

February 9, 2017

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Ms. Phillips:

Disability Rights Ohio (DRO), the Ohio Olmstead Task Force (OOTF), the Coalition for Community Living (CCL), the Arc of Ohio, the Ohio Statewide Independent Living Council (OSILC), the Center for Disability Empowerment (CDE), the Ability Center of Greater Toledo, the Access Center for Independent Living (ACIL), the Center for Independent Living Options, Universal Health Care Action Network of Ohio (UHCAN Ohio), and the University of Cincinnati UCEDD collectively submit these comments in response to the Ohio Department of Developmental Disabilities' (DODD) proposed rule, Ohio Administrative Code 5123:2-9-03, the purpose of which is to limit "the number of hours an independent provider may provide home and community-based services in a work week" and to establish "a process and the circumstances under which the limit may be exceeded."

DRO is Ohio's system under federal law to protect and advocate for the human, civil, and legal rights of people with disabilities throughout Ohio. The OOTF is a grass-roots coalition of people with disabilities, family members, and people who support people with disabilities. Its purpose is to ensure that people with disabilities have the right to live and work in their communities. The CCL is a parent advocacy group whose mission is to ensure all individuals with disabilities in Ohio are afforded the opportunity to live and participate in their community. The Arc of Ohio is a state-wide membership association made up of people with intellectual and developmental disabilities, their families, friends, interested citizens and professionals in the disability field. Its mission is to advocate for human rights, personal dignity and community participation of individuals with intellectual and developmental disabilities, through legislative and social action, information and education, local chapter support and family involvement.

The OSILC is committed to promoting a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and systems advocacy, in order to maximize leadership, empowerment, independence, productivity and to support full inclusion and integration of individuals with disabilities into the mainstream of American society. The CDE is a community-based, non-residential center that is driven by the choice and direction of people with disabilities. The Ability Center of Greater Toledo is a center for independent living serving seven counties in northwest Ohio that seeks to assist people with disabilities to live, work, and socialize within a fully accessible community through our core services and programming. ACIL has been serving individuals with disabilities in the Miami Valley since 1984,

ensuring that people with disabilities have access to the communities in which they choose to live. The Center for Independent Living Options' mission is to break down architectural and attitudinal barriers, build bridges to understanding, and create options and choices in the continual process of empowerment of individuals with disabilities.

UHCAN Ohio is a large and diverse state-based organization whose mission is to achieve high quality, accessible, affordable health care for all Ohioans and to build the voice of consumers to shape health care policies and develop solutions to meet Ohioans' needs. Finally, the University of Cincinnati UCEDD at Cincinnati Children's Hospital Medical Center is a University Center for Excellence in Developmental Disabilities and serves as a resource in the areas of education, research, and service to meet the needs of people with developmental disabilities.

First and foremost, people with intellectual and developmental disabilities have a legal right to live, work, and spend their time integrated in their communities and to avoid unnecessary segregation. In its administration and operation of the service system for people with intellectual and developmental disabilities, the state of Ohio is responsible for ensuring that sufficient provider capacity exists in the community to support people as they pursue their chosen goals and aspirations and to keep them safe and meet their needs as they do so. The proposed rule must be evaluated in recognition of these overarching principles.

The current realities of the service system for people with intellectual and developmental disabilities must also be acknowledged. People with intellectual and developmental disabilities and their families already struggle to find reliable and competently-trained providers. We have heard from many stakeholders across the state that people are discouraged from working in this field. There is an alarming rate of turnover among home care workers in Ohio, who, despite a recent rate increase, are still paid low wages inconsistent with the importance of the work they perform. Parents and families are consequently overburdened, balancing the ordinary demands of everyday life with admirable efforts to care for their loved ones. As a result, many people are placed at risk of institutionalization, and their integration within their communities is thwarted.

The state must therefore focus on strengthening provider capacity across Ohio with a robust pool of well-paid, well-trained providers, especially as more people anticipate moving from intermediate care facilities (ICFs) and into their own homes. The state must also commit to supporting parents and families as they support their loved ones and ensure that people with intellectual and developmental disabilities can choose providers whom they trust, who are reliable, and who will provide them the support they need. In many respects, as explained below, the proposed rule contravenes these commitments.

The structure of the service system for people with intellectual and developmental disabilities means county boards will determine, predominantly based on financial considerations, whether an independent provider can work more than forty hours a week.

We commend DODD for not placing an absolute limit on independent providers working more than forty hours in a work week. The proposed rule contains an exceptions process which allows service and support administrators (SSAs) at county boards of developmental disabilities (county boards) to authorize overtime work. These exceptions only allow authorization in limited, temporary circumstances.

Because of the structure of the service system designed and administered by the state, county boards are generally financially responsible for paying the non-federal share of Medicaid home and community-based waiver services, including, soon, responsibility for paying overtime to independent providers. County boards, many of which do not have sufficient resources, are faced with a conflict of interest in making this determination. County boards will have an incentive to minimize costs and to unnecessarily limit the number of hours an independent provider works in a work week to avoid financial responsibility for overtime.

To avoid this conflict of interest, the state should continue to assume financial responsibility for paying overtime to independent providers. Indeed, the state has noted, in its "Business Impact Analysis" as part of the "Common Sense Initiative," that the number of independent providers actually providing services and seeking reimbursement is far less than the number of providers who are certified. And less than 500 (5%) of independent providers providing homemaker/personal care services and community inclusion-personal assistance services submitted claims for overtime since January 2016.

The proposed rule contains no real due process protections to challenge these decisions.

The lack of due process protections in the proposed rule is especially concerning. Despite the presence of paragraph (F) of the proposed rule, in practice a person would almost never have an opportunity to challenge a decision by his or her SSA to deny overtime to his or her independent provider. The only situation in which one could challenge this decision, according to paragraph (F), is if there was also a corresponding reduction in authorized waiver services. In nearly all cases, however, this will not occur. Services will still be authorized, but the person would not have his or her chosen provider to provide needed services in excess of forty hours a week. If one cannot find another provider, this would act effectively as a denial of or reduction in services, but with no recourse.

The proposed rule should therefore explicitly state that people have the right to challenge through the Medicaid state hearing process a decision by his or her SSA not to allow an independent provider to work more than forty hours a week. Presum-

ably, the complaint process under Ohio Adm. Code 5123:2-1-12 is also available, but the proposed rule does not explicitly state this.

The state of Ohio should maintain and respect the right to a free choice of provider and should give county boards more discretion to authorize overtime work by independent providers.

As noted above, if a person's SSA refuses to authorize his or her independent provider to work more than forty hours a week, but he or she is able to find another provider for the excess hours, this still constitutes an infringement of the person's right to free choice of provider. Finding a reliable provider with whom one is comfortable and whom one trusts is not easy. Many tasks providers perform (for example, helping a person get dressed, bathe, administer medications, attend to personal hygiene, and so forth) are highly personal and private. For these reasons, the right to free choice of provider must be protected. Importantly, many people with disabilities throughout Ohio have expressed their strong interest in the ability to choose independent providers instead of agency providers. They have emphasized that their relationships with independent providers tend to be closer, more trusting, provide more stability and involve more flexibility, all of which they highly value.

The proposed rule only provides a limited set of circumstances in which an SSA can authorize independent providers to work more than forty hours in a work week, but these exceptions should be expanded. A person should be able to demonstrate to an SSA the importance of his or her relationship with an independent provider, and an SSA should have broader discretion to approve overtime to respect one's right to free choice of provider.

Moreover, the exception which states that a person may have specialized needs (for example, because of a "compromised immune system," because "unique behavioral support strategies" must be implemented, or because a provider "has been trained by a nurse on delegated tasks") requiring an independent provider to work overtime should not be further limited by having to demonstrate a "risk of harm" if authorization for overtime is denied. This qualification imposes too narrow an interpretation for people who have specialized needs.

A requirement that overtime work by an independent provider can only be authorized on a time-limited basis is problematic in many situations.

The proposed rule also states that a service and support administrator may only authorize an independent provider to exceed the hourly limit on a time-limited basis. This authorization can be extended as needed. But requiring continued, periodic authorizations (especially in situations that involve long-term issues, like the scarcity of willing and able providers and the specialized needs of the person) creates uncertainty and instability for people, families, and providers. This is especially true since,

as explained above, there are no real due process protections to challenge an SSA's decision to deny or end continued authorization for overtime work.

Furthermore, the proposed rule contains a requirement that, for situations in which there is a scarcity of providers necessitating overtime work by an independent provider, there must first be a time-limited plan that has been approved and in which implementation has already begun to eliminate the scarcity of providers. But this implicitly shifts responsibility for ensuring sufficient provider capacity from the state to people with intellectual and developmental disabilities, their families, and county boards. It is unclear how people and their families can eliminate this scarcity, other than placing more burdens on parents and family members and other sources of unpaid natural support.

The proposed rule does not address potentially competing requests by people who share the same independent provider.

The proposed rule applies to an independent provider who has worked forty hours in a work week providing any Medicaid-funded services as an independent provider. It is unclear how competing requests by people with developmental disabilities who share the same independent provider will be handled by the same or different service and support administrators. There is no guidance or recognition in the proposed rule for these types of issues.

We appreciate the opportunity to comment on DODD's proposed rule, Ohio Administrative Code 5123:2-9-03.

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Very truly yours,

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