

July 28th, 2023

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Director

The Ohio Department of Medicaid

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Subject: Proposed Rule 5160-44-32 Home and community-based Medicaid waiver program provider and direct care worker relationships.

Thank you for the opportunity to comment on Proposed Rule 5160-44-32 and how it pertains to supporting the needs of both individuals with disabilities and their families.

Context

We recognize there are real challenges in determining how to best support both the individual with a disability, as well as their family members who provide “extraordinary services.” In developing this rule, it is important to consider the potential negative impacts of the requirements outlined in section(s): (D1) part (a), (D2) part (c-d), (E), and (H).

Section (D1)(a)

The proposed rule requires that a parent/spouse/guardian of the person with a disability receiving HBCS waiver services prove that there is “no willing and able provider or direct care worker available to provide HBCS waiver services to the individual” to receive payment as their provider of care. This provision allows case workers too much discretion in making a determination and fails to provide adequate supports to family members of those with disabilities.

There is currently a crisis of the availability of direct care in Ohio. Throughout the course of the budget season, numerous disability advocates and advocacy organizations across the state testified to the increasing shortage of direct care workers (DCW) in Ohio due to the lack of adequate pay. A pay increase

was included in both the house and senate version of HB33; however, Governor DeWine vetoed the line item following the decision's made in the conference committee.

Direct Care Workers in Ohio are paid roughly \$12 an hour, and over 50% leave the profession every year.¹ In addition, a statewide disability needs survey conducted by The Ability Center of Greater Toledo found that 54.4% of respondents stated that there is high turnover, and their in-home providers change often.² With the current uncertainty surrounding pay increases for DCW's employed by agencies, the shortage of these workers will likely continue to increase.

However, without further guidance, it could be very difficult for a family member of a person with a disability to prove that they cannot find support(s). There is no structure in place for tracking, reporting, and conducting investigations into whether someone has access to a direct care worker that is not their parent/spouse/guardian. Because of this, it is infeasible to assume that someone in desperate need of HBCS waiver services would be able to "prove" to the extent the Department of Medicaid would be requiring under this proposed rule. Ultimately, this requirement will further the negative impacts of the DCW shortage on Ohioans with disabilities and will create greater barriers for family members who want to provide care for their loved ones with disabilities.

Recommendations:

Remove section (D1) (a) that requires individuals to "prove" that there is no other willing or able provider to provide them with HBCS waiver services.

Section(D2)(c-d)

Section (D2) (c-d) sets a maximum requirement that parents/spouses/guardians cannot be paid for more than 40 hours per week. This could be unrealistic for many family members of those with significant disabilities and prevent them from receiving the support that they need.

Many people with disabilities have families that provide some level of care and support. In the case of older adults and people with chronic disabilities of all ages, this "informal care" can be substantial in scope, intensity, and duration.

For a person with a disability who has access to a direct care worker that is not a family member, they likely still rely on family to provide care when the direct care worker is not able. The process for which Medicaid bills hours is also problematic. For example, a person who needs care in short intervals or at unusual hours, such as giving medication at certain time intervals throughout the night, will have to find a direct care worker who is willing to come and provide that care in increments of time. Most people will not want to drive all the way to someone's house just to provide 15 minutes of care, and so it falls on

¹ Midwest New Media, L.- <http://www.midwestnewmedia.com>. (n.d.-a). #advocacymatters: Care work in crisis. Disability Rights Ohio - Home. <https://www.disabilityrightsohio.org/news/advocacymatters-care-work-in-crisis>

² Direct care crisis. The Ability Center. (2023, June 26). <https://abilitycenter.org/direct-care-crisis/>

the family to do so. Thus, limiting paid care for family members to 40 hours a week fails to offer the support needed to family members of those with disabilities.

Recommendations:

Instead of determining the maximum number of hours that an individual can receive payment for caring for a child/spouse/other family member with a disability, make determinations on a case-by-case basis. Allow for family members/spouses/parents to receive compensation for the entirety of the time they are providing care.

Section(E)

Section (E) of the proposed rule would require a parent or other relative of an individual with a disability who is 17 and older to have legal decision—making authority to be a direct care worker for that individual. As a Center for Independent Living, we worry that a requirement such as this would force an individual with a disability into a guardianship that they would otherwise not choose because of their desperate need for care. Therefore, due to the **Direct Care Worker Crisis in Ohio**, an individual with a disability may feel that entering into guardianship with a relative is the only way they will have access to HBCS waiver services if this requirement is not removed from the proposed rule.

Recommendations

Allow an individual with a disability who is 17 or older to receive direct care support from a relative without requiring that that relative have legal decision-making authority to receive payment through the Department of Medicaid for the extraordinary services they provide.

Section(H)

Section (H) of the rule specifies that a denial of this service leaves no right to notice or an appeal. Denying providers the right to notice and appeal violates Sec. 1 of the 14th Amendment to the U.S. Constitution, which guarantees U.S. Citizens “due process of law.” U.S. Const., 14th Amend; *Mathews v. Eldridge*, 424 U.S. 319(1976). As written, Section(H) states:

A decision by ODM, ODA, DODD, or their designee related to whether someone qualifies under this rule to serve as a provider or a direct care worker for an individual is not subject to notice and appeal rights under division 5101:6 of the Administrative Code.

Ohio is required under the Social Security Act and 14th Amendment to the U.S. Constitution to give providers, and Waiver recipients, notice and a chance to appeal a denial of services. Including this provision violates federal law.

Conclusion

Parents, spouses, and other relatives should be able to receive payment through the Department of Medicaid in the same manner that a direct care worker employed by an agency receives payment. Family members of individuals with disabilities perform “extraordinary” services daily, and historically have had to sacrifice their own careers to fill gaps in the direct care worker profession. To fully support individuals with disabilities and their families, it is crucial that the Department of Medicaid understand that the sections outlined in this document would further create barriers to receiving HBCS waiver services and would effectively limit one potential solution to the current Direct Care Crisis in Ohio.

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