their employment is illegal. It also jeopardizes the foundation on which Washington's long-term services and supports program rests—care provided in a beneficiary's home by caregiver(s)—at a time when the need for these services will dramatically increase. Washington's current State Plan on Aging says Washington's elderly population is forecast to reach 1,984,800 people by 2040.⁷

The shared benefit and informal support rules are especially cynical because of whom the rules exploit—caregivers who are family members or who live with the beneficiary. The Department is betting that these caregivers will forego wages to which they are legally entitled in order to take care of beneficiaries to whom they feel a strong emotional or familial bond. This cynical approach was shot down by this Court in *Jenkins*, 160

⁷ Dep't of Soc. & Health Servs, *Washington State Plan on Aging 4* (2018), <https://www.dshs.wa.gov/sites/default/files/AL TSA/stakeholders/documents/agingplan/Wash%20State%20Plan%20on%20Aging.pdf>.

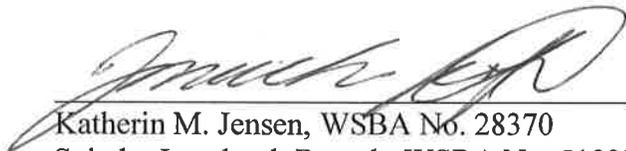
Wn.2d 287, and the cases following *Jenkins*, albeit for a different reason. But, the Shared Living rule struck in *Jenkins* shares the same policy DNA as the shared benefit and informal support rules. Those rules should receive similar treatment.

V. CONCLUSION

For the aforementioned reasons, Amicus supports Petitioner's request for direct review.

RESPECTFULLY SUBMITTED on this 29th Day of August, 2019.

By:
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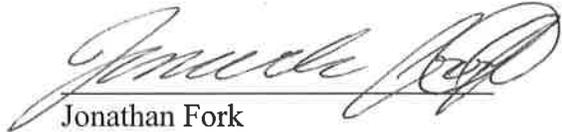
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