The Ability Center

May 30, 2024

Ohio Home Care Waiver Amendment 05/03/2024 Public Notice and Request for Comment

SUBMITTED VIA email: OHCWfeedback@medicaid.ohio.gov

Comments of The Ability Center of Greater Toledo

To the Ohio Department of Medicaid;

I am writing on behalf of The Ability Center of Greater Toledo to offer comment on the Ohio Department of Medicaid's proposed waiver amendments for the Ohio Home Care Waiver.

The Ability Center of Greater Toledo is a Center for Independent Living serving thirteen counties in NW Ohio. Our mission is to work to make our community the most disability friendly in the nation by increasing independence for people with disabilities, discovering true passions, and changing the community's perception of disability. Please accept these comments on behalf of our Center and of our constituents with disabilities in NW Ohio.

As a Center for Independent Living, we recognize that one of the most important elements to the independence of people with disabilities is access to home care. For many, it is the main service that prevents lifelong institutionalization. The Medicaid waiver system is understandably a major focus for our advocacy and we desire to see the most effective, robust health care system possible for Ohio. Examining the new proposed waiver amendments, we are pleased to see the inclusion of Self-Direction as an option for users, as Self-Direction has been a major talking point within our community for some time and a majority of the feedback has been positive. We do, however, have suggestions on ways to further improve the Ohio Home Care waiver.

Please accept our comments on these proposed amendments below:

First, we want to show our support for the inclusion of the Self-Direction option in the Ohio Home Care Waiver. We have worked directly with ODM and its Self-Direction workgroup since 2023 and believe that it is an option that should be included within every Medicaid waiver in Ohio. There are many waiver users who struggle within the traditional model of the Medicaid system due to the structure of different budgets. It must be remembered that disability must always be examined on an individual basis because of the great differences between different individuals' cases. Having an option for a waiver user to be flexible and create a budget that fits their specific needs allows for the most comprehensive benefits and services to match their lived experience. We also applaud that Self-Direction is an option but not a requirement. Not everyone under Medicaid would want to utilize this service, but having the ability to self-direct could be life-changing for those who need the extra budgeting authority to fit their needs.

We also want to highlight the added options for users of Self-Direction to choose a caregiver, given the high demand in the disabled community for more flexibility in hiring individuals of their choice to provide care. Family members, spouses, friends and neighbors. All of these are groups that have provided care for people with disabilities in the past and today, many of which provide this labor without proper compensation because that is what's required to keep their client safe and healthy. It is understood that these are regular options used by many waiver users, but to see that language added (especially under Self-Direction) is appreciated. Especially given the decade-long shortage of direct care providers, having options to hire nontraditional care providers, with family members being note-worthy for historically providing these services regardless of compensation, the added flexibility in finding care providers is necessary for the health and independence of thousands of Ohioans.

One of our most major criticisms of the new amendments is the inconsistent language across different waivers. While this issue is worse when comparing waivers across DoDD, ODA, and ODM, this is still one of the most common complaints when comparing the MyCare, PASSPORT, and Ohio Home Care waivers. It has to be acknowledged the difficulty for most people in understanding waiver systems, the various benefits, and educating themselves on the overall complexity of these systems. This difficulty is made only worse by inconsistent language across the different waivers, and most of the disabled and advocacy community agree that this is a

step that ODM must take in simplifying waivers as a whole. Having the term “participant-direct” used in one waiver, and “self-directed” in another is confusing for two main reasons. The first is a lack of consistency across the system. The second, and potentially more impactful, is the confusion from using similar-but-different terms to describe different aspects of services. If someone hears two terms that are almost identical, it’s much harder to differentiate the two than if their names had a stronger distinction. For a new enrollee, trying to tell the difference between a “Choices Home Care Provider” and a “Home Care Attendant” will only lead to more confusion and frustration, leading to decreased enrollment and understanding. While this would be a lengthy process, having all three of the recently updated waivers use standardized naming conventions and terms would dispel much of the struggle that is reported with waiver users in the ODM workgroup and lead to a simpler, more manageable system.

Our final criticism is directed at the Goals for Participant Direction, found on Table E-1-n. This table lists the state’s goal for the number of people who would adopt budget authority under Self-Direction for each year after the program’s unveiling. This table lists that for each year of the program, ODM is expecting zero individuals to sign up for the first three years and then less than 200 in the following two years, which we find to be surprisingly low. We struggle to understand why the goal for enrollment is this low, given the wide support from the disabled community for Self-Direction. Having a number that low listed within the amendment sets the impression that this will not be a commonly used feature of the waiver, which we believe is an incorrect prediction. Not only does this set a negative frame around enrollment before the program starts, but it would also see that administration would allocate a more limited number of staff and resources to manage Self-Direction. This could lead to an overload when the program unveils, which can create staffing issues for ODM and longer wait times for waiver users trying to adopt the option for their service. We firmly suggest increasing ODM’s goals for enrollment and prepare for a larger number of users to begin converting their services to Self-Directed ones.

Conclusion

The Ability Center is in favor of the inclusion of Self-Direction as an option within this waiver, but there are still improvements that can be made. In general, the inconsistent language across different waiver systems does nothing but make an already complex system more complex for first-time users, which will lead to frustration and lower overall participation. Related to this, however, the number of participants listed in the goals for ODM are far too low. If you expect so few new enrollees a year, you will be surprised by the wave of new users and your staff will become overwhelmed. That being said, the inclusion of language for a self-directed caregiver is a feature that the disabled community has been wanting for years and is a great addition to this program.

Sincerely,

The Ability Center of Greater Toledo

Jules Patalita

Disability Rights Advocate