

Quality of Life Findings

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As children with CdLS age, family discussions may start to include questions about long-term care and whether a residential care center is the next best step. This can be a very difficult decision: What is best for our child? If and when should we make this transition? How will this decision, either way, impact our family? The effect of residential care decisions on a family with a child with CdLS had not been researched; this study aimed to explore this topic and help address some of these questions for caretakers of individuals with CdLS.

Overall, the study found that there is no difference in family well-being, defined as satisfaction with overall family life, between families whose child with CdLS lives at home and families whose child lives in a residential care center. Parents of a child with CdLS can be reassured that overall family well-being does not significantly differ based simply on the residence of the individual with CdLS. The study is consistent with the current literature that describes how family well-being is multifaceted and defined differently for each family.

On the other hand, there are similarities between families, and the study identified a few common themes introduced by many study participants. For example, aggressive behavior was a major concern; results suggest that families whose child with CdLS has more severe behavior problems have a lower overall satisfaction with life. Additionally, from these common themes emerged suggestions for caretakers of individuals with CdLS on ways to improve and protect family well-being:

- Establish a relationship with a behavioral psychologist early on in the child's development. For example, a behavioral psychologist can help caretakers of a child with CdLS determine the best timing for transitioning to a residential living situation; possibly before behavior problems for the child with CdLS become too severe.
- Be proactive in seeking intervention at the first sign behavioral problems are developing to help address the problem-behaviors before they escalate.
- Children with CdLS can have a difficult time adjusting to transitions, both daily and long-term. For transitions to living situations outside the home, families may want to consider slowly introducing their child to the new location. For example, one family found it helpful to start by driving by the new residence, then walking in to look around, followed by the individual with CdLS being able to show it to his/her friends; this method provides time for the child to internalize and fully adjust to the change.
- Family support, not just support by friends and neighbors, but by relatives, is important to prevent isolation and stress-fatigue. Engage other family members early on to walk with you through the joys and difficulties of raising a child with

CdLS. Whether it be emotional, physical, or financial, allow your family to help support you in this journey.

Family well-being is not determined by a single decision of living arrangements, but involves many aspects of family life. There is still much to learn about what specific factors have the strongest impact on family satisfaction of life; however, through the invaluable participation and thoughts of the participants, this study has been able to provide a few considerations for caretakers of individuals with CdLS as they navigate the ups and downs of life.

As a final thought, thank you to all the families who filled out the survey; this study would not have been possible without you. In addition, thank you to the CdLS Foundation for your support, resources and guidance of my research.

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