

To The Office of Developmental Programs:

I am writing this letter in support of the Lifesharing program that Shared Support provides for adults with special needs.

My sister, an adult with down syndrome, lived with our parents for 43 years. Our father and mother passed away within 16 months of each other; our mother's passing was quite sudden and no provision was in place for my sister's care. I am my sister's legal guardian and her only sibling so she moved in with my family while my husband and I began to research residential options.

Prior to our research, I thought that group homes were the only residential option so I began to look into group homes. I learned that not all group homes are the same; the care in some was quite good while the level of care in others was not. I also learned that the need for housing is greater than the number of group homes that are available and it could take many years before a space became available for my sister. The base service unit I was working with encouraged me to look into shared living. The traditional shared living, having my sister move in with another family, was something I did explore. After a great deal of research, I found the traditional shared living option to be greatly lacking. Unfortunately, the family we met and the families we had talked about meeting were not prepared to support an adult with special needs. In some cases, not all family members spoke English, many did not have a room for the special needs person, some had one bathroom for many people, others had small children requiring time and care, and the list can go on. The questions that arise are: How much time and energy will be spent working with the special needs adult to help them grow to reach their potential? Where does this special needs adult fall in the list of priorities for the members of the household? The result of my research led me to believe that my sister would not be a high priority in this type of living situation. The time and energy required to work on goals set up in her ISP just didn't seem to be available. These people with special needs are adults who require stability, routine and care. This living situation does not seem to provide these things.

By the time we met with a representative from Shared Support, I was frustrated with the lack of available options. After speaking with Shared Support and learning about their model of lifesharing, I decided that it was exactly what I had been searching for. My sister [REDACTED] currently lives in a home with a roommate who is a caregiver. [REDACTED] has the supervision and support she needs to be able to function as independently as possible. She and her roommate work together on many different life skills ranging from laundry to communication, cooking, nutrition, money skills and many other goals found in her ISP. They work together to keep their home neat and clean and have even planted a small garden in the back that they can both enjoy. The caregivers in Shared Support have planned several different activities on weekends for both the caregivers and their roommates to attend. All of this has given my sister a stable environment, a sense of pride in her home, and a feeling of belonging to a community.

[REDACTED] roommate makes all of her medical and dental appointments, provides transportation to and from these appointments, and provides documentation of what has taken place at these appointments. The system of checks and balances that is in place does not allow these routine visits or any necessary follow-up visits to be ignored. Each month, we have a Circle Meeting at my sister's home. The people at this meeting are all involved in my sister's care. These people

are her supports coordinator from the county, her caregiver and representative from Shared Support, myself and my sister. These meetings provide all parties with the opportunity to discuss problems and/or successes and work together to provide continuity in support and services.

The lifesharing opportunity that I found through Shared Support offers so much more than the traditional shared living option. My sister is happy and well cared for. She is in a living situation that is monitored by my husband and me along with her supports coordinator, her roommate, and her coordinator at Shared Support. We have all been working together and have had much success on all fronts. Please do not cut the funding for this wonderful program. Looking back, I am glad that there were no group homes available when we were looking. The growth my sister has shown in the past few years has been wonderful. I don't believe we would have seen this change with any other program. The attention to detail and the focus in each individual being supported results in a very high quality of care.

From the time my sister was a child until now, our society has changed a great deal in how adults with special needs are viewed in the community. I believe a move to the traditional shared living is truly several steps backward.

Sincerely,

