



**You wouldn't let
strangers
watch you use the toilet...**

**but the
US Department of Labor
says I don't have a choice.**

The Obama administration is developing labor rules that will require seniors and people with disabilities to bring strangers into their homes, force others into institutions, and reduce the take home pay of attendants.

Learn more and take action at: www.DOLoffMYbody.org



**It's a crime
when strangers watch
other
women
shower...**

**but the
US Department of Labor
is forcing me
to let them in.**

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**Secretary Perez Listening Session
Regarding the Companionship Exemption**

August 19, 2013

The Department of Labor (DOL) has proposed changes in federal labor rules that will have a significant negative impact on people with disabilities. These changes will most seriously impact people who have the most significant disabilities and rely on Medicaid services to live in the community.

Labor advocates have urged people to support these rules to assure that attendants get paid minimum wage and are paid time-and-a-half for overtime work. The disability community recognizes the invaluable role that attendants play, but the proposed changes will have a serious negative impact on people with disabilities and ultimately not improve the lives of attendants.

The proposed changes will force seniors and people with disabilities into institutions!

Increasing the cost of home and community based services by requiring overtime pay, without increasing the Medicaid rates or raising the Medicaid caps for available funding, will result in a reduction in hours of personal assistance or the loss of available workers, forcing some people with disabilities into unwanted institutionalization. The Department of Labor, itself, identified that some people would be forced into institutions because of these rules.

There are a number of different ways that the rules will promote institutionalization.

1. Individuals with significant disabilities on individually-capitated waivers may find that the additional costs generated by these proposed rules will exceed the established cap, forcing them to go without needed services or be institutionalized. It should be noted that when individuals go without needed services, they are most-likely just delaying institutionalization.
2. When there is an overall aggregate cap established for the group of individuals being served, increasing individual costs results in an overall decrease in the available hours of support which may not directly result in the institutionalization of specific individuals based on their individual cost but will impact the ability of these programs to meet the needs of people with the most significant disabilities.
3. When an individual receives services and supports through a Medicaid state plan benefit – like the Personal Care Option, states may not immediately reduce services, but eventually will need to contain increased costs and will most likely do so by reducing the availability of services.

4. Alternatively, these proposed changes will result in caps on the hours the attendants may be allowed work, reducing the available workforce. Because Medicaid and Medicare rates are not being increased to cover the additional cost associated with these changes, states and home care agencies will simply limit the hours attendants can work. Although some attendants who currently work more than 40 hours a week will choose to work for multiple agencies in order to match their current standard of living, the complexity of managing schedules through multiple agencies and the increased travel time will mean that overall, they will have fewer hours available to work.
5. Some attendants - who can no longer make a good living doing this work because their hours are capped - will simply choose to stop doing it and seek other employment. This will likely impact people living in areas with a high cost of living as well as consumer directed programs which draw from a wider pool of workers who may have other options for employment.
6. Family and friends frequently who work as attendants in consumer directed programs generally won't do attendant services for a stranger. Consequently, limiting the hours that these attendants may be paid as attendants so overtime costs are not incurred will significantly reduce this vital component of the attendant workforce.
7. Limiting the hours that trusted family and friends may work will impact individuals living with their families where the family may not want to bring strangers into their home. By limiting the hours of those trusted attendants, some families will choose to institutionalize a loved one rather than have strangers come into their homes.
8. These changes will disproportionately impact attendant service users in rural, frontier and tribal communities. There is a shortage of a traditional attendant workforce in these communities where consumer directed services provided by family and friends have filled the gap. These proposed rules will likely cap the hours of those workers and worsen the workforce issues. Additionally, the new requirement that attendants be paid for travel time between cases could further reduce the availability attendant services as home care organizations will simply choose not to schedule attendants to work for multiple people in the same day or with an individual who doesn't live within close proximity to other individuals.
9. Non-English speakers are another group of people who will be disproportionately impacted by these rules. Often elders who do not speak English and need assistance are underserved by traditional providers, often relying on friend and family attendants who can provide culturally-competent assistance. Limiting the hours their attendants can work will destabilize their services and may result in institutionalization.

10. Individuals with the most significant disabilities have the most hours of service and often require consistent coverage, therefore they are most likely to generate the need to pay overtime. Consequently, to limit risk, state programs, managed care companies and home care agencies will likely try to limit their exposure to this risk by limiting enrollment of individuals with more significant disabilities or will discharge individuals with significant disabilities who generate overtime payments – most likely when such individuals are hospitalized and the home care organizations can indicate that the reason for discharge is “safety”.
11. The Department of Labor acknowledged that these rules may impact “continuity of care” but that disruption in services is likely to have serious consequences for attendant service users with the most significant disabilities – like those who use ventilators. While it may be unpleasant for some people to bring strangers into their homes, cutting the hours of long-term, knowledgeable attendants for these individuals may have dire consequences.
12. Finally, because the Department of Labor has indicated that it will not enforce this rule on households that privately and directly pay their attendants, these households will continue to be able to offer premium shifts of extended hours, drawing attendants away from Medicaid-funded programs, further reducing the available workforce to support people with significant disabilities living in the community.

The proposed changes will negatively impact our attendants!

While we have highlighted how these changes will hurt people with disabilities and promote institutionalization, we are equally concerned with the negative impact that these rules will have on our attendants. For every person with a disability who would be hurt by these proposed rule changes there is an attendant who is hurt as well. While we face the loss of our freedom and independence, our attendants face the loss of income and their financial stability. Some attendants will lose large amounts of money – like in California and New York – where individual attendants may have their earnings cut in half, in some cases losing \$20K a year. Others, who may only work a few hours over 40 in a week, face more dire circumstances. Even though these attendants may lose significantly fewer dollars, those dollars are needed for necessities like shelter, food and clothing. We stand together in opposing these changes because they will hurt all of us.

The proposed changes will devastate consumer directed programs which are consistent with the intent of the original exemption!

The Department of Labor did not adequately assess the impact of their proposed

rules on consumer directed programs. In their analysis, the Department of Labor stated that "There is no consolidated source of data on state consumer-directed programs". That is absurd. There are several national resources devoted to the services within the disability community and DOL would have known that if it had effectively engaged the disability community in drafting the proposed rules.

The DOL analysis mischaracterizes consumer directed services and fails to assess the impact that the proposed changes will have on that system for providing services and supports to people with disabilities.

In the proposed rule, the Department dramatically mischaracterizes the nature, scope, and intent of consumer directed (also referred to as self-directed) personal assistance and minimizes the prescribed role of the consumer (or designated representative) in that model. DOL asserts that consumer directed personal services are "over-the-back-fence network of women [who are] usually untrained, unscreened, and unsupervised, but more affordable without an agency's fee, less constrained by regulations and hired through personal recommendation" (RIN 1235-AA05, page 81208). This statement is categorically untrue, and completely misrepresents the model.

It is our understanding that the Department of Labor has decided to determine who is the "employer" using an economic determination, which would determine that the agency is the employer in the vast majority of consumer directed programs. Even though the individual hires, trains, supervises, and dismisses their attendants. This approach disenfranchises the vast majority of people with disabilities who receive Medicaid services.

Because DOL did not look at consumer directed personal assistance services, it was unable to consider the consistency between consumer directed services and Congressional intent regarding the exemption. The Congressional Committee on Education and Workforce's Subcommittee on Workforce Protections held a hearing on "Ensuring Regulations Protect Access to Affordable and Quality Companion Care ." That hearing provided useful insight into the Department's interpretation of Congressional intent.

At the hearing, Ms. Leppink, on behalf of the Department, noted that the reason for the original "carve out" of companionship services from the extension of the FLSA to domestic services employment, back in 1974, was due to an understanding that companions "were typically friends, neighbors, or fellow parishioners of the individual receiving the companionship services, performing the services in those roles and not as employees engaged in a vocation." These workers performed the services for the purpose of providing care to their specific friend or family member; not as typical employees engaged in a vocational path toward health care services.

The Department's description of the original "carve out" is, in fact, extremely consistent with the description of consumer directed services. In a consumer directed model, the majority of attendants are not focused on career paths and professionalization, but rather are focused on providing transfers, meal preparation, and suctioning to their cousin (for example) so they do not have to go into a nursing facility. This workforce is not concerned about securing overtime, but rather making sure the necessary hours and supports are provided for their family or friend to remain independent at home.

It is clear, even in the DOL analysis, that the consumer directed model is based on a non-traditional workforce. In looking at the Cash and Counseling demonstration states, DOL notes that in New Jersey and Arkansas, the percentage of paid family and friend attendants is 71 percent and 78 percent respectively (RIN 1235-AA05, page 81209). Even in Florida, family caregivers are a prominent component of the consumer directed workforce as 58 percent of attendants hired under the Florida program were family members or friends. DOL notes that 80 percent of these family caregivers had previously provided unpaid assistance to the individual with a disability prior to becoming involved in the Cash and Counseling demonstration program (RIN 1235- AA05, page 81210).

We can look more closely at these non-traditional attendants' perceptions of their work and their motivations. According to an analysis of worker's satisfaction in the consumer directed program in Arkansas, "Despite receiving modest (and sometimes late) pay and almost no fringe benefits, about 45 percent of directly hired workers reported being very satisfied with their wages and benefits; only 16 percent reported being dissatisfied. In contrast, 22 percent of agency workers reported being very satisfied with their wages and fringe benefits, whereas 38 percent reported being dissatisfied. Thus, although policymakers might be concerned that directly hired workers receive inadequate wages and benefits, the workers themselves are fairly satisfied with their compensation, especially in comparison with agency workers." ("The Experiences of Workers Hired Under Consumer Direction in Arkansas", June 2003)

More recently, PHI released a study ("Self-Determination and the MI Choice Medicaid Waiver Program: A survey of direct-care workers people using the MI Choice self-determination option", October 2011) that clearly demonstrated the applicability of the companionship exemption to consumer directed services. PHI found that, "The most popular motivation for people choosing to work for a self-directed participant is that a family member or friend needed support (78%), followed by personal satisfaction (55%)..."

These are not career attendants who are seeking opportunities for advancement in the field. They are concerned family members and friends who are willing to help this individual. DOL doesn't acknowledge the consistency with the original

companionship exemption or consider the impact that this change would have on those family members who provide critical supports to individuals.

There are practical problems with implementing these rules within consumer directed models. For example, when an attendant works for multiple consumers within a consumer directed system, there is no clear understanding of which consumer would be responsible for paying the travel time between jobs. Additionally, because the fiscal intermediary doesn't manage the schedule, they are unable to control the utilization of overtime. Although they could modify the wage structure to accommodate time-and-a-half for overtime, not all attendants work those hours and such changes would hurt those attendants. Additionally, some areas have living wage laws that require a wage much higher than the minimum which makes time-and-a-half completely unaffordable.

Consumer directed fiscal intermediaries – like those in New York State – have expressed concerns that the proposed rules undermine the model because they will require fiscal intermediaries in the state to assume responsibilities that had previously been done by consumers. Even Independence Care Systems – a managed care organization sponsored by PHI – doesn't require or fund time-and-a-half wages in the contracts it has with consumer directed fiscal intermediaries! PHI's organization has applied these rules to agency-managed services, but has been unable to develop a sustainable model for applying time-and-a-half to consumer directed services. This clearly demonstrates that consumer directed services must be addressed separately.

The process used to develop these rules violated Executive Order 13563 – Improving Regulation and Regulatory Review – signed by President Obama in January 2011!

Executive Order 13563 – Improving Regulation and Regulatory Review – established an expectation that “Before issuing a notice of proposed rulemaking, each agency, where feasible and appropriate, shall seek the views of those who are likely to be affected, including those who are likely to benefit from and those who are potentially subject to such rulemaking.” Despite this explicit requirement in the Executive Order, the Department of Labor never worked with the disability community, including ADAPT and groups representing people with disabilities who use consumer directed personal assistant services. After the Obama Administration released the proposed rules and in response to the public outcry from the disability community, there have been meetings – such as this one – where the administration has “listened” to the concerns being raised by the community. However, because the rule-making process had already been initiated, there has been no dialogue between the administration and the disability community.

ADAPT and the National Council on Independent Living have proposed a compromise that would allow President Obama to keep his promise to modify

these rules, while holding consumer directed programs harmless from the changes. The ADAPT-NCIL compromise would simply eliminate the exemption for third party employers, treating Medicaid consumers who function as the employer under a common law assessment, as private employers. This change, alone, would eliminate the companionship exemption for 70% of home care workers, while minimizing the negative impact on people with disabilities. This would then allow the Department of Labor to sit down with representatives from the disability community to craft additional changes to the rule in a manner that minimizes the negative impact on people with disabilities and our attendants.

We have proposed this compromise as a show of good faith that we are trying to find a path to move forward while giving the disability community an opportunity to come to the table as full partners in developing the rules which will impact consumer directed services. During our Spring Action, ADAPT secured meetings with SEIU and AFSCME which agreed to bring proposals to the table which would address our concerns. We have been engaged in substantive meetings to develop an approach we can all support. Rather than truncate this process by finalizing the rules, the administration should wait and give the unions and disability community an opportunity to find common ground. Alternatively, the administration could formalize this process and utilize a negotiated rule-making process.

We have heard that the administration intends to finalize the rules around Labor Day. This listening session – where we have three minutes to explain the complex impact of these proposals – should not signal the end of a process that has disempowered and steam-rolled over the disability community. It should be the start of a process that fully engages us.

The ADAPT Community

For more information, including our original comments on the proposed rules go to: www.DOLoffMYbody.org