

To Whom it May Concern

My name is Julie Ward and I am a single mom of Nikki who is an adult with developmental disabilities who requires 24/7 care. I am writing this letter to share my experiences with the Ohio Shared Living program along with recommendations for adjustments to the program.

Up until 3 years ago I worked in corporate America and had several DSPs caring for Nikki under her IO Waiver. Then life suddenly changed and I left my 25 year long career to care for my Mom in my home.

That's when I learned of Shared Living. When I first starting caring for my mom, Nikki had her normal caregivers (DSPs) providing her care in my home as well as taking her out into the community. She loved spending time with her caregivers. They helped her with personal care such as get a shower and ready for the day and also to get out and do fun things. They gave her a real sense of being independent of 'mom'. Then I was hit with the requirement that I had to switch to Shared Living. Due to the Shared Living restraints Nikki was no longer provided caregivers through her IO Waiver.

This change suddenly required me to care for both my elderly Mom and daughter with disabilities ALL BY MYSELF. Both requiring 24/7 care. I was so overwhelmed that I had to spend my personal savings to pay out of pocket for caregivers for Nikki just so I could give proper care to my mom.

The 3 years of caring for my mom and Nikki, losing mom (Nikki's Mamaw) in March 2020, the pandemic, and the Shared Living restrictions has been very difficult for both of us. As I look ahead, I do not see a path to move from where we are today to getting back to where we were prior to Mom's illness.

The Ohio Shared Living program in its current state is a 24 hour 7 days a week job that has no means for relief. It does not allow for any relief even for a couple hours a week in-home help or a day off without significant financial impact. It causes isolation and extreme stress for both the caregiver and individual with developmental disabilities.

Case in Point - ...when I hear parents say they've been 'stuck home' with their kids 24/7 this past year during the pandemic with no relief, unable to go out to dinner, see friends, etc. I just think... Welcome to my last 3 years under the rules of Shared Living. I've had No at home relief, no days off, no one for back up, no vacation." The mental stress the pandemic isolation is causing our society has been going on for years with Shared Living caregivers and their individuals with developmental disabilities.

Below are recommendations for changes to the program that will improve the health and welfare for both the individual with developmental disabilities and the Shared Living caregiver.

Recommendations for Improvement:

1. Add to the program 16 HPC hours per week with no impact to billing the Shared Living daily rate. HPC hours would be covered by one or more DSPs who are not the Shared Living caregiver. As part of the program these 16 hours would not require county approvals. Additional HPC hours up to 30 hours per week may be requested with additional approvals.

Justification:

HPC hours allow for the individual to have interaction with other caregivers and a break for the Shared Living caregiver without impacting the Shared Living caregiver's income. Adding 16 HPC hours to the program without additional approvals streamlines the process. Allowing for additional HPC hours up to a weekly maximum provides flexibility to the counties who recognize circumstances that require more hours per week. Say for example...a Shared Living caregiver also caring for an elderly parent.

2. Keep the pandemic rule change that allows for the same agency who provides the Shared Living caregiver to provide DSPs to cover HPC and OS/OC hours as long as a different person from the Shared Living caregiver.

Justification:

Restricting the use of an agency goes against the individual disabilities freedom of choice which allows them to choose the agency they want to provide services.

3. Add rule - Shared Living caregiver may take 14 respite days per budget year without requiring additional approvals to put into the budget. These respite days would be covered by one or more DSPs using HPC/OSOC hours. This means the DSPs would be paid hourly for the day and night care. The Shared Living caregiver would not be paid the Shared Living daily rate on respite days. This respite care could be provided either in or out of the home depending on the situation.

Justification:

These 'pre-approved' respite days provide the ability for the Shared Living caregiver to have a day off here and there without having to provide the county justification why they want the day off and the exact dates for each and every day. To put this in perspective... allowing an employee 14 days off during the year from a job that requires 24 hours a day for 365 days. (we don't get weekends off)

4. Clarify "temporarily unavailable" Rule – Provide clear verbiage regarding when the Shared Living caregiver is not available to care for the individual. Remove the wording "temporarily unavailable" and change as follows:

Short-Term Unavailability

– The Shared Living caregiver is unavailable to care for the individual for 1-21 consecutive days. HPC and OS/OC hours may be used to care for the individual during this time. Services may be provided in or out of the Shared Living home depending on the circumstances. The Shared Living caregiver would not be paid the Shared Living daily rate during this time. (includes #2 above)

Long-Term Unavailability

– The Shared Living caregiver is unavailable to care for the individual for 22 or more consecutive days. The Shared Living rate is to be used to care for the individual during this time. Services may be provided in or out of the Shared Living home depending on the circumstances. The Shared Living caregiver would not be paid the Shared Living daily rate during this time. Provide a clause that allows for the use of HPC/OSOC hours for this time only due to extreme circumstances and requires additional approvals. (includes #2 above)

By better defining this clause it ensures consistent implementation of the rule.

Justification:

Using the term “temporarily Unavailable” without clear definition is too vague and causes total confusion across the counties. Depending on the interpretation, the “temporarily unavailable” clause can mean one day or 6 months.

Shared Living is a long-term solution. It cannot be successfully used for short term needs. It is unrealistic to require the Shared Living daily rate for the short time period of 1-21 days. There is no way a qualified caregiver will be willing to work a 24/7 job for less than \$100 a day for just a couple days or even a couple weeks.

5. Update rule regarding Medication Support as follows

– Shared Living may use Medication Support services that utilizes assistive technology along with remote monitoring to manage medication distribution and refilling. The remote monitoring would be specific to Medication Support.

Justification:

Assistive technology coupled with remote monitoring for medication support ensures medication distribution and refills will always be consistent. It provides a long-term solution for managing medication for individuals with disabilities regardless where and from whom they receive care. Additionally, it will prevent interruption of an individual’s medication regimen and refills should something suddenly happen to the Shared Living caregiver.

I believe there are good intentions behind Ohio's Shared Living program and with some adjustments it could be a great program for individuals with developmental disabilities and their Shared Living caregivers.

Please feel free to contact me for more in-depth details.

Sincerely,

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