A missed opportunity:
One month in, as stakeholders warned, Illinois’ rigid and ill-advised new overtime restrictions are disrupting the care system and harming workers, consumers, and families.

Access Living
Caring Across Generations
SEIU Healthcare Illinois
National Employment Law Project
Illinois Network of Centers for Independent Living

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Introduction

In 2015, the U.S. Department of Labor (DOL) put into effect new home care rules extending federal minimum wage and overtime protections under the Fair Labor Standards Act (FLSA) to over two million home care workers across the United States. This historic move finally ended the exclusion of a workforce comprised of 90% women and 50% people of color from basic protections that more than 130 million American workers rely on. It also recognized the significant efforts and contributions these workers make to keeping older adults and people with disabilities living independently in their own homes, reinforcing the intent of the U.S. Supreme Court *Olmstead* decision.

Home care employers are now required by federal law to pay workers at least the minimum wage for all hours worked, and overtime at time-and-a-half the worker’s regular rate of pay for hours worked over 40 in a week, just as other employers have long been required to do. In states that already provided minimum wage protections for home care workers before 2015, like Illinois, the US DOL reform primarily affects workers who work over 40 hours per week and their consumers.

The demand for personal care services provided in the home continues to climb, with projections of an additional 1.6 million new home care positions being needed by 2020. In Illinois, home care jobs are expected to grow by 36% by 2022 while all other occupations will grow by only 8%. To comply with the DOL rules, Illinois would have to invest an estimated $7.5 million for overtime pay; a dollar-for-dollar Medicaid federal match mean that roughly $15 million in funding will go to underpaid workers and back into local and state economies. As home care is one of the fastest-growing occupations in the country, ensuring that these jobs are good jobs is critical to both quality of care for seniors and people with disabilities, and to sustaining strong local and state economic growth.

The U.S. DOL gave states flexibility and ample time for implementation, understanding that states needed time to prepare to budget for and properly implement these new protections. At the same time, the U.S. Department of Justice (DOJ) advised that states must be careful to not violate *Olmstead*, which held that unjustified institutionalization of people with disabilities in nursing homes or other institutional settings may constitute discrimination under Title II of the Americans with Disabilities Act.

States such as California, Massachusetts, Florida, Minnesota, Oregon, Washington, and New York are taking positive steps towards compliance with the new federal rules by collecting data on the home care workforce, engaging affected stakeholders, budgeting necessary Medicaid dollars to pay for increased costs, where necessary, and taking steps to improve the quality of home care jobs by raising wages and improving benefits. Massachusetts and New York have taken additional steps towards establishing task forces to advise the States on their implementation of the US DOL rules.

However, in Illinois, the State has used a budget crisis as an excuse to weaken its Home Services Program (HSP), in which customers with disabilities hire and train Medicaid-funded, state-paid workers. Illinois' draconian new limits to overtime hours for home care workers serving people with disabilities has thrown the care system into disarray, threatens *Olmstead* protections for people with disabilities, and is being implemented through intimidation and threats from state agency offices. Unlike other states' more measured approaches to the federal rules implementation, the state of Illinois' policy does not reflect the input of any of the stakeholders in the program other than the State itself.

SEIU Healthcare Illinois, the union representing approximately 8,500 impacted home care workers known as Personal Assistants, is joined by Access Living, National Employment Law Project, Illinois Network of Centers for Independent Living, and Caring Across Generations in releasing this paper highlighting some of the problems with Illinois' overtime policy, offering solutions to restore the choice, rights and dignity of consumers, while protecting the pay and work hours for the low-wage caregiver workforce.
Overview of Illinois’ Policy & Problems with Implementation

Over the years in Illinois, people with disabilities have seen home care services expand in ways that not only provided for greater consumer control, but which have also saved Illinois taxpayers hundreds of millions of dollars. Currently, Independent Providers (IPs) in the Department of Human Services Division of Rehabilitation Services (DHS-DRS) Home Services Program (HSP), also known as Personal Assistants, provide vital home care services to 28,000 people with primarily physical disabilities, empowering those individuals to live independently in their own homes rather than be forced into costlier nursing homes.

By supporting these consumers at home, the Home Services Program saves the State hundreds of millions of dollars; the average cost of HSP home care services is $15,217 per year\(^\text{10}\) and the average cost of nursing home services is $52,000 per year.\(^\text{11}\)

Unfortunately, rather than engaging stakeholders in a thoughtful process to explore options for implementing the US DOL rules while strengthening HSP, as other states have done, DHS chose to unilaterally impose a strict and inflexible policy that disrupts long-time worker-consumer relationships.

In November of 2015, DHS unveiled its plans to implement unreasonable worker hours caps with an inadequate exceptions process. There was no public comment process, nor did the State appear to undergo an *Olmstead* review of its policy per the DOJ guidance – even though the state had known it would be responsible for these changes since the U.S. DOL formally announced the changes in 2013.\(^\text{12}\)

Advocates, consumers, and workers immediately raised alarms about their ability to come into compliance with the newly-imposed Illinois policy in just 30 days. SEIU Healthcare Illinois also demanded to bargain over the impact of the policy on affected workers, calling for implementation to be delayed until an agreement could be reached. DHS agreed to delay implementation twice under pressure from advocates and stakeholders, but on May 1, 2016, moved forward with full implementation of its policy without consulting stakeholders, despite the concerns of disability advocates and the State’s duty to bargain over the issue.

### Violating Consumer Rights

The State has an obligation under Title II of the Americans with Disabilities Act (ADA) and the *Olmstead* Supreme Court decision to ensure its implementation of the Federal overtime rules do not place people at serious risk of institutionalization. The U.S. Department of Justice and U.S. Department of Health and Human Services’ Office of Civil Rights have given states guidance on the type of exceptions process that is required by the ADA and *Olmstead*. The very narrow exceptions policy now in place in Illinois does not comply with the ADA and *Olmstead*; in fact, it provides zero guidance or flexibility to consumers who find themselves at risk of being forced into a nursing home. Furthermore, from disability advocates to the federal government, stakeholders agree that person-centered plans are a crucial element of successful community-based services,\(^\text{13}\) which incorporate not just the needs of the consumer, but also their safety and preferences. The State’s policy may place consumers at risk when taking away a skilled provider without replacing them with someone who can give intimate support with bathing, toileting, dressing, etc.

- **Judith Hamlen**, Personal Assistant from Galesburg provides home care services for her son who is easily agitated and does not react well to strangers in their home – much less strangers helping him bathe or use the restroom.

- **Melissa Walker**, a person with a disability in Chicago Heights, says she is unable to tolerate a stranger coming into her home and touching her when her mother is there and has always been there to provide her services.

- **Theresa Russell**, Personal Assistant from Salem, cares for her son, Jordon, who has chronic seizures and low-immunity. Jordon would likely be more exposed to infectious diseases if additional workers were introduced into their home.
home, and Theresa is contemplating moving out of the state to reduce this risk to her son’s compromised immune system.

**Difficulty in Finding Additional Caregivers**

The State claims to have added an additional 5,000 Personal Assistants who are available for people with disabilities to hire. However, that number would be reached through historic turnover in the program without any recruitment effort. According to data provided by DHS to SEIU Healthcare Illinois, the State generally requires an inflow of roughly 9,400 new workers annually just to replace the workers who leave the program each year due to low-pay and difficult working conditions, resulting in industry-wide historically high turnover rates. Consumers in smaller, more rural communities are especially struggling to find skilled, reliable caregivers to take over part-time hours at a low pay rate with few benefits.

• **Stephanie Rodriguez**, a person with a disability in Chicago, currently has a Personal Assistant who is a live-in Certified Nursing Assistant and is authorized to give shots. Stephanie also has a service animal. She has been unable to find an additional worker with these skills willing to take over only 5 hours per week that the State has now prohibited her current PA from working, and who is willing to work in a home with a service animal.

• **Gaileen Roberts**, Personal Assistant from Cameron who cares for her daughter, Jody Roberts, lives in a very rural community in a home that is only accessible with a four-wheel drive vehicle. Jody’s needs require a worker who can work a split-shift — that is, several hours in the morning and several hours per night with a break in between — and Gaileen has been unable to find any additional caregivers who can work split shifts and have a vehicle that can access their home.

• **Michael Grice**, a person with a disability from Chicago, reports long waits in getting State approval for new Personal Assistants work. The paperwork package that must be compiled in order to approve a new worker can take months to piece together.

• **Sharon Lamp**, a person with a disability from Des Plaines, has spent months trying to hire a second Personal Assistant, but is unable to find someone able to travel to the suburbs for only a few hours of work per week, which her primary Personal Assistant currently works.

• **Jennifer Kostanski**, a person with a disability from Chicago, has been unable to hire a second Certified Nursing Assistant to cover weekend hours. As a result, her husband has been forced to fill in the gaps without pay.

**Threats, Intimidation, & Potential FLSA Violations**

Under the policy, except under circumstances that don’t reflect the reality of the Home Services Program, caregivers are banned from working over 40 hours in one week, and are subject to a cruel ‘three strikes and you’re out’ approach if they submit time sheets for over 40 hours in a given week, despite the law that workers must be paid for all hours worked. The State has not provided clear guidance on how it will support consumers when it terminates their caregivers, which presents serious risks to consumer safety because it can take months for the consumers to find replacements.

The State is poised to fire thousands of caregivers whose only crime is to remain loyal to the people they serve by refusing to walk out on them if there is no other caregiver to relieve them and provide services. Workers have reported threats of termination from local DHS offices, being instructed to ‘shave off’ hours from their time sheets to keep their reported hours under 40 per week, even where they have worked and are due pay for more than 40 hours, and some have even come under investigation after speaking out on this policy.
Consumers have received threatening letters demanding that they hire additional caregivers or the State will bring in agencies to provide care against the consumers’ will.

- **Elaine Walker**, Personal Assistant from Chicago Heights has been told she must choose one of her two daughters with disabilities to care for. After speaking out against the State’s overtime policy, Elaine has now been told she is under investigation regarding occurrences of working overtime hours before the policy was implemented.

- **Joyce Conroy**, Personal Assistant from Kankakee, was told by the DHS supervisor in her local office that if she didn’t hire two additional caregivers for her son, they would tell the State’s Attorney, get her fired, and have her put in jail.

**Narrow Exceptions Process + Unequipped DHS Offices**

Even though the State has the information it needs to determine consumers’ eligibility for overtime hours for their caregivers under the narrow exceptions policy, it has left it up to the consumer to navigate the process of applying and getting approval for overtime. According to data from advocates, less than one thousand people have actually applied for overtime exceptions, and only a few hundred have been approved. Data collected from the State of Illinois through a FOIA request showed that 8,600 people with disabilities required overtime hours to be worked at least once during calendar year 2015, meaning thousands are not even eligible to have authorized overtime hours under the restrictive exceptions process. Further, consumers and workers who have asked for the exceptions forms have reported that staff at DHS offices claimed to not have the required application forms. Those persons with disabilities who have been approved for overtime exceptions are still facing very narrow situations where overtime will be approved. DHS will not allow reasonable uses of overtime when additional caregivers are not available.

- **Rick Schnetzler Sr.**, Personal Assistant from Girard who cares for his son, Shaun, was told by his local DHS office that Shaun was approved for Category A overtime under the policy, which defines eligible individuals as those with the highest care need due to the nature of their disability. However, Rick was informed that he cannot work overtime hours and Shaun has to hire additional caregivers regardless. Shaun may only use overtime due to loss of a caregiver, caregiver illness, or inclement weather delays preventing another provider from arriving on time to provide care; any overtime worked will be scrutinized and allegations of fraud will be referred to law enforcement according to the letter they received.

- **Marcia Lewis**, Personal Assistant from Chicago Heights, was refused overtime justification forms from her local DHS office when she requested them.

- **Beth Fairweather**, Personal Assistant from Chicago, was told by her local DHS office that the State was no longer accepting applications for overtime exceptions after May 1, 2016, a clear misstatement of the actual policy.

- **Randy Sorrells**, Personal Assistant from Canton, was unsuccessful in getting overtime justification forms from his local DHS office.

- **Virginia Grant**, Personal Assistant from Charleston, was told by her local DHS office that they do not have any overtime forms.

- **Barbara Nolan**, Personal Assistant from Rockford, requested overtime justification forms and was told by local DHS office that they do not have the forms.
Conclusion: It Doesn’t Have to Be This Way

The State has had ample time and opportunity to do the right thing, but unfortunately moved forward with a policy that stands to harm thousands of people with disabilities and their caregivers in Illinois. The State did not incorporate any sort of public comment process in the development of its policy. It has attempted to avoid any additional costs in the short term, even where its policies raise the risk of expensive hospitalizations or consumers’ transition to costly institutional care. While states with some of the nation’s largest Medicaid home care programs acted early to assess the impact of the new federal minimum wage and overtime rules and prepared accordingly, Illinois instead adopted a draconian approach that threatens consumers and workers alike.

States such as California, Washington, and Oregon have provided a significantly higher weekly hours cap for many workers and also a more nuanced and expansive exceptions policy. Massachusetts elected to simply pay the overtime rather than handle the potential negative consequences and burdensome administrative costs - a smart investment in its home care program and workforce, especially when taking into consideration that the federal government matches the state’s Medicaid expenditures. Illinois does have a choice to be more flexible, but instead the rollout of this policy has generated distrust, fear of retaliation, and flat out panic among people with disabilities and workers.

While the State enforces this harmful policy, Governor Bruce Rauner further threatens the stability of the home care system in Illinois while at the bargaining table demanding elimination of health insurance and training for Personal Assistants, on top of a four-year wage freeze for the lowest paid state workers.

Access Living, SEIU Healthcare Illinois, National Employment Law Project, Illinois Network of Centers for Independent Living, and Caring Across Generations urge Governor Bruce Rauner and the State of Illinois to immediately suspend their myopic, misguided, harmful overtime caps policy, and to return to the table and bargain with stakeholders to develop a just policy that does not infringe upon the rights, independence, and dignity of people with disabilities, and does not adversely impact the caregiver workforce.
Endnotes

1 https://www.dol.gov/whd/fsa/companionship_factsheet_ENGLISH.pdf


5 http://phinational.org/growing-demand-direct-care-workers

6 http://phinational.org/policy/states/illinois

7 Data obtained from a January 2016 FOIA request to DHS. The State could not provide a breakdown of overtime by week, but rather by pay period (bi-monthly), estimated by assuming that any hours worked over 87 in a pay period are overtime hours.

8 The U.S. Department of Labor formally announced a generous non-enforcement policy in the Federal Register, granting states as long as a year to come into compliance with the new protections before DOL began enforcement. The delay in enforcement granted employers additional time to prepare, coming on the heels of a 15-month phase-in period between the issuance of the final rules in Oct. 2013 and the Jan. 1, 2015 effective date. See https://www.dol.gov/whd/homecare/non-enforcement_policy.htm

9 For specifics of more positive implementation across states, see http://www.nelp.org/content/uploads/Fact-Sheet-USDOL-Home-Care-Rules-Good-Implementation.pdf

10 Estimated using HSP program and overhead budget lines on the DHS website (http://www.dhs.state.il.us/page.aspx?item=77120) divided by the estimated total of 40,117 HSP consumers.

11 Cost is estimated using an average of each IL nursing home's per diem rates found on the IL Dept. of Health and Family Services' website (https://www.illinois.gov/hfs/MedicalProviders/MedicaidReimbursement/Pages/LTC.aspx) within the document titled, “Nursing Home Per Diems as of January 1, 2015 (pdf).” Direct link to document: https://www.illinois.gov/hfs/SiteCollectionDocuments/rateinfo.pdf

12 See http://webapps.dol.gov/Federalregister/PdfDisplay.aspx?DocId=27104

13 https://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/self-directed-services.html

14 Employees must be paid for work “suffered or permitted” by the employer even if the employer does not specifically authorize the work. If the employer knows or has reason to believe that the employee is continuing to work, the time is considered hours worked. See Regulation 29 CFR 785.11. https://www.dol.gov/whd/regs/compliance/whdfs53.htm


Expenditure budget lines of “Home Services Program” ($352,231,900), “Home Services Program Care Coordination” ($12,234,500) and “Home Services Program Medicaid Fund 120” ($240,000,000) and divided by the estimated total of HSP consumers in FY16. The consumer total comes from the State's estimated number of consumers in Year 1 in each of the three applications for §1915(c) HCBS Waivers for Persons with Disabilities, Traumatic Brain Injuries, and HIV/AIDS.