

Home is Where the Heart Is

For people with CdLS, a major transition is one into different housing, and navigating funding for the future. After dealing with a mixture of living models and confronting various financial barriers, Jan and James share their experience with planning this transition for their son, Gregg (pictured left).

Until our son, Gregg, turned 18, there were few changes in his life with us, except for different school situations. Once he turned 18, we filed for legal guardianship and were able to enroll him in our state (New Mexico) Medicaid waiver. He continued in school until age 22, while still living with us. Gregg is now 47 years old.

A new group home opened around the same time that he could no longer go to school. We wanted to be sure he could be independent of us, so he moved to the group home with the Medicaid waiver funding. At the time, we felt group homes were the best answer to assure his care and independence, while still having the ability to monitor him.

After six years, New Mexico stopped funding group homes and institutions, and placed the people in independent living situations within the community. Most people lived in rentals, with staff there on a full-time basis to care for them. Generally, the rentals were paid by the residents from their Social Security income and were at the low-cost end of the rental market. This meant they were not always the best houses or landlords, so changes of residence were common. We did not want this to happen, so we purchased a home in 1996, where Gregg and one other client live and pay rent still today.

It was initially a supported living model, staffed by people working eight-hour shifts. While we monitored the situation and caregiver staff carefully, there were always problems having different people providing care at different times. The pay for caregivers was not high, so the turnover in personnel was frequent as well.

We changed to a home-based care model, where the caregiver does not change and lives in Gregg's home. Many clients live in homes owned by



the caregiver. In our case, the caregiver resides in Gregg's house full time and receives a salary. We do not charge the caregiver rent or utilities, and she has 700 to 1,000 hours of respite time off.

Gregg gets out of the house daily through a "day-hab" program three days per week or doing

volunteer work. He volunteers at our church every Saturday for five hours as well. He also goes to the gym three days per week to work on flexibility, which has become a problem as he ages.

Planning Ahead

At one point, we funded a Supplemental Needs Trust to provide money for Gregg's brother to obtain the extra things Gregg might need that are not funded under the Medicaid waiver. We didn't spend any of the funds in the trust, but found the tax filings and reports were more effort than it was worth.

A Special Needs Trust wasn't too expensive in our case, though it could be for some families. The problem is that agencies that monitored Gregg's program really didn't understand what it was. Gregg had no access to this money, only we did. They would hear the word "trust" and think he had money stashed away. It took a lot of explaining so we stopped bothering to mention it.

We now have a Family Trust, of which Gregg's brother is the recipient and executor. Gregg has no access to this trust, but we've included a letter of intent, which is updated periodically concerning Gregg. In this letter, we describe Gregg, his medical information, his personal needs, his likes and dislikes, his living arrangements, and our concern for his welfare in the future. As Gregg ages, care giving and living arrangements change and therefore information has to be updated as well.

For now Gregg's situation is stable, with his care assured when we are gone. However, programs change, and certainly budgets and funding change. His caregivers change from time to time and finding the right person to live with him is not always easy. At one point we took over his care for a few months





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until we found the right person to live in the house and care for him. As parents and legal guardians, whether it is us or Gregg's brother, we must always monitor and guide his programs.

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CdLS Foundation | 302 West Main Street, #100 | Avon, CT 06001 | www.CdLSusa.org

