

March 21, 2012

Submitted via www.regulations.gov

Mary Ziegler
Director, Division of Regulations
Legislation and Interpretation Wage and Hour Division
U.S. Department of Labor
Room S-3502
200 Constitution Avenue NW
Washington, DC 20210

**Re: Comments to Proposed Revisions to the Companionship Exemption
Regulations, RIN 1235-AA05**

Dear Ms. Ziegler:

These comments are being submitted by ADAPT and the National Council on Independent Living (NCIL). ADAPT is a national grass-roots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom. NCIL is a national membership organization that advances independent living and the rights of people with disabilities through consumer-driven advocacy. NCIL envisions a world in which people with disabilities are valued equally and participate fully.

Our organizations recognize the invaluable role that attendants play in supporting the independence of people with disabilities and have long advocated for increased funding for attendant services to improve wages. However, in reviewing the changes proposed by the Department of Labor (herein referred to as DOL or Department), it is clear that, although well-intentioned, these changes will have a significant negative impact on people with disabilities and most seriously affect people who have the most significant disabilities, particularly those who rely on Medicaid home and community based services to be independent. In these comments NCIL and ADAPT have identified potential unintended consequences of the proposed rule which promote institutionalization, negatively impact consumer directed services, and negatively impact workers.

Although the Department of Labor suggests that Medicaid and Medicare rates will increase and offset the additional costs associated with these changes, the Obama administration has proposed cutting Medicaid over the next decade and supported efforts by states to reduce their spending on the program through rate reductions. By increasing the cost of home and community based services without addressing the

funding mechanisms, these proposed changes will reduce the availability of home and community-based services that allow people with significant disabilities to live in the Most Integrated Setting. Even if the administration and states were not actively cutting Medicaid, home and community based services are most frequently structured in a manner that caps the available funding. Under this zero-sum model, increasing the cost of services will result in a reduction in hours of personal assistance and promote institutionalization.

The Department's analysis also fails to adequately assess the impacts that its proposed changes will have on the "consumer directed services" (CDS) model of providing home and community-based services and supports. That analysis is based upon its disturbingly inaccurate characterization of CDS as "a fringe, unregulated system" and is not an adequate basis for rulemaking. Left entirely unexplored is a complex interaction of a number of factors such as the source of CDS funding, the relationship of consumer and personal care attendant, and the shifting responsibility of the consumer and the fiscal intermediary to act as the employer. The proposal would limit the availability of family and friends as paid attendants in consumer directed personal assistance programs, reducing the available workforce and potentially forcing people with disabilities into unwanted institutional placement.

Because the Department of Labor failed to adequately involve the disability community in the development of this proposed rule, DOL needs to announce that it is rethinking the changes to the Companionship exemption rules and that, after additional stakeholder review, it will put them out for further comment. As an alternative, the Department could also consider using a negotiated rule-making process to create an opportunity for the disability community to enter into a dialogue with DOL over the impact of these proposed rules and how they could be constructed to minimize the negative impact on people with disabilities and consumer directed personal assistance services.

We further believe that because of the intense pressure on state Medicaid budgets and the determination of policy makers to curtail spending on long term services and supports, attendants will not benefit from the proposed rule. In fact, the changes are likely to negatively impact them as well. For attendants who work in Medicaid-funded programs, these changes will result in reductions in the hours that attendants may work, downward pressure on their wages, and the obligation to work for more agencies to sustain a living. This is not conjecture; we have already seen this occur. These real-world negative implications for workers reinforce our argument that the proposed changes be postponed.

The Department of Labor failed to adequately involve the disability community in the development of this proposed rule and needs to consider how it can effectively address that issue.

ADAPT, NCIL and other organizations in the disability community are deeply concerned about the potential impact of these proposed rules and the fact that our community

wasn't effectively engaged in the rule-making process. (See the comments provided by the National Disability Leadership Alliance.) Because DOL failed to effectively engage the disability community prior to starting the formal comment period, there has been no possibility of having any informal dialogue between the Obama administration and our community which could have proactively addressed our concerns and mitigated these unintentional, but serious, consequences.

In an effort to find common ground on these rules, we have worked diligently to start a dialogue with labor and attendant advocates. Unfortunately they have been unwilling to work with us to resolve our concerns. They have also been our only source of information about DOL and the Obama administration's intentions regarding these rules, and they are telling us that the administration is trying to get these rules out as soon as possible. According to one advocate, *"The companionship exemption is a political hot button and symbolic issue. The Obama DOL began work on developing regs as soon as it could, knowing that developing new regs is a lengthy process. They want the regs finished and signed before the election is in its final stages and it becomes an immediate target for criticism for implementing controversial policy at the end of the term...and there may be a new administration that would never do it."*

Whether DOL just didn't think to really engage the disability community or deliberately minimized our involvement because we would complicate things, the process for developing these rules is unacceptable. As we look at the administration's actions on these rules, it's clear that people with disabilities - as a constituency - are undervalued by the Obama administration and its Department of Labor.

As people with disabilities raise serious concerns about how these changes could negatively impact our freedom as Americans, we find that neither the left nor the right support our efforts. Those on the right ignore us, while the left seems to have taken every opportunity to undercut or minimize our concerns.

These rules have, indeed, become another fight in the culture war between Democrats and Republicans. Now, that culture war isn't just at our front door. It's being fought in our homes... and it's playing out in our bathrooms. Most unfortunately, our freedom and independence are considered acceptable "collateral damage" of that war.

Disability advocates found the DOL analysis difficult to follow as it appears to have made a large number of assumptions that sometimes contradicted each other. Because the Department didn't effectively engage the disability community or make that information available about its analysis, it was difficult for the disability community to assess the veracity of the DOL assessment.

The DOL analysis does raise questions. For example, in its analysis about the proposed rules, DOL says an amicus brief filed by New York City in the Coke case "asserted that changing the FLSA companionship services exemption would significantly increase the cost to the City and State for providing home healthcare services. The brief included an estimate of the increased costs. The additional costs for

home health care workers in New York City attending patients requiring 24-hour attendance is by far the largest component of these costs, exceeding the Department's estimate of nationwide overtime for all workers in all states not currently covered by overtime. DOL says that the amicus "does not adequately describe how the cost estimates were arrived at, nor does it provide estimates of the number of patients requiring 24-hour care or the workers caring for them." (page 81217) DOL references the amicus brief in other instances and uses it to support other parts of its analysis, but dismisses the analysis in this case. We simply don't understand the DOL's reasoning and question whether it attempted to resolve these questions as it would be irresponsible for DOL to dismiss the concern of a state that would be so seriously impacted by this proposed change.

There are also some notable errors and omissions in DOL's analysis which have been cause for serious concern, including DOL's understanding of the structure of the Medicaid program. For example, there are significant differences between home health care, personal care and consumer directed personal assistance services, but the DOL analysis uses the terms interchangeably. Given that these are very different types of services, it would seem that DOL should have assessed the impact of the proposed rules on each of these systems. As we analyze the policy issues, we will identify further concerns.

Given that DOL effectively marginalized the disability community in the development of these rules, representatives of the administration have told us that they can't resolve mistakes from the past. In response to that, we must point out that it is, indeed, possible to address this concern because CMS has run into a similar problem with proposed rules that were important to the disability community. CMS had issued rules on the definition of community but gotten strong push back from the states. They have announced that they intend to rethink the rules and put them out for further comment. We strongly urge DOL to do the same in this case. This would give the Department an opportunity to work with the disability community to revisit and expand this analysis prior to taking final action on this proposed rule.

The Department could also consider using a negotiated rule-making process to create an opportunity for the disability community to enter into a dialogue with DOL over the impact of these proposed rules and how they could be constructed to minimize the negative impact on people with disabilities and consumer directed personal assistance services.

The proposed changes will promote institutionalization, particularly those with the most significant disabilities.

The DOL analysis of these proposed changes doesn't assess the impact on people with disabilities receiving personal assistance services, and there is significant concern about the potential negative impact that these rules will have. Most seriously, there is grave concern that these proposed rules will increase the likelihood of institutionalization.

These concerns are not unwarranted. The disability community is deeply concerned that these rules will, by DOL's own analysis, promote institutionalization. The Department specifically identifies the institutionalization of people with disabilities as an outcome, although it was being used as an offset in the analysis of the impact. On page 81224 of the NPRM, the Department says that "these patients are more likely to search for lower cost alternatives, including... institutionalizing the patient..." This disturbing impact is mentioned a second time in the NPRM on page 81230.

There are several ways in which the proposed rule could promote institutionalization.

First, the Department correctly asserts that families privately paying for assistance may use institutionalization as a lower cost alternative. Unfortunately, the Department seems to have recognized the concern being raised by people with disabilities and, rather than address the concern, is minimizing it and distancing itself from that analysis. On March 20th at the hearing entitled "Ensuring Regulations Protect Access to Affordable and Quality Companion Care", Nancy J. Leppink, Deputy Administrator Wage and Hour Division, indicated that the cost differential between community based services and institutional placement is so significant that any increase that would potentially result from this rule wouldn't result in people choosing institutionalization. What that statement fails to take into account is that resources to pay for assistance are frequently limited and for those who the cost of services in the community is at or very near that amount, the additional cost will, in fact, force them onto Medicaid and into a nursing facility.

This concern is not limited to individuals who privately pay. DOL expects home care agencies will pass the increased costs through to Medicare and Medicaid. The Department asserts that Medicaid rates will increase to reimburse agencies for the increased cost of complying with these regulations. This assessment seems highly unlikely and consequently flawed. In fact, the Obama administration has proposed cutting Medicaid by \$72 billion over the next decade. Many states are also significantly cutting Medicaid services and Medicaid rates, not increasing them. This situation is likely to worsen as states face increased pressure on their Medicaid programs as they expand services as required under health care reform.

Within this context, Medicaid recipients who use home and community based long term services and supports could see increased institutionalization in two ways from the proposed rules.

Some Medicaid home and community-based services (HCBS) waivers use a mechanism where an individual is paid to be available to assist during a block of time, typically overnight. This is used by some states as an approach to support people with significant disabilities while containing Medicaid costs. For individuals in Medicaid waiver programs where the cost of services is individually capped based on the cost of institutional placement, imposing a minimum wage requirement on this service could increase the cost of serving an individual above the cap. The individual will either be

forced to go without needed assistance or forced into a nursing facility. Even those that go without needed assistance are likely to eventually end up placed in a nursing facility when they are unable to meet their needs and are declared “unsafe” in the community.

DOL needs to assess the impact that these rules will have on individuals in such circumstances, including identifying the specific states where this type of approach is being used to fund long term services and supports and assessing the number of individuals who could be impacted.

Other provisions within the proposed rule, such as payment for travel time and the overtime requirement, will increase the cost of these Medicaid long term services and supports as well. Again, in the case of people receiving services through these types of HCBS waivers, these additional costs could negatively impact the ability of individuals to remain in the community.

The Department should also explore ways to mitigate the impact of this unintended consequence. Neither home care agencies nor the states are empowered to change this policy under the federal rules which govern these programs and mandate cost neutrality, but states currently have flexibility to choose an individual or aggregate cap for approval of services. States may also limit access to services with an individual cap, but report on an aggregate basis. At the disability community meeting with the White House, Portia Wu suggested that this issue should be addressed by CMS. While it seems unlikely that the administration would want to limit states’ flexibility in these programs, this issue must be fully analyzed and addressed concurrent with the release of the final rules. *One option might be that the Department would, within its own rules, create a process that affords people in these circumstances with a reasonable accommodation so their ADA/Olmstead rights are not violated by enforcement of these FLSA rules.*

Our concerns also extend to states that use an aggregate model for funding long term services and supports. This may be done under a 1915(c) HCBS waiver or through managed care. In both approaches, there is an overall cap established for the group of individuals being served. While the impact of increasing individual costs under these models may not directly result in the institutionalization of individuals based on their individual cost, in this zero-sum game, increasing the costs decreases the available hours.

The necessity to balance efforts to enhance workers’ wages and benefits with the needs of people with disabilities was identified and addressed in Guiding Principles which were developed between SEIU and disability advocates. According to those Guiding Principles, signed on November 16, 2011, “As a general principle, enhancements to workers’ wages and benefits shall be paid for through increased funding.” The Department’s proposal as written simply does not do this.

The proposed rules would also likely increase institutionalization within fee-for-service Medicaid. Under this model, states will manage their budgets by simply by not

increasing their Medicaid rates to cover the additional cost created under this rule. Because the additional costs will not be absorbed by increases in the Medicaid rates, the burden will fall to the Medicaid home care organizations. Although there are reports that home care organizations are “highly profitable” with agencies making between 30 and 40 percent profit, the highly profitable professional services are generally not covered by this rule. In fact, Medicaid-funded programs providing long term services and supports are much more likely to be under-funded and losing money. As an example, a Pennsylvania organization that serves as a Medicaid fiscal intermediary attempted to pay time-and-a-half for overtime hours but nearly went bankrupt because the Medicaid rates would not support the initiative.

The DOL analysis asserts that, “it seems doubtful that many agencies can support their caseloads without at least some overtime payments.” Under both a fee-for-service model and capitated model where the rates aren’t adjusted for the increased costs, the additional financial strain generated by these rules will require home care organizations to manage their liability in a different manner. One of the most effective ways for them to do that will be to limit the number of individuals with significant disabilities receiving services. Because those individuals have the most hours of service and often require consistent coverage, they are most likely to generate the need to pay overtime. Consequently, these organizations will limit enrollment of individuals with more significant disabilities. They will also take the opportunity to discharge individuals with significant disabilities who generate overtime payments. This can easily be done when such individuals are hospitalized and the home care organizations can indicate that the reason for discharge is “safety”.

The concern that these rules could disproportionately impact people with the most significant disabilities is reinforced by the Department’s own analysis. DOL is clear that it is particularly concerned with the overtime pay associated with providing assistance to people with the most significant disabilities, specifically those individuals requiring 24-hour assistance. It should, therefore, be particularly concerned about the impact that these changes will have on that population.

The Department needs to assess and address any potential chilling effect that these rules will have on the availability of long term services and supports for people with significant disabilities. When doing this analysis, they should be careful to consider the availability of services for people with the most significant disabilities and, rather than do a simplistic analysis of states that have these wage and hour provisions, they should evaluate the potential problems in states like New York and California which have programs that generally approve significantly more hours of service than states like Michigan and Illinois.

This failure to understand the differences between the Medicaid programs is highlighted in the NPRM. The Department notes that the State of New York (and related parties) filed an amicus brief in the *Coke* case asserting that changing the exemption would significantly increase the cost of providing services to individuals with the most significant disabilities. The Department dismisses the state’s assertion because that

amicus brief did not adequately describe how the cost estimates were derived. It then did its own analysis and compared the New York State numbers to its own estimate for 34 states and Washington, DC. The Department, however, does not seem to understand or simply chooses not to acknowledge that a nationwide statistically representative sample of states would not be reflective of New York State in this regard, particularly when comparing access to 24-hour home care in New York City. Comparing New York to a statistically representative sample of other states is the equivalent of comparing a grapefruit to a representative sample of grapes.

The concern that this policy could promote institutionalization seemed to be acknowledged by Ranking Minority Member Woolsey (CA) during March 20th hearing. Although it was clear that she supported the proposed change, she actually posed a question about the potential for institutionalization. Rather than ask about DOL's own analysis that includes institutionalization as an outcome of these changes, she asked Nancy Leppink whether there were any studies that demonstrated that these policies created widespread institutionalization. Ms. Leppink stated that she wasn't aware of any studies to that effect.

As advocates for people with disabilities we are deeply offended that any level of increased institutionalization could be considered acceptable by members of Congress, the Department and the Obama administration. *Prior to finalizing any changes to these rules, the Department needs to clarify what it considers to be an acceptable amount of institutionalization. To give the disability community a way to benchmark this standard, the Department should also indicate what level of discriminatory impact from its rules is allowable for other groups as well, including people of color and women.*

Although intuitively offensive to the disability community, the Congresswoman's comments do suggest a course of action that the administration should take on this matter. Despite the fact that this issue cuts to the core of the rights of people with disabilities, there do not appear to be any credible, peer-reviewed studies of these issues to draw on, and DOL clearly lacks the expertise to adequately assess the impact of these changes on Medicaid programs and recipients. *The administration should fund credible, peer-reviewed research on the potential impact that this change will have on levels of institutionalization (by an entity without an established interest in this process) as part of its due diligence prior to making any changes to the existing exemption.*

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.

Virtually every state offers consumer directed services either through state plan or home and community-based waiver services. Congress even codified the significance of consumer direction in the Deficit Reduction Act of 2005 by adding section 1915(j) to the Social Security Act to create a Self-Directed Personal Assistance Services State Plan Option to the Medicaid program.

The consumer directed model for service delivery allows individuals to hire non-traditional attendants, including family members. Although some individuals may privately hire attendants, consumer directed services are in fact a well established, vital component of many Medicaid programs serving people with the most significant disabilities. In consumer directed services, the individual, or their designated representative, is responsible for performing the functions that are traditionally handled by an agency. DOL’s assertion that attendants are “untrained, unscreened, and unsupervised,” is incorrect. In fact, the individual (or designated representative) assumes the management responsibilities including screening, hiring, training, and supervising the attendants. Although the Department’s mischaracterization may have been deliberately intended to discredit consumer directed services while reinforcing the Department’s position on the proposed rules – by arguing that such an unregulated system needs federal oversight – this error may in fact simply be the result of DOL’s failure to engage the disability community in these discussions.

The failure to engage the disability community is most clearly highlighted by DOL’s assertion that “there is no consolidated source of data on state consumer-directed programs” (RIN 1235-AA05, page 81209). In fact, there is a great deal of expertise on these programs within the disability community. Aside from the National Council on Independent Living and ADAPT, other national resources include:

- The Center for Personal Assistance Services
- The Center for Self Determination
- The National Resource Center for Participant Directed Services

There is also expertise within the Administration. Within the US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, there is an Office of Disability, Aging and Long-Term Care Policy that has published research on these services. There are even state organizations focused on these issues, like the Consumer Directed Personal Assistance Association of New York State.

It is not surprising that the Department overlooked the wealth of resources available on the consumer directed model because the Department relied exclusively upon data provided by organizations representing labor. The disability community is, and has always been, available to work with the Department of Labor in order to help the Department access the copious amount of academic studies on the consumer directed model.

In considering the potential impact of these proposed rules on consumer directed personal assistance services, it is critical to understand the role of the organization that processes payroll and frequently the Medicaid billing. The structures used for consumer directed services vary dramatically and these fiscal intermediaries may take various forms. When we met with Department of Labor staff at our meeting facilitated by Kareem Dale, DOL staff repeatedly assured us that consumer-directed model fiscal intermediaries wouldn't be considered the employers under these rules. The individual or designated representative would be entitled to claim a companionship exemption and the fiscal intermediary wouldn't be held responsible for compliance (as long as the individual worker and their work qualified them as a companion.) We expressed grave concerns about whether DOL audit staff would all understand these distinctions and urged the department to work with the disability community to clarify language on these issues before any rule is finalized. We specifically raised concerns that without such clarity the rule would have a chilling effect on this model for supporting people with disabilities.

We reiterated that it would be important to clarify that a fiscal intermediary wouldn't be considered a joint employer even if it performed several of the employer functions. For example, fiscal intermediaries in some states establish pay rates which are based on Medicaid payments, but do not assert themselves as the employer. They don't train the attendants, schedule them, or send attendants out to serve individuals. They don't evaluate the attendants' performance. These models are extremely nuanced and it is critically important that DOL work with experts from the disability community in assuring that any final rule is reflective of the intent of the consumer directed model.

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.”¹

More recently, PHI released a study² 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

¹ Dale, S., R. Brown, B. Phillips, and B. Carlson. “The Experiences of Workers Hired Under Consumer Direction in Arkansas.” Mathematica Policy Research, Inc. Prepared for Office of Disability, Aging, and Long-Term Care Policy Office of the Assistant Secretary for Planning and Evaluation U.S. Department of Health and Human Services, Contract #HHS-100-95-0046. June 2003.

² PHI, for the Michigan Department of Community Health. “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.

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

In our experience, it is highly unlikely that they would provide personal assistance to someone outside their family or circle of close friends. The proposed DOL changes would limit the hours these individuals would be able to work. Again, this policy would disproportionately impact individuals with the most significant disabilities because paid family caregivers who would most likely be affected by this change would be working for these individuals. By reducing the overall availability of this vital component of the attendant workforce, this DOL policy change increases the strain on the home care system and threatens the independence and freedom of Americans with disabilities who depend on these services and supports to live independently.

The use of the companionship exemption is also defined by the permissible tasks that may be done by an exempt companion. The proposed rules go too far in equating companionship to "elder-sitting". The world has changed dramatically since the mid-1970s, particularly for people with disabilities. Back then, the people with significant disabilities were, more often than not, institutionalized. The tasks that family and friend companions performed would have been almost indistinguishable from "elder-sitting". The current broad definition has allowed the definition to align itself with the changing needs of people with disabilities.

The Department uses formal training as a way to distinguish between companionship tasks and those tasks which don't qualify for the exemption. This approach is not only wrong, it is inconsistently applied. First, families and friends now often perform many personal assistance functions, including tasks for which workers typically require training to provide. This may include assistance with what appear to be very "medical" functions, such as assistance with a ventilator, but those medical functions have become part of everyday life. In fact, the individual with a disability, a family member or designated advocate may provide the instruction on how to do these tasks. Conversely, there are certification programs for babysitting, even though that remains squarely within the companionship exemption under the new rules. Additionally, the DOL rules clearly distinguish tasks based on the type of disability the individual has. We don't think that distinguishing the tasks based on the type of disability the individual had was Congressional intent either. That said, the Department is trying to determine Congressional intent in a very different world where people of all ages who have significant disabilities live in the community just like the "elders" did back in the 1970s. DOL should consider these factors as it considered the permissible tasks of exempt companions. *Rather than look at the tasks based on whether training is typically needed, the Department should consider whether certification or licensure as proof of training is required for that job.*

In recognition of the increasing role of these informal supports who provide assistance, states have modified nurse practice acts to acknowledge that what were once commonly considered "medical" tasks have now become a part of daily living for people with significant disabilities. In the consumer directed model, attendants are permitted to

perform a whole host of skilled nursing tasks such as catheter and vent care. They are not required to secure either a license or certification in order to do these tasks. The very fact that attendants are permitted to perform these skilled tasks under the training and supervision of a consumer (or designated representative) is precisely the reason that the original "carve out" in the companionship exemption made sense.

In assessing the impact of their proposed changes to the companionship exemption, DOL acknowledges that people with disabilities and seniors may prefer to have the same caregiver(s), rather than a sequence of different caregivers. They point out that consumer may be less satisfied with the assistance they receive and communication between attendants can suffer with such disruptions affecting the quality of assistance that is provided. DOL sets that concern aside by pointing out that the turnover rate for workers in the home health care industry has been estimated to range from 44 to 65 percent per year. Other studies have found turnover rates to be much higher, up to 95 percent, in some cases, 100 percent annually. "Thus, many clients already experience a sequence of different caregivers, and it is not apparent that the proposed rule will necessarily worsen the turnover rate" (RIN 1235-AA05, page 81229). Yet, in the consumer directed models, turnover is far, far lower. In fact, attendants often remain with individuals for many years and it isn't uncommon for attendants to work with an individual for three, five, or even ten or more years. DOL failed to consider this in its analysis. We raise this issue because DOL should seriously assess the consumer directed model separately from home health care or other traditional forms of in home assistance.

Before moving forward with final rules, it is imperative that DOL work with the disability community to evaluate how this rule change impacts consumer directed services and those who provide service and supports within the context of that model.

Veterans who receive Aid and Attendance benefits would be in a similar situation as individuals in consumer-directed Medicaid programs. Aid and Attendance benefits refers to cash paid directly to the veteran with a service connected disability who meets a certain level of need. That money is in addition to the monthly disability compensation paid to the service-connected veteran. That extra monthly compensation is referred to as "special monthly compensation" (SMC). Thus, whereas a basic 100% service-connected disabled veteran draws \$2,769, an SMC R-2 veteran draws \$7,925, and a veteran that just meets the basic A&A (SMC L) status draws \$3,446. They may use the money to supplement the household income so a spouse can provide assistance or pay other family members who don't live with the veteran to provide the assistance they need.

Currently, these veterans currently can claim the companionship exemption in meeting their needs, but because the Department has proposed to severely limit the tasks that an exempt companion may do, the exemption becomes almost entirely irrelevant and DOL's analysis utterly fails to assess the impact of these proposed rule changes on those veterans. *It is critical that the Department work with the Veterans Administration*

and advocates for veterans with disabilities to adequately assess any negative impact and find ways to mitigate that.

In terms of addressing the consumer directed programs within these rules, we have demonstrated how consumer directed services are consistent with Congressional intent surrounding the companionship exemption. *The most straight-forward solution is to clarify that the exemption would apply, even when an individual or family uses a fiscal intermediary, while maintaining the broad definition of permissible tasks. The Department could limit the tasks based on whether licensure or certification is required to perform them as well. This approach would be consistent with Congressional intent.*

There are additional negative impacts on people with disabilities.

NCIL and ADAPT are concerned about other unintentional consequences of these proposed rules on people with disabilities.

The proposed rules may make it more difficult for people with disabilities to maintain their independence and become self-sufficient.

Although we have focused most of our comments on the individuals who use Medicaid home and community based services, many of these concerns also apply to people with disabilities who are employed and may be privately paying for assistance. Although as individuals they would still be able to claim the exemption, the proposed changes so significantly narrow the permissible tasks of exempt companions that virtually anyone who needs personal assistance would find that the exemption wouldn't apply to them.

It isn't uncommon for gainfully employed people with significant disabilities to privately hire companions who assist them with their activities of daily living. These individuals may use a variety of approaches to getting their personal assistance needs met on an extremely limited budget. *The DOL analysis must explicitly analyze the impact of these proposed rules on this population and the potential that restricting the permissible tasks of an exempt companion may force individuals who are currently able to privately pay for assistance to go without needed assistance or go onto public benefits programs because they can no longer afford to pay for those services privately.*

The proposed rules may make traveling with an attendant unaffordable.

The disability community is significantly concerned that people may pay an attendant for a block of time while traveling for work or vacation. When we raised this issue at our White House meeting, DOL staff told us the changes did not apply to the travel provisions of the Fair Labor Standards Act. This staff person didn't understand that we are concerned that these changes will require that people with significant disabilities pay more for that assistance. This could seriously impact their ability to travel because it would be unaffordable to bring an attendant under these rules.

This would have a number of negative consequences, e.g. where people must travel long distances for medical and rehabilitative services (as in rural, frontier and tribal communities), often needing to stay overnight; or simply want to visit an infirm or dying

relative, or be part of a family reunion. This change would additionally severely restrict the ability of people with disabilities to participate in state and federal committees, commissions and task forces, to testify in person at their state legislatures, and to otherwise be personally present when decisions and policy about their lives are being made. *DOL needs to assess and address any negative impact that these proposals would have on the ability of individuals with disabilities to travel.*

The proposed rules could limit access to services in rural, frontier and tribal communities.

There is a shortage of a traditional attendant workforce in rural, frontier and tribal communities where consumer directed services provided by family and friends has filled the gap. These proposed rules will likely cap the hours of those workers and worsen the workforce issues. The requirement that attendants be paid for travel time between cases needs to be further evaluated in the context of these communities as well. It is very likely that this policy could further reduce the availability attendant services as home care organizations may 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. *The Department needs to specifically analyze the potential impact that proposed changes will have on the ability of individuals with significant disabilities living in those communities.*

The proposed rules could limit access to services for non-English speakers.

Non-English speakers are another group of people who often rely on paid family and friends as attendants in consumer directed services. Often elders who do not speak English and need assistance are underserved by traditional providers. *The Department must analyze the potential impact that these rules will have on the ability of these families to meet their needs if the hours of family and friends hired through consumer directed personal assistance programs are capped.*

The proposed rules create an onerous record-keeping requirement to assure attendants are paid minimum wage.

We urge the Department to rethink this requirement as individuals will be required to track the specific times services are provided within the context of a live-in or similar arrangement and these requirements seem onerous.

The proposed changes will likely not significantly improve the lives of attendants.

We have explained the unintended, but serious, consequences of this policy change for people with disabilities, including the potential for Americans with significant disabilities finding themselves forced into unwanted institutional placement. Because we are committed to balancing the needs of attendants and those they assist, as we developed our comments on these proposed rules, we also considered the real world implications for these policy changes on attendants.

Given that the Medicaid rates for home care are (at best) likely to remain stagnant, home care organizations simply are not funded at a level to support time-and-a-half

wages for overtime. As discussed in the DOL analysis, home care organizations will be forced into one of two potential scenarios directly impacting attendants to contain the costs created by these proposed rules.

First, and most likely, home care organizations will simply limit the number of hours attendants will be allowed to work to avoid paying overtime. Although attendants will have the symbolic right to be paid time-and-a-half wages for overtime hours, they won't see their earnings increase because they simply won't be allowed to work the extra hours. Consequently, in states affected by this change, home care organizations will limit the hours attendants can work. Likewise, fiscal intermediaries, which provide support functions in the consumer directed personal assistance program, will also limit the hours attendants are allowed to work under the program. Because attendants' hours will be reduced, their earnings will actually be cut under this policy. To make up the difference, they will need to work for multiple home care organizations so that they can earn the income they had previously earned under the FSLA exemption. The biggest difference to these attendants will be that they will have increased complications related to scheduling shifts for multiple agencies and consumers. They will also have additional unreimbursed travel time related to working for multiple organizations, further reducing their actual net pay. These are practical realities for workers that the Department failed to address in their analysis.

Alternatively, although less likely, home care organizations will reduce the base wages of all attendants in order to pay time-and-a-half overtime hours. In the discussion of the proposed rules, the Department indicates that 8 to 15 percent of attendants work overtime (RIN 1235-AA05, page 82123). That means, in this scenario, 85 to 92 percent of attendants will have their hourly wages reduced under the proposal.

Although the intent of the proposal is to improve the lives of attendants, in each of these scenarios, there is a significant negative impact on the people who the change is supposed to benefit. In the first scenario, the attendants who work overtime hours will be forced to work longer hours for multiple organizations in order to receive the same earnings. In the second, the vast majority of attendants will have their hourly wages reduced in order to meet the new requirements. In all likelihood, a combination of both situations will occur. Attendants who are able to work overtime hours will likely find their hours capped to mitigate the impact of the overtime provision, while *all* attendants will have their wages reduced to pay for the other new requirements.

To illustrate our concerns about the serious negative impact on attendants, one attendant from New York shared her story.

Nikki's story

I'm an attendant and I've just heard that the federal government is trying to "help" me by changing labor rules, but their new rules don't change Medicaid rates so I won't be able to keep working 56 hours a week.

All 56 hours are with one person. I work in the consumer directed program and we've been together for six years. Working for her isn't like working in a factory or hospital. I provide personal care, but we also hang out and have a good time together.

*This change won't help me.
In fact, it will hurt me financially.
I will lose 16 hours of pay each week.*

So here is some simple math to show you what that looks like.

*I make \$11.20 an hour.
 $\$11.20 \times 16 \text{ hours/week} = \179.20 a week.
I will lose that from my paycheck. Every week.*

*Let me make this picture even clearer for you.
 $\$179.20 \times 52 \text{ weeks/year} = \$9,318.40.$*

*That is almost \$10,000 a year I will lose.
It's like one-third of my income. Gone!*

I am a very frugal person, but even the most frugal person can't pay their bills if they take a \$10,000 a year pay cut. How would people at the Department of Labor deal with losing one-third of their income?

This is just complete bullshit, and the government is truly overstepping its boundaries. Once again, government bureaucrats are trying to put their noses into business they have no clue about.

I am going to lose hours helping someone I am close to, and will have to go work with someone else to make up for it. Probably several people. And my current hours are going to be given away to other people. That doesn't make any sense.

There's a reason the consumer directed program exists. It gives the consumer the power of managing their personal care hours. If someone feels comfortable with only two people, and they decide they want people to work 50 hours or more a week, why are you going to intrude on their rights?

All I can say is please rethink this proposal before you make a decision that is going to devastate many people's lives, consumers and attendants alike.

Although the Department has identified this as a potential result of their proposed rule change, it has not fully assessed the impact on these attendants or even estimated the

number of attendants who will find themselves in this situation. *Before moving forward with any plan that would reduce attendants' earnings, DOL must have clearly identified, analyzed and minimized the negative impact on those workers.*

Summary of Recommendations

Because the Department of Labor failed to adequately involve the disability community in the development of this proposed rule, DOL needs to announce that it is rethinking the changes to the Companionship exemption rules and that, after additional stakeholder review, it will put them out for further comment. As an alternative, the Department could also consider using a negotiated rule-making process to create an opportunity for the disability community to enter into a dialogue with DOL over the impact of these proposed rules and how they could be constructed to minimize the negative impact on people with disabilities and consumer directed personal assistance services.

In these comments NCIL and ADAPT have identified specific recommendations to address the potential unintended consequences of the proposed rule which promote institutionalization, negatively impact consumer directed services, and negatively impact workers. They are as follows:

I. Address potential unintended consequences of the proposed rule which promote institutionalization

The Department needs to assess the negative impact that these rules will have on individuals who receive services and supports under waivers, including identifying the specific states where overnight support or payment for a block of time is being used to fund long term services and supports and assessing the number of individuals who could be impacted as well as work with the disability community to find ways to mitigate these effects.

The Department needs to assess and address any potential chilling effect that these rules will have on the availability of long term services and supports for people with disabilities in Medicaid fee-for-service and managed care systems.

The administration should fund credible, peer-reviewed research on the potential impact that this change will have on levels of institutionalization (by an entity without an established interest in this process) as part of its due diligence prior to making any changes to the existing exemption.

The Department must, within its own rules, create a process that affords people in these circumstances with a reasonable accommodation so their ADA/Olmstead rights are not violated by enforcement of these FLSA rules.

Prior to finalizing any changes to these rules, the Department needs to clarify what it considers to be an acceptable amount of institutionalization. To give the disability

community a way to benchmark this standard, the Department should also indicate what level of discriminatory impact from its rules is allowable for other groups as well, including people of color and women.

II. Address potential unintended consequences of the proposed rule which negatively impact consumer directed services

First, clarify that the exemption applies to the consumer directed model and that a fiscal intermediary wouldn't be considered a joint employer even if it performed some of the employer functions, and rather than define the impermissible exempt tasks based on whether training is typically needed, impermissible exempt companion tasks should be those that require certification or licensure as proof of training is required for that job. This approach would maintain the current companionship exemption for consumer directed services while covering over 70 percent of all home care workers.

Alternatively, in conjunction with the disability community, DOL would need to:

- evaluate how this rule change impacts consumer directed services and those who provide service and supports within the context of that model and address the negative consequences for that model;
- work with the Veterans Administration and advocates for veterans with disabilities to adequately assess any negative impact and find ways to mitigate that;
- explicitly analyze and address the impact of these proposed rules on people who privately pay for personal assistance and the potential that restricting the permissible tasks of an exempt companion may force individuals who are currently able to privately pay for assistance to go without needed assistance or go onto public benefits programs because they can no longer afford to pay for those services privately;
- assess and address any negative impact that these proposals would have on the ability of individuals with disabilities to travel;
- analyze and address any potential negative impact that proposed changes will have on the ability of individuals with significant disabilities living in rural, frontier and tribal communities;
- analyze and address the potential impact that these rules will have on the ability of non-English speakers to meet their needs if the hours of family and friends hired through consumer directed personal assistance programs are capped; and

- rethink the onerous record keeping requirements placed on individuals who will be required to track the specific times services are provided within the context of a live-in or similar arrangement.

III. Address potential unintended consequences of the proposed rule which negatively impact workers

Before moving forward with any plan that would reduce attendants' earnings, DOL must have clearly identified, analyzed and minimized the negative impact on those workers.

Finally, both NCIL and ADAPT appreciate the opportunity to raise these serious issues with you and look forward to working with the administration to finding an approach that meets the needs of both workers and those they assist. Finally, these comments were developed by a committee that included the perspectives of disability rights advocates, people who use personal assistance services, and attendants.

Sincerely,

Bruce E. Darling
ADAPT

Kelly Buckland, Executive Director
NCIL

Wage and Hour Division

Us Department of Labor

Comments on proposed regulations

RIN 1235 – AA05

The Topeka Independent Living Resource Center (TILRC) is a civil and human rights organization. Our mission is to advocate for justice, equality and essential services for a fully integrated and accessible society for all people with disabilities. TILRC has been providing cross-age, cross-disability advocacy and services for over 30 years to people with disabilities across the state of Kansas. Our agency has been particularly interested in and committed to assuring that people who require long term services and supports have access to information, services and supports that offer choices; choices that promote freedom, independent lifestyles and dignity, including the dignity of risk. TILRC is owned, managed and operated by people with disabilities.

As an agency staffed and managed by people with significant disabilities, some of whom require personal assistance, TILRC understands the need to improve wages and conditions of work for the direct service workers. Without assistance, many of us wouldn't be able to work, volunteer and be engaged with community life. Personal assistants are one of the key underpinnings of independent living for people with disabilities. TILRC supports efforts to stop exploitation of workers by agencies and private for profit businesses. However, the solution to these problems as proposed in the draft regulations goes too far and will unnecessarily impact vital services, and the people with disabilities who need them. In a very tight employment market where wages have been stagnant for a long time, the proposed rules will also negatively affect income of many workers.

The proposed regulations create significant concerns in two areas: 1) concerns for the people with significant disabilities my agency serves and the type and scope of services that will be available to assist them so they do not have to enter nursing facilities and 2) concerns for the direct services workers my agency acts as employer of record for and the size of their paychecks.

My agency used to limit hours of work of the direct service workers to 40 hours per week. I support unions and workers rights to organize. I always had a strong belief that if someone worked more than 40 hours per week, they had a right to overtime pay. However, other providers allowed hours per week worked to exceed 40 hours. I had a serious problem of competitive disadvantage. I was losing business because people wanted their workers to be able to make more money and every other provider in the State was allowing workers to put in more than 40 hours per week; at straight time wages. Moreover, many disabled HCBS recipients advocated strenuously with me to be allowed to have their personal attendants work more than 40 hours per week in order to have a bigger paycheck and to limit the number of people coming and going into and out of their homes and putting their hands on the bodies

and possessions of the individuals with disabilities. Because of these reasons, TILRC started allowing people to work more than 40 hours per week many years ago.

Under the proposed rules, the Medicaid HCBS Waiver programs in Kansas and the people they serve would be negatively impacted. Workers putting in more than 40 hours per week are going to suffer a cut in take home as their hours are reduced because the HCBS reimbursement rate doesn't even come close to being enough to pay time and a half for overtime. In the same vein, people with more than 40 hours per week of service needs will have to hire another worker in order to receive all of the services they are allotted. Since TILRC is only involved with self-directed services, for our consumers this will mean another person to train, insure, schedule, manage, etc. It also often means yet one more stranger coming into the disabled person's home, perhaps with a key, one more person handling personal possessions, putting their hands on often times intimate parts of the body, etc.

The other main concern is loss of services. One of the biggest barriers to independent living for people with disabilities is being able to get needs met; to ensure that health and safety is protected. This is particularly true for people transitioning out of nursing facilities. Many people are assessed, or otherwise determined to need so-called "24 hour care", or close to it. This is obviously very expensive; typically much more expensive than a nursing facility. This can cause eligibility issues because these large service plans may not be "cost effective" according to CMS rules. My state, for example, has addressed this barrier by providing "night support", or "sleep cycle support". This is paid by the night at a rate of \$25 to \$60 or so dollars per night with "a night" defined as 8 to 12 hours. The service is further defined as a sleep-over attendant who is there to provide incidental or emergency assistance for people who may need to be turned, or who use technology such as ventilators and need to be suctioned occasionally or need someone there in case of an emergency such as a fire. The workers providing night support are almost always family members who are also almost always employed during the day as the direct service worker. Under the proposed rules, this would mean massive amounts of overtime payments. The proposed rules would require at least minimum wage paid by the hour for these types of supports. This would dramatically increase the cost of the service. The likely result, especially in the current budget cutting climate, would be elimination of the service. The large cost increase could also very likely cause program compliance problems with CMS cost effectiveness requirements.

Any regulations should take into account these kinds of issues. Language should be drafted so that people who need 24 hour coverage to stay or transition to the community are protected. The definitions need to be broadened to allow for incidental, sleep-over type arrangements to be provided in a cost effective manner.

I appreciate the opportunity to provide comments and appreciate the extra time allowed for comment on this complicated and controversial issue. TILRC sincerely hopes that some sort of compromise can be reached so that workers benefit and individuals with disabilities and their critically necessary services are protected.

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