

Stories from the Homefront: Discussions on Living Arrangement Choices

By Natalie Scacco, M.S.W., former Family Service Coordinator

The decisions involved in choosing appropriate living arrangements for children or adults who have CdLS may be daunting. For some, feelings of guilt and betrayal may leave a parent or caregiver wondering if they can make a choice that will bring them comfort, knowing that their child is being cared for away from home. But, for others, the decision may come more naturally if they are not able to adequately care for their child's medical and/or behavioral needs. They may realize that their child requires professional help that is beyond their expertise.

As children with CdLS age, it may become impossible for their families to continue to care for them in their homes, while other people with CdLS may have the ability and desire to care for themselves independently. The choice to make a transition to a different living arrangement is very personal and must be made to best suit the entire family and give everyone a sense of comfort. Not only does the child go through this transition, but the entire family experiences it as well. There is no doubt that these decisions can be difficult and perplexing. It is advised that caregivers utilize state and local agencies which may provide services to support this transition and help them explore their choices.

The following individuals shared their stories of various living arrangements and the decision-making process that they experienced when making this choice.

Home away from Home

Kelly was born on April 11, 1985. Around the age of 12, Kelly began to require around-the-clock care due to various medical and behavioral issues. It was in early adolescence when Kelly's family began to realize that Kelly was going to need an alternative living arrangement. Kelly's family began their quest to find the perfect place for their daughter in 1997.

During their search to find the best living arrangement for Kelly, they utilized the help of a county caseworker. After reviewing several living arrangement options for Kelly, the search appeared to be unsuccessful. Kelly's parents began to wonder if these alternative living arrangements were the right choice for Kelly. They considered whether Kelly was meant to live at home. Finally, after searching for approximately eight months, they came across Flat Rock Homes. Kelly's father Dan reports, "When we found Flat Rock, things fell into place so quickly, and our feelings about it were so positive, we felt that we needed to make a leap of faith and place her there." Flat Rock Homes is a faith-based Intermediate Care Facility located in Northern Ohio.



In making the decision to move Kelly to Flat Rock Homes, Dan expressed that “The decision to place, or not to place, your [child with special needs] in the care of someone else is one of the most personal and difficult decisions a parent will ever make for their child. Whatever the decision is, there are sacrifices made by the parents, step-parents, siblings, step-siblings, other relatives and obviously, your child.”

Kelly is now 20 years old, still living in the care facility, and is continuing to flourish. Even though she still functions at a two-year-old level, she has learned to communicate through the use of pictures and hand signals, and she has also mastered toilet training. Dan shares, “I am convinced it is through the people at Flat Rock and the School of Opportunity that Kelly has come to where she is today. We would not have been able to take Kelly to this level by keeping her at home.”

Living at Home

Stephen, a 22-year-old man with CdLS, currently resides at home in New York with his mother Robin. When Stephen was born, Robin was told that he should live in an institution because he was diagnosed with CdLS. Robin, however, decided to keep Stephen at home with her. Little did Robin know that at the age of 18, her son would be an Assistant Boy Scout Leader. Robin shares, “Stephen obtained his GED early and passed it with flying colors.” He also enjoys softball, Karate, and dance class.

Robin and Stephen have had many conversations about the possibility of his living independently one day. Robin reports, “Stephen can be fine one minute and two seconds later he can be extremely ill.” She finds that the emergency room visits are now happening more and more. Right now, hopes of him living on his own still remain a dream.

Robin and Stephen enjoy life and what it has to offer. Both Robin and Stephen share two sayings that guide them each day, “Being *disabled* does not mean you are *unable*” and “Take one day at a time.”

Independent Living

Gary is a 24-year-old adult with CdLS who currently lives independently. Four years ago, Gary decided that it was time for him to move out on his own. He started by applying at the Housing Authority through which he received a housing voucher. Since then, he has lived in two apartments. He has considered having a roommate but reports that it is much more comfortable living alone. For anyone living independently and wishing to have a roommate, Gary suggests, “You should try it out first before you make a final decision.”

Gary was diagnosed at six months old. He still battles Gastroesophageal Reflux (GERD) and arthritis. He currently wears braces on his feet to help him walk and stand better.

When asked what he misses most about living at home, Gary replies, “I miss hanging





CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

out with my parents every day.” However, Gary is not without his own activities and interactions. He is currently very involved in Special Olympics. He participates in “Snow Shoes” in the Winter Games and he hopes to do track and field, bowling, and the softball throw in the Summer Games. Gary reports that his best game in bowling was a 165. He also volunteers to do lighting at puppetry theatres.

Gary is currently saving money to travel to the CdLS Conference in June of 2006. He states, “I’m very excited to go to the next conference. I hope that my family will also be able to come.” The next goal Gary wishes to accomplish is going back to school to study computer programming. He hopes to become a computer technician.

Although parents and caregivers of children with CdLS face many challenges, you truly are their best advocates. There is support available for parents and caregivers through the Foundation. If you wish to be in contact with someone who is facing similar challenges, or would like to share your story, please contact the Foundation at 1-800-753-2357 or info@CdLSusa.org.

REACHING OUT. PROVIDING HELP. GIVING HOPE.

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

