[NOT SCHEDULED FOR ORAL ARGUMENT]

No. 15-5018

IN THE UNITED STATES COURT OF APPEALS FOR THE DISTRICT OF COLUMBIA CIRCUIT

HOME CARE ASSOCIATION OF AMERICA, et al.,

Plaintiffs-Appellees,

v.

DAVID WEIL, Administrator of the Wage and Hour Division, U.S. Department of Labor, *et al.*,

Defendants-Appellants.

ON APPEAL FROM THE UNITED STATES DISTRICT COURT FOR THE DISTRICT OF COLUMBIA

BRIEF FOR ADAPT AND THE NATIONAL COUNCIL ON INDEPENDENT LIVING AS *AMICI CURIAE* SUPPORTING APPELLEES

Stephanie Woodward Center for Disability Rights, Inc. 497 State Street Rochester, NY 14608 (585) 546-7510 swoodward@cdrnys.org Counsel for *Amici Curiae*

CERTIFICATE AS TO PARTIES, RULINGS, AND RELATED CASES

- **A. Parties and** *Amici*. All parties appearing before the District Court and in this court are listed in the Brief for Appellees.
- **B.** Rulings Under Review. References to the rulings at issue appear in the Brief for Appellees.
- **C. Related Cases**. We are unaware of any pending related cases.

s/ Stephanie WoodwardStephanie WoodwardCounsel for *Amici Curiae*

CORPORATE DISCLOSURE STATEMENT

The National Council on Independent Living (NCIL) and ADAPT are nonprofit corporations. NCIL has no parent corporations and no publicly held corporation owns more than 10 percent of its stock. ADAPT has no parent corporations, and no publicly held corporation owns more than 10 percent of its stock.

NCIL is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. Its mission is to advance independent living and the rights of people with disabilities. ADAPT is a national grass-roots community comprised of people with disabilities, attendants, and allies who join together to ensure the civil and human rights of disabled people to live in freedom. Both NCIL and ADAPT are committed to ensuring people with disabilities have the choice to live in the community rather than nursing facilities and other institutions, and therefore have a substantial interest in any rule that will impact home and community based services for disabled people, including rules impacting the wages of attendants because attendants are vital to individuals with disabilities who receive attendant services to live in freedom in the community.

STATEMENT REGARDING RULE 29(C)(5)

Pursuant to Rule 29(c)(5) of the Federal Rules of Appellate Procedure, amici

curiae certify that:

(A) No party's counsel authored the brief in whole or in part;

(B) No party or party's counsel contributed money that was intended to fund

preparing or submitting the brief; and

(C) No person, other than amici curiae, their members, and their counsel,

contributed money that was intended to fund preparing or submitting the

brief.

s/ Stephanie Woodward

Stephanie Woodward

Counsel for Amici Curiae

iv

TABLE OF CONTENTS

CEI	RTIFICATE AS TO PARTIES, RULINGS, AND RELATED CASES	. ii
CO	RPORATE DISCLOSURE STATEMENT	iii
STA	ATEMENT REGARDING RULE 29(C)(5)	iv
INT	ΓEREST OF THE AMICI CURIAE	1
SUI	MMARY OF THE ARGUMENT	2
AR	GUMENT	5
I.	DOL FAILED TO ADDRESS THE DISRUPTION IN VITAL MEDICAID SERVICES WHICH THE NEW RULE WILL CAUSE	5
	 a. The New Rule Was Introduced Without Time for State Budgeting Processes to Adapt to its Requirements, and Will Cause Attendant Hours to be Capped. b. The New Rule Has Caused States to Cap Attendant Hours and Restrict Access to Home and Community Based Services. 	
II.	IMPLEMENTATION OF THE NEW RULE WILL RESULT IN LOWER ATTENDANT WAGES, HIGHER TURNOVER, AND A DECREASE OF WORKERS IN THE INDUSTRY	
	a. Capping Hours Will Reduce Attendants' Incomes.b. The New Rule Does Not Help Attendants, but Instead Disrupts Vital Services to People with Disabilities.	
III.	THE NEW RULE WILL RESULT IN A LOWER QUALITY OF CARE AND AN INCREASED RISK OF INSTITUTIONALIZATION FOR INDIVIDUALS WITH DISABILITIES.	16
	 a. Continuity of Care for People with Disabilities Will Be Disrupted, Resulting in Negative Health Consequences. b. People with Disabilities in the Community Will Be Forced into Institutionalization in Violation of Their Rights c. The Personal Autonomy and Bodily Integrity of People with 	

Disabilities Will Be Undermined	22
d. The Freedom of Movement for People with Disabilities Will Be	
Inhibited	25
e. The Safety, Health, and Lives of People with Disabilities Will Be At	
Risk	27
CONCLUSION	29
CERTIFICATE OF COMPLIANCE	30
CERTIFICATE OF SERVICE	31

TABLE OF AUTHORITIES

CASES:

Attorney Gen. of New York v. Soto-Lopez, 476 U.S. 898 (1986)	25
Armstrong v. Exceptional Child Ctr., Inc., No. 14-15, _ U.S, 2015 WL 1419423 (U.S. Mar. 31, 2015)	9-10
Corfield v. Coryell, 6 F. Cas. 546 (C.C.E.D. Pa. 1823)	25
Crandall v. State of Nevada, 73 U.S. 35 (1867)	25
Dunn v. Blumstein, 405 U.S. 330 (1972)	25
Griswold v. Connecticut, 381 U.S. 479 (1965)	22
Lawrence v. Texas, 539 U.S. 558 (2003)	22, 23
Long Island Care at Home, Ltd. v. Coke, 551 U.S. 158 (2007)	12
McFall v. Shimp, 10 Pa. D. & C.3d 90 (Pa. Com. Pl. 1978)	22
Memorial Hospital v. Maricopa County, 415 U.S. 250 (1974)	25
Olmstead v. L.C., 527 U.S. 581 (1999)	1-2, 22
Planned Parenthood of Se. Pennsylvania v. Casey, 505 U.S. 833, (199	2)22, 23
Roe v. Wade, 410 U.S. 113 (1973)	22
STATUTES	
Administrative Procedures Act, 5 U.S.C. § 706	5
Community First Choice Option, 42 U.S.C. § 1369n(k)	3
Medicaid Act, 42 U.S.C. § 1396a	9

RULE, REGULATIONS, AND REGULATORY MATERIALS

76 Fed. Reg. 81,190 (Dec. 27, 2011)13-14, 16-17, 19, 22
78 Fed. Reg. 60,454 (Oct. 1, 2013)6, 8, 13
Code Ark. R. 016.06.10-242.311
Code Ark. R. 016.06.10-213.220
Edmund G. Brown Jr., 2015-16 Governor's Budget Summary (Jan. 2015)11
Edmund G. Brown Jr., 2014-15 Governor's Budget Summary (Jan. 2014)11
Executive Order 13,5635
Terence R. McAuliffe, Executive Amendments to the 2014-2016 Biennial Budget (Dec. 2014)
U.S. Dep't of Labor, Administrator's Interpretation No. 2014-2 (June 2014)8
U.S. Dep't of Labor, Wage and Hour Division, Fact Sheet #79E: Joint Employment in Domestic Service Employment Under the Fair Labor Standards Act (FLSA) (June 2014)
V.T.C.A. Government Code § 301.00111
OTHER AUTHORITIES:
Affidavit of American Association of People with Disabilities, <i>Home Care Association of America et al. v. Weil</i> , Case No. 14-cv-967 (D.D.C. 2015) (cited herein as R. 27-6)
Affidavit of Bruce Darling on behalf of ADAPT, <i>Home Care Association of America et al. v. Weil</i> , Case No. 14-cv-967 (D.D.C. 2015) (cited herein as R. 23-4)
Affidavit of Kelly Buckland on behalf of National Council for Independent Living, <i>Home Care Association of America et al. v. Weil</i> , Case No. 14-cv-967 (D.D.C. 2015) (cited herein as R. 23-5)21, 27

Brief for the United States as <i>Amicus Curie, Long Island Care at Home, Ltd. v. Coke,</i> Docket No. 06-593 (U.S. 2007)
Centers for Medicare and Medicaid Services, <i>Self Directed Services</i> , Medicaid.gov, <i>available at</i> http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html (last visited Apr. 3, 2015)
Corrected Brief for the States of New York, Illinois, Massachusetts, and New Mexico, as <i>Amici Curiae</i> in support of Appellants, <i>Home Care Association v. Weil</i> , Case No. 15-5018 (2015)
Consumer Directed Choices, WHD-2011-0003-941610
Consumer Directed Personal Assistance Association of New York State, The High Cost of Overtime (Oct. 2014)
D. Kip Brown et al., Strengthening the Direct Service Workforce in Rural Areas (Aug. 2011)
Ericka Herrell, U.S. Dep't of Justice, <i>Crime Against Persons with Disabilities</i> , 2009-2011 – Statistical Tables (Dec. 2012)
Kaiser Commission on Medicaid and the Uninsured, <i>Medicaid and Long-Term</i> Services and Supports: A Primer (July 2014)
Laurie E. Powers and Mary Oschwald, <i>Violence and Abuse Against People with Disabilities: Experiences, Barriers and Prevention Strategies, available at</i> http://www.phinational.org/sites/phinational.org/files/clearinghouse/AbuseandViolenceBrief%203-7-04.pdf (last visited Apr. 2, 2015) 27-28
Nan Greenwood et al., Barriers to Access and Minority Ethnic Carers' Satisfaction with Social Care Services in the Community: A Systematic Review of Qualitative and Quantitative Literature (Aug. 2014)20
National Association of Medicaid Directors (NAMD) Comment, WHD-2011-0003-91796, 7, 9
National Council on Disability, The Case for Medicaid Self-Direction: A White Paper on Research, Practice, and Policy Opportunities (2013)

National Disability Leadership Alliance, WHD-2011-0003-9360	25-26
NYS Assoc. of Health Care Providers Comment, WHD-2011-0003-9	51710
PHI, Which States Provide Minimum Wage and Overtime to Home C Workers? (Oct. 2011)	
Rebecca L. Stotzer, Violence Against Transgender People: A Review States Data (May 2009)	v
Trish Erwin, Intimate and Caregiver Violence Against Women with Disabilities (July 2000)	27-28
U.S. Dep't of Veteran Affairs, <i>Aid & Attendance and Housebound</i> , benefits.va.gov, <i>available at</i> http://www.benefits.va.gov/pension/aid_attendance_housebourvisited Apr. 2, 2015)	. `

GLOSSARY

DOL: Department of Labor

CDPA: Consumer Directed Personal Assistance

FLSA: Fair Labor Standards Act

INTEREST OF THE AMICI CURIAE

The National Council on Independent Living (NCIL) is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. NCIL works to advance independent living and the rights of people with disabilities. NCIL's members include individuals with disabilities, Centers for Independent Living, Statewide Independent Living Councils, and other organizations that advocate for the human and civil rights of disabled people.

ADAPT is a national grass-roots community comprised of disabled people, attendants, and allies who join together to ensure the civil and human rights of people with disabilities to live in freedom. Many ADAPT members were forced into nursing facilities and struggled for years to leave those facilities and live in the community. Because of this, ADAPT is committed to freeing disabled people who are institutionalized and preventing unwanted institutionalization.

In this matter, NCIL and ADAPT have a shared interest in protecting and expanding options for disabled people to live in the community instead of being forced into institutions in order to receive necessary supports and services, such as assistance with activities of daily living and instrumental activities of daily living, including showering, toileting, using the phone, handling money, and taking medication. The right to receive services in the most integrated setting, recognized in *Olmstead v. L.C.*, 527 U.S. 581 (1999), is illusory if individuals are not able to

secure this assistance. Accordingly, *amici* have a substantial interest in ensuring that attendants, who are indispensable for disabled people to live in the community, do not have their hours capped or their income reduced.

Amici are not mere advocates for disabled people and attendants; both organizations are led by people who provide and receive attendant services. *Amici* oppose the new rule, as it will detrimentally impact disabled people and attendants.

SUMMARY OF THE ARGUMENT

The new DOL rule is an attempt to overrule the clear intent of Congress by narrowing the long-established and undisturbed FLSA exemption. The effect of this rulemaking bears no rational relation to the problem DOL claims it wishes to solve. It will instead have disastrous effects on the lives of disabled people and attendants. For all of these reasons, the rule was rightly vacated by the District Court. The District Court's ruling should be upheld.

Many people with disabilities cannot live in the community without attendant ¹ services. Attendants assist with showering, eating, using the telephone, taking medication, and many other tasks. With this assistance, disabled people are able to live successfully, happily, and independently in the community. When

¹ Although there are differences between personal care attendants and home health aides, for simplicity throughout this brief, the term "attendant" is used to refer to both.

disabled people who rely on attendant services cannot find quality attendants – or lose their attendants – due to hour caps and other cost cutting measures, their health, independence, and freedom are put at risk.

In 1974, Congress created the companionship exemption with the intention of assisting disabled people and seniors to live at home through the use of attendant services. At that time attendant services were already an integral, paid, paraprofessional component of the Disability Rights Movement, not a mere informal support. See National Council on Disability, The Case for Medicaid Self-Direction: A White Paper on Research, Practice, and Policy Opportunities (2013). The intention of Congress, both when it created the exemption, and when it has, over the years, preserved it through multiple revisions of the FLSA, is clear: Congress intended attendant services to be exempt from overtime requirements. Congress has never indicated that attendant services should be subject to the FLSA overtime requirements, but it has reaffirmed its intent to assist seniors and disabled people to live at home through affordable attendant services when it passed the Community First Choice Option (CFC) as part of the Affordable Care Act. 42 U.S.C. § 1369n(k). Not only does CFC encourage states to provide attendant services, it incentivizes these services by providing a six percent match in federal funding. *Id.* Eliminating the companionship exemption is contrary to the legislative intent to help people live in the community through the use of affordable attendant services. Moreover, it is harmful to the very people that the exemption was created to help, and to the attendants that the DOL claims it intends to help.

The new rule will have little positive effect, if any, on worker incomes, and will highly disrupt the incomes of many workers and the lives of disabled people.

The harm is so significant, and the potential benefit so insignificant, that the effect of the rule is not rationally related to its purpose.

If implemented, the new rule will produce unintended consequences which will reduce the availability of attendant services, reduce the income of attendants, and force disabled people back into institutions. This rule, intended to attract and sustain more attendants, will impose unfunded costs on state Medicaid programs. However, before even finalizing the rule, DOL illustrated how states could contain these costs by capping hours so that attendants could not earn overtime. States and agencies are already planning to follow DOL's suggestion to cap hours if the new rule is implemented.

The new rule will also have highly disruptive effects on the lives of disabled people. In many cases, people will lose services which enable them to live in at home, resulting in forced institutionalization. DOL's action will, therefore, harm both attendants – the very workers it intended to assist – and people with disabilities. For this reason, the new rule is an arbitrary and capricious action of DOL, and was rightly overturned by the District Court.

ARGUMENT

The Disability Community has fought for decades for the right to live in the community. Although this struggle has been long, much progress has been made. It is the law and policy of the Federal government that people with disabilities have the right to live in integrated settings. Nevertheless, the progress that has been made on this issue remains precarious and can be too easily undone.

The new rule imposes increased costs that State Medicaid programs will not pay, which will result in capping attendant hours. As hours are capped, disabled people will be forced back into institutions, in violation of their rights. The new rule will have the effect of making home and community based services, and with them, the rights of people with disabilities to live in freedom, an option, not a right.

III. DOL FAILED TO ADDRESS THE DISRUPTION IN VITAL MEDICAID SERVICES WHICH THE NEW RULE WILL CAUSE.

The new rule will cause significant and widespread disruptions to the provision of Medicaid long-term services and supports. The economic and moral costs of these disruptions are so great as to render the rule not rationally related to its intended effect. The DOL's rulemaking action therefore violates both the Administrative Procedures Act, 5 U.S.C. § 706 and Executive Order 13,563. Both of these require the effect of a potential rule to be rationally related to its intended cause, and Executive Order 13,563 requires the DOL to engage the stakeholders

prior to filing the notice of proposed rulemaking. DOL did not engage the Disability Community.

The new rule introduces serious complications to the provision of Medicaid services, and provides little or no gross benefit to workers, at a cost that includes violating the rights of people with disabilities. This action can only be characterized as a *net* benefit of any sort by entirely disregarding the rights of disabled people.

a. The New Rule Was Introduced Without Time for State Budgeting Processes to Adapt to its Requirements, and Will Cause Attendant Hours to be Capped.

The new rule will increase the cost of attendant services by requiring paid overtime². It will not ensure that consumers can receive overtime services when necessary, or that agencies will be sufficiently reimbursed to pay for those overtime services. Instead, the new rule will result in a reduction of hours of personal assistance. See National Assoc. of Medicaid Directors (NAMD) Comment, WHD-2011-0003-9179 at 3.

² *Amici* focus on the overtime requirement, rather than the minimum wage requirement, because, in 2010, DOL found no attendant was paid less than minimum wage (78 Fed. Reg. 60,454, 60,535) and because *amici* have fought to increase attendant base wages for years.

CDPA attendants will be particularly and significantly impacted because the vast majority of states do not require overtime pay for CDPA attendants and have not allocated funding to cover the additional cost of overtime. Home and community based services are state plan and waiver services with defined funding levels. See NAMD Comment at 3. CDPA programs are self-directed Medicaid services where the disabled consumer has "employer authority": that is, personal choice and control over how and by whom their services are provided, through their own recruiting, hiring, training, and supervision of their attendants. See Centers for Medicare and Medicaid Services, Self Directed Services. CDPA is an alternative to traditional home care services. *Id.* A significant amount of overtime hours are worked in CDPA programs. See Consumer Directed Personal Assistance Association of New York State (CDPAANYS), The High Cost of Overtime (Oct. 2014). However, in the limited number of states that require overtime pay for attendants, CDPA attendants are usually excluded.3 This has benefitted attendants, allowing them to work beyond 40 hours and earn higher incomes. If the new rule is

-

³ In NY, CDPA attendants are paid overtime at time and half of minimum wage, not base wage. Additionally, CO, HI, IL, MI, MT, PA, and WI do not require overtime pay for attendants who work for "private households" which includes CDPA attendants. See PHI, *Which States Provide Minimum Wage and Overtime to Home Care Workers?* (Oct. 2011).

implemented, their hours will be capped because state Medicaid programs do not have the funding to cover the additional overtime costs.

The new rule does not include funding to pay the costs it imposes on agencies that provide attendant services. Instead, DOL relies on employers and fiscal intermediaries (FIs) to cover or mitigate the costs. Medicaid is the primary payer of long term services and supports, and reimbursement rates are set by the state agency which administers Medicaid services. See Kaiser Commission on Medicaid and the Uninsured, Medicaid and Long-Term Services and Supports: A Primer (July 2014); U.S. Dep't of Labor, Administrator's Interpretation No. 2014-2 (June 2014). The costs associated with this rule have led states to impose caps either actively, by explicitly limiting attendants' hours, or passively, by refusing to reimburse agencies for the additional costs of overtime. This cost-management "solution," suggested by DOL, has the effect of reducing the availability of attendant services, and with it, the ability of people with disabilities to live in the community.

Under the new rule, all joint employers of an attendant are liable to pay overtime wages.78 Fed. Reg. 60,454, 60,483. Determining joint employment under the FLSA is a complex, fact-intensive inquiry. *Id.* Some states and managed care plans will likely be joint employers of attendants paid by Medicaid. In some cases, then, the state, the managed care plan, and the agencies can all be liable for

overtime even if the attendant works fewer than 40 hours for any single agency. Not only will this further incentivize states to cap hours, but it contains implications for the entire Medicaid delivery system. See NAMD Comment at 4. States and managed care plans have not had a meaningful opportunity to assess their exposure under this rule. *Id.* at 6. States and plans will likely actively restrict worker hours in order to manage the unknown, and potentially significant, liability that the rule creates. *Id.* at 3.

b. The New Rule Has Caused States to Cap Attendant Hours and Restrict Access to Home and Community Based Services.

Without reimbursement to cover the additional costs, providers cannot pay attendants to work over 40 hours, and, just days ago, the Supreme Court decided that providers cannot sue Medicaid programs to raise their reimbursement rates. *Armstrong v. Exceptional Child Ctr., Inc.*, No. 14-15, _ U.S. _, 2015 WL 1419423 (U.S. Mar. 31, 2015).

In *Armstrong*, providers of habilitation services assisting disabled people living in home and community based settings sued Idaho's Department of Health for reimbursing providers at lower rates than §30(A) of the Medicaid Act allows. 2015 WL 1419423 at *1. Section 30(A) requires Idaho's Medicaid Plan to pay enough to ensure that the providers' services are available to the general population in the geographic area. 42 U.S.C. §1396a(a)(30)(A). However, on

March 31, 2015, the Supreme Court decided that providers cannot compel States to comply with this law. 2015 WL 1419423 at *10.

This means that providers of attendant services cannot compel State Medicaid Programs to reimburse them enough to ensure disabled people can receive the attendant services they need to live in the community. The costs will fall to providers who cannot afford to pay overtime. See NYS Association of Health Care Providers, WHD-2011-0003-9517 at 4. In New York, FIs for CDPA programs are reimbursed, on average, at a rate that is only 13 cents higher than the applicable overtime wage. See CDPAANYS, *The High Cost of Overtime*. Without increased reimbursement from Medicaid, FIs will be forced to cap hours just to make ends meet. See Consumer Directed Choices, WHD-2011-0003-9416 at 2-3.

Agencies have already begun capping hours in anticipation of the new rule. R. 23-4 ¶ 4(b)(ii). This is not because they want to prohibit overtime hours: in fact, most FIs in New York, for example, allow attendants to work more than 40 hours, either regularly or under special circumstances. See CDPAANYS, *The High Cost of Overtime*. However, low reimbursement rates serve as a passive cap on overtime, even where states have not explicitly capped attendant hours. In either case, employers and FIs are forced to limit attendants' work.

Arkansas proposed capping hours at 40 per week and limiting attendants to only work with one consumer per day, with no exceptions. Code Ark. R.

016.06.10-213.220; 242.31. California has also proposed hour caps in the Governor's 2014-15 and 2015-16 budgets. Edmund G. Brown Jr., 2014-15 Governor's Budget Summary (Jan. 2014); Edmund G. Brown Jr., 2015-16 Governor's Budget Summary (Jan. 2015). Virginia proposed a 56 hour cap and limiting attendants to only work with one employer of record. Terence R. McAuliffe, Executive Amendments to the 2014-2016 Biennial Budget (Dec. 2014). New York, Illinois, New Mexico, and Massachusetts acknowledged capping hours as a solution to avoid paying overtime. New York et al., Amicus Br., at 18.

Even if states had the political will and financial ability to cover these costs, DOL did not release guidance on how the new rule will affect states as potential third-party employers until June 2014, just six months before the rule was set to take effect, and after many states had already established their budgets and legislative sessions had ended. U.S. Dep't of Labor, Wage and Hour Division, *Fact Sheet #79E: Joint Employment in Domestic Service Employment Under the Fair Labor Standards Act (FLSA)* (June 2014). By the time the rule was to take effect, Texas had not yet even begun its biennial legislative session, which begins on the second Tuesday of January of odd-numbered years. V.T.C.A. § 301.001. If this Court reverses the lower court and allows for implementation of this rule, many states will have already completed their budget by the time that decision is made

and there will, again, be no time for states to even consider funding this rule.

Attendant hours will simply be capped.

IV. IMPLEMENTATION OF THE NEW RULE WILL RESULT IN LOWER ATTENDANT WAGES, HIGHER TURNOVER, AND A DECREASE OF WORKERS IN THE INDUSTRY.

Because the new rule requires employers and FIs to pay attendants overtime, states and agencies are forced to cap worker hours. Thus the new rule will have the effect of reducing the income of attendants who, at present, work and are paid for more than 40 hours per week. *Amici* are aware of many attendants who have worked with the same consumer for years, and whose income will, because of the new rule, be reduced by as much as 40%. R. 23-4 ¶ 4(b)(iii).

a. Capping Hours Will Reduce Attendants' Incomes.

Reducing attendants' incomes is particularly concerning to *amici* because attendant services are instrumental in securing the right of disabled people to live in freedom. Without attendants providing services in the community, people with disabilities will be forced into institutions. The Disability Community is strongly in favor of attendants receiving a living wage for their important work.

DOL discussed this issue in its amicus in *Long Island Care at Home, Ltd. v. Coke*, 551 U.S. 158 (2007). In that brief, DOL contemplated the problem of narrowing the companionship exemption to exclude workers who are jointly employed by an agency and consumers and identified that this could make it more

difficult for people with disabilities to receive attendant services, would lead to institutionalization of disabled people, and would reduce attendant pay due to hours being capped. *Long Island Care at Home, Ltd. v. Coke*, Brief for the United States as *Amicus Curie*, Docket No. 06-593 (U.S. 2007).

The new rule is likely to have precisely the effect that DOL identified in 2007: causing attendants' hours to be capped, and their incomes limited, in some cases dramatically. It is entirely foreseeable that these effects will cause many attendants to exit the workforce, particularly attendants who, under the current rule, have consistently worked overtime. As the DOL acknowledges, "a significant overtime compensation issue ... is associated with 24-hour care." 78 Fed. Reg. 60,454, 60,528. This means that a large portion of the effect of this rule will fall on the attendants of those with the most significant need for services. DOL discusses at length the ways agencies may be able to mitigate these overtime costs by rebalancing workloads or hiring additional attendants; nowhere in this section are the needs of consumers for consistent, quality service, and minimal disruption addressed. *Id.* at 60,528-60,530.

b. The New Rule Does Not Help Attendants, but Instead Disrupts Vital Services to People with Disabilities.

The requirement for overtime pay is arbitrary and capricious because, in its discussion of the costs associated with this rule, DOL suggested capping hours as a

cost-saving measure. 76 Fed. Reg. 81190, 81226. As previously discussed, states have already indicated that they will cap hours to avoid paying overtime.

In explaining the need for rulemaking, DOL cited the increased demand for attendants and the importance of attracting and sustaining attendants in the industry. *Id.* at 81191-92. However, because DOL suggested capping hours to avoid paying overtime, and because states have already begun following this suggestion, attendants' wages will not increase. Rather, workers who regularly work more than 40 hours will see decreased income due to capped hours.

Prior to the rule's scheduled January 1, 2015 implementation, attendants and consumers in New York received notices that attendant hours would be capped at 40 hours. R. 23-4 ¶ 4(b)(ii). In practical terms, this means that attendants like Kathy⁴, who for the past 15 years has been providing 72 hours of services per week for a woman with cerebral palsy named Sue, would lose 32 of her hours, or over 40% of her income. This also means that Sue would have to find another attendant to help her with her most intimate activities, including showering, dressing, and toileting. These relationships are very personal. Forcing Kathy to find another job, and Sue to find another attendant, is not what either wants, and is harmful to both.

⁴ All individuals specifically named in this brief are real attendants and disabled people who will be impacted by the new rule.

When attendants lose income due to hour caps, they are forced to find another job to replace that income. Some attendants will choose to leave the industry completely in pursuit of jobs that will allow them to maintain the level of income they had prior to their hours being capped. Family and friends who became attendants in CDPA programs specifically to assist their loved one with a disability will not perform attendant services for someone else. This means they will not seek to supplement their income by working for another consumer through a different agency. Consequently, when their hours are capped, the hours that these attendants lose are hours the entire industry loses. By limiting the availability of family and friends as paid attendants in CDPA programs, the new rule will reduce this vital component of the attendant workforce which will further threaten the independence of Americans with disabilities.

The new rule will not achieve DOL's stated intentions of increasing wages to attract and sustain more attendants in the home care industry; rather, it will amplify the very workforce issues that DOL seeks to address. The majority of attendants will not receive higher base wages or overtime pay; instead, those who currently work over 40 hours will see decreased incomes due to hour caps, the current workforce will shrink, and it will be more difficult to attract people to perform this work.

IV. THE NEW RULE WILL RESULT IN A LOWER QUALITY OF CARE AND AN INCREASED RISK OF INSTITUTIONALIZATION FOR INDIVIDUALS WITH DISABILITIES.

The new rule will cap attendants' hours and people with disabilities will be harmed. Capping hours will force disabled people to hire additional attendants to assist them because their trusted attendants are not able to work all of the hours that they previously worked, or because their attendants, having had their incomes capped, will leave the workforce to work in a different job altogether. In either case, capping hours will disrupt the continuity of care, increase institutionalization, undermine personal autonomy, inhibit freedom of movement, and risk the health, safety, and lives of disabled people.

f. Continuity of Care for People with Disabilities Will Be Disrupted, Resulting in Negative Health Consequences.

When trusted attendants' hours are capped, disabled people will be forced to hire new attendants to cover the additional hours. Because there is already an attendant shortage, many people with disabilities will experience gaps in services. For those who are able to hire new attendants immediately, the new workers will not be familiar with their bodies, needs, or routines. In either case – a gap in services or a new, unfamiliar attendant – the disabled person is at risk of serious negative health consequences from not receiving the appropriate services.

This rule places in jeopardy the trusting relationship between attendant and consumer. DOL acknowledges that people with disabilities prefer to have the same

caregiver, rather than a sequence of different caregivers. 76 Fed. Reg. 81190, 81229. DOL obscures this real and valid preference through the misleading use of statistics of high turnover. *Id.* DOL's turnover statistics combine the turnover rate for post-acute home health care, long term services and supports, and CDPA. Turnover for post-acute home health care is high due to the nature of the short term work; by contrast, many attendants and consumers in CDPA work together for years and have deep and trusting relationships. Sometimes this relationship already exists because the attendant and consumer are family or friends, but also, as the American Association of People with Disabilities has highlighted in its affidavit,

"Over time, the best home health care workers form a relationship with their clients – both as a result of the services they perform and the large amount of shared time and space – which results in more individualized and efficiently delivered care."

R. 27-6 ¶6.

In New York, Shelly, a 50 year old woman with cerebral palsy which significantly impairs her mobility, speech, and ability to perform daily activities, requiring her to use attendant services, has had the same attendant, Hope, for a decade. Hope works 72 hours per week assisting Shelly with transferring in and out of bed, showering, toileting, dressing, eating, interpreting Shelly's speech, and many other tasks. Hope and Shelly have grown so close that they spend holidays together as a family. Hope's grandchildren have sleepovers at Shelly's house and see her as another grandmother. With Hope's hours capped, Shelly will lose hours

of assistance from her trusted attendant and friend who knows her needs, body, and speech. Shelly will have to hire a stranger – if she can find one – who will not understand Shelly's speech, and will have to direct that stranger on how to assist her with showering, toileting, eating, and more.

Shelly is not alone. The interruption in continuity of care resulting from the new rule will disrupt the lives of disabled people in innumerable ways. Disabled people will no longer have uninterrupted, consistent service delivery from attendants who know their needs and can skillfully work with them.

Furthermore, in states like Arkansas that limit attendants to assisting only one individual, people who have low hours of services and "orphan hours" may not be able to find attendants to work these hours. Some people need minimal hours of attendant services, such as 12 hours per week. Others have many hours which do not break down into perfect 40 hour schedules. "Orphan hours" are the small number of hours beyond a 40 hour schedule that disabled people have to fill after their trusted attendants' hours are capped. For example, if a person receives 84 hours of service per week, their hours cannot be met by two full-time attendant positions at 40 hours each; they will require a third attendant to work just four hours. Attendants limited to only working for one individual will choose to work for the person that offers 40 hours of work, leaving people with disabilities with orphan hours and other small shifts that attendants will not cover.

Unfilled shifts and lack of continuity in home care will create healthcare problems for disabled people. Without consistent attendant services, disabled people can quickly and easily develop infections, skin breakdowns, pneumonia, and other life threatening conditions. Some people will die as a result of these gaps in assistance.

g. People with Disabilities in the Community Will be Forced into Institutionalization in Violation of Their Rights.

Disabled people who use attendant services to live in the community will be at risk of institutionalization as a result of the reduction in hours that attendants are allowed to work. In its own findings, the DOL identified that some people would be forced into institutions because of the new rule. 76 Fed. Reg. 81190, 81224. Finding a new attendant to cover additional hours that a trusted attendant is no longer allowed to work can be difficult or impossible. Disabled people will be at risk of institutionalization if an attendant cannot be found to work those hours. Those most seriously impacted are people that have the most significant disabilities and rely on Medicaid services to live in the community, as well as people in rural, frontier, and tribal communities, language minorities, veterans, and individuals who privately pay for their attendant services.

First, people with the most significant disabilities often need more hours of services due to the constant high level of assistance that they need. These individuals, who have complex needs, will need to hire more new attendants than

other consumers. However, due to the complexity of their needs, these individuals are less attractive for many attendants, who would prefer to work for an individual who requires a lower level of assistance. Since the attendant workforce is already facing a shortage, and the new rule will only exacerbate that shortage, individuals with the most significant disabilities will be less likely to find attendants. Because they will not be able to receive the assistance needed to live in the community, they will be forced into institutions.

Second, access to services in rural, frontier, and tribal communities will be even more limited than it is now. See D. Kip Brown et al., *Strengthening the Direct Service Workforce in Rural Areas* (Aug. 2011). The attendant shortage is even more extreme in rural, frontier, and tribal communities, where CDPA services provided by eligible extended family and friends has filled the gap. The new rule will cause the paid hours these family and friends provide to decrease. This will either force the provision of unpaid, "free" services, or create gaps in critically necessary services since there simply are no other available workers in these areas.

Third, people who are members of language minority groups will be at risk of institutionalization because of the limited attendants in those groups. Language differences are barriers to receiving services in the community. See Nan Greenwood et al., *Barriers to Access and Minority Ethnic Carers' Satisfaction with Social Care Services in the Community: A Systematic Review of Qualitative and*

Quantitative Literature (Aug. 2014). For example, because there may be a shortage of attendants who speak Mandarin in Topeka, Kansas, an elderly Chinese woman who receives attendant services from her Mandarin speaking niece for 60 hours per week would lose 20 hours of service because there is no one else to work those hours who can communicate with her. Like people in rural areas, this will force language minorities to rely on unpaid, informal services or be forced into institutions where no workers may be able to communicate with them.

Fourth, veterans receiving "Aid and Attendance" will be at risk of institutionalization. "Aid and Attendance" is cash paid directly veterans with service connected disabilities who meet a certain level of need. See U.S. Dep't of Veteran Affairs, Aid & Attendance and Housebound. Veterans may use the money to supplement the household income so a spouse can provide assistance or pay other family members to provide the assistance the veteran needs. Currently, veterans can claim the companionship exemption in meeting their needs, but because the DOL has severely narrowed its scope, the exemption becomes almost entirely irrelevant. R. 23-5 ¶ 7(G). Although the cost will increase, veterans will not receive additional financial support. Consequently, without the ability to privately pay for assistance that meets their needs with their benefits, these veterans will be at risk of institutionalization.

Like veterans, many other disabled people privately pay for assistance because they are employed, have high levels of savings, or are otherwise not eligible for Medicaid. Although these individuals are able to claim the exemption currently, the new rule so significantly narrows the permissible tasks of exempt companions that virtually anyone who needs personal assistance would find that the exemption would not apply to them. DOL has noted that if the cost of home care increases, disabled individuals who privately pay for their services may be forced into an institution. 76 Fed. Reg. 81190, 81224.

Many people with disabilities are currently living independently in the community; however, the new rule will force some people into institutions. DOL has recognized that private pay individuals would be at risk of institutionalization, but many more are at risk. Still more importantly, forcing any individuals with disabilities who can live independently in the community into institutions is a violation of their rights under the Americans with Disabilities Act and *Olmstead*.

h. The Personal Autonomy and Bodily Integrity of People with Disabilities Will Be Undermined.

Personal autonomy and bodily integrity are fundamental human rights. Our courts have upheld these rights in a variety of situations where others have sought to regulate an individual's body. See *Griswold v. Connecticut*, 381 U.S. 479 (1965) (birth control), *Roe v. Wade*, 410 U.S. 113 (1973) (abortion), *Planned Parenthood of Se. Pennsylvania v. Casey*, 505 U.S. 833 (1992) (abortion), *McFall v. Shimp*, 10

Pa. D. & C.3d 90 (Pa. Com. Pl. 1978) (bone marrow), and *Lawrence v. Texas*, 539 U.S. 558 (2003) (sodomy and same sex relationships).

Despite the respect courts have paid to these fundamental rights, the Disability Community continues to be marginalized and experience violations to their personal autonomy. In discussing the bodily integrity and personal autonomy of women, the Supreme Court recognized that "the ability of women to participate equally in the economic and social life of the Nation has been facilitated by their ability to control their reproductive lives." *Casey*, 505 U.S. at 856. Similarly, the ability of disabled people to equally participate in the economic and social life of our Nation relies on their ability to control the most intimate aspects of their lives, including who sees and touches their naked bodies, who assists them in preparing for sexual activity, and who touches their genitals in the shower and after toileting.

For Dominick, a disabled transgender man in Ohio, personal autonomy and bodily integrity are particularly important. Dominick has had the same attendant, Christy, for 13 years. Christy assists Dominick with dressing, showering, toileting, feeding, and other tasks for 80 hours every week. Christy and Dominick have grown so close that they are now roommates. If Christy is limited to working 40 hours, not only will they not be able to afford their rent because of Christy's lost income, Dominick will have to find another attendant to assist him with his most intimate daily tasks. Having to hire another attendant places Dominic at risk

because he will have to reveal his transgender identity to the potential attendants he interviews. These potential attendants – these strangers – will see his private body parts and scars if they are hired. Hiring a new attendant means allowing a stranger, who does not know him, his needs, or his body, to touch him. Dominick knows all too well that many people are not accepting of transgender individuals, thus making it difficult to find attendants that he feels safe with, which is why he has had the same attendant for 13 years. His fear of violence is very real: transgender individuals, and people with disabilities, are at high risk of violence. Rebecca L. Stotzer, *Violence Against Transgender People: A Review of United States Data* (May 2009). The new rule not only puts Dominick at risk for violence, it also strips him of his personal autonomy and bodily integrity.

These fundamental rights do not just belong to the majority of Americans: they belong to all Americans, including people with disabilities. The personal autonomy and bodily integrity of disabled people will be violated by the implementation of the new rule because attendant hours will be capped, forcing individuals who need attendant assistance to hire strangers to assist them with intimate tasks that some people would not even allow their spouse to assist them with.

Furthermore, the Federal government and state governments have laws regarding sexual misconduct, assault, and battery. These laws are in place to

protect individuals from experiencing unwanted touching from another person. However, under the new rule, disabled people will be forced to allow unwanted touching by new attendants if they want to live in the community. If a person does not want additional attendants touching their bodies, they will lose service hours and be forced into an institution to receive the services they need to live, and will be forced to allow the workers in the institution to touch their bodies. In either situation, disabled people are not afforded the same rights and protections as nondisabled people.

i. The Freedom of Movement for People with Disabilities Will Be Inhibited.

Freedom of movement is a fundamental Constitutional right with extensive implications. *Corfield v. Coryell*, 6 F. Cas. 546 (C.C.E.D. Pa. 1823). Courts have struck down as unconstitutional laws inhibiting people from moving freely across states, imposing residency time periods to receive healthcare and to vote; giving preferences to state veterans; and taxing residents for leaving the state. See *Memorial Hospital v. Maricopa County*, 415 U.S. 250 (1974) (healthcare), *Dunn v. Blumstein*, 405 U.S. 330 (1972) (voting), *Crandall v. State of Nevada*, 73 U.S. 35 (1867) (tax), and *Attorney Gen. of New York v. Soto-Lopez*, 476 U.S. 898 (1986) (preference to state veterans).

The new rule will inhibit disabled people from moving freely across states because they will not be able to travel with their attendants. Individuals who

receive attendant services paid by Medicaid will not be able to leave their state for work or leisure because the hour limitations will prevent their attendant from coming with them. See National Disability Leadership Alliance, WHD-2011-0003-9360 at 2.

Jensen, a 24 year old with spinal muscular atrophy, receives attendant services from his best friend of 20 years, Wilfredo. Wilfredo is paid through Medicaid and can work up to 16 hours a day, 72 hours a week. When Jensen travels for work, he can travel for five days at a time with Wilfredo because Wilfredo can be paid for up to four sixteen hours days and one eight hour day. If Jensen is traveling to a state on the West Coast, it will take one day to travel there and one back, leaving Jensen two and a half to three days to work on the West Coast. If Wilfredo's hours are capped, Jensen will no longer be able to perform his job because he will not be able to go on week long business trips since Wilfredo will only be paid for up to two days and eight hours of work and Jensen cannot bring multiple attendants. When traveling to the West Coast, Jensen will have one day to travel there and one day back, leaving only a half day to work on the West Coast.

Individuals who privately pay for attendant services will be similarly harmed because traveling with an attendant will be unaffordable. People with disabilities currently negotiate to pay an attendant for a block of time while traveling for work

or vacation. Under the new rule, they will be required to pay considerably more for the same assistance. As a result, they may no longer be able to travel long distances for medical and rehabilitative services (a particular concern for individuals in rural, frontier, and tribal communities); visit dying relatives; travel to visit family during the holidays; participate in federal committees and task forces; or attain professional advancement because they cannot take jobs or attend conferences that require significant travel. R. 23-5 ¶ 7(E).

Not only do individuals with disabilities have the right to live in the community, but they have the right to travel just as anyone else. By imposing unreasonable overtime requirements on attendant services, DOL is impinging on both the right of disabled people to live in the community and their right to travel.

j. The Safety, Health, and Lives of People with Disabilities Will Be At Risk.

Beyond the dangers associated with the disruption in the continuity of care, having to hire new attendants creates significant risk to the health, safety, and lives of disabled people due to the increased risk of personal violence by attendants. People with disabilities experience personal violence at a significantly higher rate than people without disabilities. In 2011, women with disabilities experienced violence at three times the rate of women without disabilities and disabled men experienced violence at twice the rate of nondisabled men. See Ericka Herrell, U.S. Dep't of Justice, *Crime Against Persons with Disabilities*, 2009-2011 – Statistical

Tables (Dec. 2012). People with disabilities often experience domestic violence – including physical and sexual violence – at the hands of their caregivers. See Trish Erwin, *Intimate and Caregiver Violence Against Women with Disabilities* (July 2000); Laurie E. Powers and Mary Oschwald, *Violence and Abuse Against People with Disabilities: Experiences, Barriers and Prevention Strategies*.

Forcing disabled people to hire additional attendants to make up for the hours that trusted attendants will no longer be able to work increases the risk of personal violence. For Shelly, the 50 year old woman with cerebral palsy mentioned earlier, the risk of violence is all too real. Shelly was institutionalized for many years before she began receiving attendant services in the community. When Shelly was 11, she was raped multiple times over a series of months in an institution. A male worker would come into Shelly's room at night, and begin raping her while she slept. She would wake up to him touching her and forcing himself into her vagina. In addition to raping Shelly, he would physically assault her by beating her head with shoes. 39 years later, Shelly fears being alone with any men she does not know. She fears having to find new attendants if her attendants hours are capped. Most of all, Shelly fears that if she cannot find new attendants, due to her complex needs and difficult to understand speech, she will be forced back into an institution where employees may slip into her room at night and rape her again and again.

Shelly is not the only one at risk or the only one in fear. Forcing people to take on more attendants will force them to take on an increased risk of being victimized, either by new attendants or in the institutions they may be forced into if they cannot find new attendants.

CONCLUSION

For all of the foregoing reasons, this Court should affirm the District Court's ruling.

Respectfully submitted this 6th day of April, 2015,

s/ Stephanie Woodward
Stephanie Woodward
Center for Disability Rights, Inc.
497 State Street
Rochester, NY 14608
(585) 546-7510
swoodward@cdrnys.org
Counsel for Amici Curiae

CERTIFICATE OF COMPLIANCE

- 1. This brief complies with the type-volume limitation of Fed. R. App. P. 32(a)(7)(B) because this brief contains 6,810 words, excluding the parts of the brief exempted by Fed. R. App. P. 32(a)(7)(B)(iii).
- This brief complies with the typeface requirements of Fed. R. App. P.
 32(a)(5) and the type style requirements of Fed. R. App. P. 32(a)(6) because this brief has been prepared in a proportionally spaced typeface using Microsoft Word 2010 in 14-point Times New Roman.

Dated this 6th day of April, 2015.

s/ Stephanie Woodward
Stephanie Woodward
Center for Disability Rights, Inc.
497 State Street
Rochester, NY 14608
(585) 546-7510
swoodward@cdrnys.org
Counsel for Amici Curiae

CERTIFICATE OF SERVICE

I hereby certify that on April 6, 2015, I electronically filed the foregoing brief with the Clerk of this Court by using the appellate CM/ECF system. The participants in the case are registered CM/ECF users and service will be accomplished by the appellate CM/ECF system.

s/ Stephanie WoodwardStephanie WoodwardCounsel for *Amici Curie*