

As requested, I am submitting my comments regarding my experience with Family Living. My 23-year-old daughter is non-verbal, ambulates with guidance, and requires 24/7 total personal care. She has sensory integration and sleep issues, which make living in a large setting problematic. For the past two years she has resided in a non-traditional Lifesharing arrangement. The agency which provides her supports rents the home which she shares with two Lifesharing staff. She also has a full-time habilitation person to take her into the local community on a daily basis for various individualized activities, including volunteer opportunities. These three women have embraced my daughter as a young adult, have bonded as a group, and brought her into their family circles as well. She is fortunate to have a lifestyle that meets her needs and suits her personality. She is well cared for and seems happy and content.

For the most part, Lifesharing is more cost effective than CLA placements and consumers are afforded a more person-centered lifestyle. I am concerned that potential changes in the current arrangement would be detrimental to my daughter's health and safety. Reduction in reimbursement rates for ineligible provider costs would make programs like this unsustainable.

I have a few suggestions I believe should be taken into account regarding Lifesharing:

- Lifesharing is not a one size fits all proposal. It needs to be carefully individualized and requires time to arrange a suitable match between the consumer and Lifesharer.
- Prospective Lifesharers need to fully understand the philosophy of Lifesharing and that this is not just a job, but a lifestyle. It may be better to consider those who have no experience caring for individuals with intellectual disabilities. Using a questionnaire like those of online dating programs would be better in finding a proper match than listing the consumer's likes and interests.
- Initial and ongoing training and information regarding the consumer's specialized needs should be provided to Lifesharing staff on a regular basis. This could be informal, such as background information from the family, and formal training, such as attending an autism conference.
- Although the consumer's needs are central, do not disregard support for the Lifesharing caregiver. Substitute/respite care is essential to prevent burnout and ensure longtime commitment to the arrangement. Provider agencies should assume responsibility for making substitute care available.
- Finding sufficient established families/individuals willing to share their homes is difficult. They may not be open to having outsiders come into their home to provide support for consumers who require additional services. Promoting unconventional Lifesharing arrangements will allow access to more consumers. Providers should have the option of setting up a non-existing residence by renting a property and locating a Lifesharer to move in along with the person being supported. This flexibility allows the consumer to remain in the home if/when a caregiver leaves.

Respectfully submitted,

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