

Brenda Aguilar
Office of Information and Regulatory Affairs
Office of Management and Budget
New Executive Office Building, Room 10235
725 13th Street, N.W.
Washington, DC 20503

RE: OMB Review of Department of Labor's Proposed Changes to the Application of the Fair Labor Standards Act to Domestic Service, RIN 1235-AA05

Dear Ms. Aguilar:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) Long Term Supports and Services Task Force and Employment Task Force have deep concerns about certain elements of the Notice of Proposed Rulemaking (NPRM) issued by the Department of Labor (DOL) on December 27th 2011 regarding the application of the companionship exemption to the Fair Labor Standards Act (FLSA). The Task Force strongly recommends that the Office of Management and Budget (OMB) return the final draft rule currently under its review to DOL for further study and revision.

The Consortium for Citizens with Disabilities (CCD) is a working coalition of national organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of the 57 million children and adults with disabilities in all aspects of society.

CCD understands the goal of the NPRM to ensure that workers engaged in the profession of providing home-based supports and services to "individuals who (because of age or infirmity) are unable to care for themselves" can avail themselves of FLSA wage and hour protections. We recognize that the Department of Labor (DOL) has taken the position that the nature and scope of the home health care and support industry has changed greatly in the last 35 years, and that the current regulations governing the companionship exemption may no longer provide an appropriate basis for distinguishing between a professional individual, engaged in a vocation, and a caregiver whose role may be more informal and better described as an avocation.

Redrawing that line requires balancing the important rights of workers to fair wages with the equally important right of individuals with disabilities, affirmed in the Supreme Court decision *Olmstead v. L.C. and E.W.*, to live and receive public supports in the most integrated setting possible. There has been much discussion and controversy about the path DOL has navigated between those two essential values. This letter is not intended to address those issues,¹ but rather to draw OMB's attention to the

¹ There are members of CCD that are concerned about the health and institutionalization risks of the proposed rulemaking for fixed income and lower income private payers who must spend a very

unintended consequences of the proposed rule that will negatively affect the rights of individuals with disabilities without having any positive impact on the rights of workers. Specifically, we are concerned about the impact the rule would have on the ability of people with disabilities to choose to receive supports from friends and family, and on innovative, effective support arrangements that do not resemble an employer/employee model. There are two main provisions of the rule that raise these concerns: The “20% rule” limiting the amount of time companions can spend on certain tasks; and the determination that any support worker employed by a third party could not be considered a companion. Further, we are concerned that DOL’s focus, in its research on the economic impact of the rule, on Medicare has resulted in a lack of understanding regarding the real impact of the rule on those sectors of the economy where the companionship exemption is most often used—specifically, Medicaid Home and Community Based Services (HCBS) and the private pay market, primarily for seniors.

We believe that the new definition of companionship services, and especially the types of services that would be considered “incidental” and therefore limited to 20% of the caregiver’s time, as well as the blanket exclusion of caregivers paid by a “third party,” will eliminate most paid family caregivers and other similar types of care providers from the companionship exemption. Paid family caregivers are not typically career attendants; rather they are usually family members and friends who are willing to help the individual in need of care. Family and friends who function as paid caregivers routinely perform tasks such as dressing, grooming, toileting, driving to appointments, errands, and social events, feeding, doing the laundry, bathing, wound care, injections, blood and blood pressure testing, and turning and repositioning. Many of these personal care or general household services are not incidental to companionship services, in fact they are part and parcel to assuring that effective companionship services can be delivered, and contrary to DOL’s assertion, many of these personal care or health related services do not require “specialized training.”

While paid family caregivers clearly will have something other than a typical employment relationship with the individuals they serve, there is often nominal involvement by a third party to ensure that certain employer responsibilities are met. Hiring, managing, and functioning as the employer of a direct support provider can be a complicated business. For many individuals with disabilities, this involves dealing with Medicaid rules and regulations, and reimbursement processes, in addition to the usual difficult array of employer-related responsibilities. For this reason, service systems have adopted a number of employment arrangements that seek to provide the individual with disabilities the self-determination and control associated with directly employing a caregiver, while locating official employer responsibilities with a third party. This could be a fiscal intermediary, who may become the employer of record for the purpose of taking responsibility for such things as payroll taxes, while leaving hiring, firing, and management authority in the hands of the individual with disabilities;

significant proportion of their income on the personal assistance services that enable them to live and work in the community. We are aware that many of these groups have submitted their own comments on this issue.

another example is known as “Agency with Choice,” which allows the individual to select, manage and dismiss personal attendants, while the agency takes responsibility for payroll, taxes, insurance, etc. Service recipients can even be encouraged to find their own attendants and send them to the contract agency for employment. The consumer is responsible for selecting the employee, setting the employee’s hours, daily management of employee responsibilities, etc. This model differs from the concept of direct employment with the help of a fiscal intermediary because the Agency with Choice and the consumer share responsibility for training and evaluation of employee performance. A consumer under the Agency with Choice model may indeed wind up receiving services from a Direct Support Professional for whom personal care is a job. However, in cases where a fiscal intermediary or an Agency With Choice model is used to support the individual with disabilities to hire a family member or friend to provide them with support, the relationship between the actual decision-maker (i.e., the individual managing his or her own services) and the service provider would clearly not be the typical employee/employer relationship one imagines when thinking of wage and hour protections.

Removing caregivers who are family or friends and not typical employees from the purview of the companionship exemption will raise the costs associated with the care they provide, which has severe implications for disability service systems. Individuals with disabilities have the right to live and receive services in the most integrated setting possible. Allowing individuals receiving supports and services to select a paid caregiver with whom they have a relationship beyond that of employer or “client” is an important freedom that allows individuals to determine their own support arrangements in the manner best suited to maximize their ability to live a full and integrated life.

Companionship services and the accompanying elements of personal care involve a great deal of intimate interaction between caregiver and care recipient; having these services provided by a series of professional providers with no personal connection to the recipient, beyond being uncomfortable for the recipient, has the impact of decreasing their sense of personal autonomy and control over their personal space. Many individuals with disabilities who require significant amounts of support (and the public entities that often provide funding for their services) will be unable to afford overtime pay, and instead will be forced to rely on multiple caregivers working in shifts, leading to serious concerns about continuity of care, and the frustration of trying to provide a real home for people when having to employ shift staff. More than one administrator has expressed frustration with their inability under such circumstances to assure that people with disability will live a life they choose in a home over which they have control.

We are also concerned that under these provisions, many innovative, appropriate, and mutually beneficial (to both the service recipient and caregiver) service arrangements, which do not resemble the typical employer/employee relationship, would fall on the side of the line that requires minimum wage and overtime protections, rendering them unaffordable for individuals with disabilities and for the publicly funded service system. Although DOL may have intended the companionship exemption to continue to be

applicable to some of these innovative arrangements that more closely resemble informal caregiving than professional services, the rule is not explicit enough to allow states, providers, or individuals to draw that conclusion and could have a “chilling effect” on states, providers, families, and individuals’ use of many service arrangements that lead to the best outcomes for people with disabilities because of a fear of future liability.

An example of such a service arrangement, used most often to support individuals with intellectual and developmental disabilities (I/DD), is shared living. Shared living describes an arrangement in which an individual, a couple or a family in the community share life's experiences with a person with a disability. The person who lives with and provides companionship support to the person with a disability is typically referred to as the shared living provider. Other terms that can encompass the shared living approach include mentor, host family or family home, foster care or family care, supported living, paid roommate, housemate, and life sharing. Shared living providers do not work specific hours, nor do they have a specific job description—in fact, those very ideas are anathema to the purpose of the shared living model. The term shared living emphasizes the vision that people choose to live together and share experiences. This concept of sharing presupposes a mutual experience not a hierarchical one. The shared living relationship is nothing like an employer/employee relationship, and does not even reflect the standard service recipient/service provider relationship—rather, it most clearly mirrors the relationship between roommates. As such, they seem clearly to fall outside the rubric of such concepts as wage and hour protections, or restriction of duties. And yet, the challenge in the context of these regulations is that shared living providers receive compensation—often from a third party provider agency or directly from the state’s Medicaid program. Since the shared living provider is quite literally sharing their life with an individual with I/DD, rather than working specific hours, a requirement to pay them minimum wage and overtime would not only be administratively impossible, but would also make the shared living model fiscally unsupportable for states and providers. On the other hand, the very nature of the model and the relationship between the provider and the individual obviate any need for these economic protections.

The Task Force is also concerned about the lack of due diligence in the proposed rule’s economic impact study. While DOL asserts that home care agencies will try to pass the increased costs resulting from the narrowing of the companionship exemption through to Medicare and Medicaid and only acknowledges the risk of institutionalization created by the rules as it pertains to private pay individuals, the Department’s understanding of the Medicaid system is flawed. Medicaid home and community based services are most frequently offered through 1915 (c) waiver programs with defined funding levels. Unlike state plan services, these HCBS waivers are not entitlements; rather, states can target services to particular populations, limit the number of people who will be served, and limit the amount of money that the state will spend on a particular service. Under this zero-sum model, providers will not simply be able to bill Medicaid for increased costs. In addition, in some states, the increased

expenses will risk the cost-neutrality of the affected HCBS waiver programs, imperiling the programs' ability to continue thus resulting in increased institutionalization.

Moreover, the *Olmstead* decision did not endorse an individualized accounting approach for determining if it was reasonable for the state to provide services in the community instead of in an institution, and certainly court decisions that have interpreted *Olmstead* have for the most part refused to require states to undertake an individual calculation with regard to cost, instead accepting that states have a responsibility to maintain a broad range of Medicaid care contexts and balance many treatment opportunities. That is, the state is given leeway to take into account how much it costs to maintain a minimal level of institutional care for some individuals with disabilities, even if a specific person with an individual does not need or want to live in an institution. This is how the state can set cost caps on providing HCBS that are lower than the actual cost of living in a nursing facility, how it can propose across-the-board cuts in HCBS, and how it can establish a set limitation on the hours than an individual worker can work within one week.

Furthermore, in state plan services, the rate is for a unit of service and won't increase for the overtime hours. If the state will not increase its budget for HCBS, it cannot pay providers a higher rate for the overtime hours, and the only alternative is to stop overtime from occurring. We understand that California has already developed a bill that would limit its Medicaid reimbursed personal assistance employees to daily and weekly hours that would not trigger overtime. This may not stop family and friends from providing those needed hours, but it will stop them from receiving reimbursement for those hours. While CCD supports extending wage and hour protections to those individuals that can be described as being part of the workforce, it is important to have a clear understanding of the impact this will have on HCBS systems so that this impact can be properly mitigated beforehand by other policy changes.

CCD believes that the purpose of the Companionship Exemption is to preserve the opportunity for individuals who need long term supports and services (LTSS) provided in their residence to make use of informal and/or nonprofessional caregivers if such caregivers can best meet their needs. We share DOL's concern that Direct Support Professionals—those who have made a vocation of providing personal care services to those the FLSA refers to as the “elderly and infirm”—should not lose the basic economic protections afforded to equivalent workers in other industries because they have been captured in an exemption that was never meant for them. However, we believe that DOL, in its proposed regulations, will exclude nonprofessional caregivers operating in some of the most innovative, progressive, and successful support models from the exemption. We urge OMB to return the draft final rule to DOL so the department can work with CMS to better assess the likely impact of the proposed rules on the Medicaid-funded and private pay sectors of direct care, both in general, and specifically on such aspects of direct care as paid family caregivers and innovative arrangements such as shared living. Further, we request that OMB recommend to DOL that they enter into a negotiated rulemaking process with representatives of both

the disability and labor communities, to ensure that the resulting regulation protects both the rights of individuals with disabilities and the people who serve them.

Sincerely,

Autistic Self-Advocacy Network

Brain Injury Association of America

Disability Rights Education and Defense Fund

Lutheran Services in America Disability Network

National Association of State Directors of Developmental Disabilities Services

National Multiple Sclerosis Society

United Spinal Association

The Consortium for Citizens with Disabilities is a coalition of over 100 national consumer, advocacy, provider and professional organizations headquartered in Washington, D.C. Since 1973, the CCD has advocated on behalf of people of all ages with disabilities and their families. CCD works to achieve federal legislation and regulations that assure that the 54 million children and adults with disabilities are fully integrated into the mainstream of society.

For more information, please contact: Dan Berland, CCD LTSS Task Force co-chair, National Association of State Directors of Developmental Disabilities Services (703) 683-4202 dberland@nasdds.org