



A Hard Choice: Choosing Residential Care

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Introduction

“Moving him to a residential program was the hardest decision I ever had to make.”

“She belongs here at home with us.”

Both of these statements express the deep emotions of parents with children who have severe physical disabilities, requiring extensive physical care, supervision and support. Too often, families find themselves perceived as “bad” parents who are “abandoning” their child when they choose a residential program or, conversely, as “saints or martyrs” when they care for their child at home. Neither label is a beneficial or realistic portrayal of the challenges and conflicts faced by these parents.

Years ago, parents had few choices when a child was disabled due to a birth-related condition and/or chronic or progressive illness. At that time, large state institutions often were the only option for medical and nursing care. Before 1975 landmark legislation establishing laws for special education and guaranteeing a child with special needs the right to an education in the local public school, state schools were the main facilities that educated children with severe disabilities. The main drawback to these state schools was that receiving an education meant removing the child from the family.

A Shift from Institutions to Community Care

With the growth of the disability rights movement and class action lawsuits in many states, we have shifted from an institutional- to a community-based service delivery system. More children with severe disabilities now are living at home. Additionally, a higher number of individuals with TBI now are surviving their injuries because of advances in emergency medicine and trauma care. Many of these individuals require extensive physical care and even ventilator support, with others being unable to communicate by speech or having impaired hearing or sight. Particularly with TBI, some individuals require intensive supervision for inappropriate and/or challenging behaviors.

The families of these individuals face enormous challenges and frustrations to find adequate services. As one parent commented, *“Now that medicine helped my child survive, where are the services and funding to give her the quality of life that she deserves?”*



The day-to-day care of a child with a severe disability is physically draining, emotionally exhausting and expensive. Home care is not always easy; it requires juggling nurses and therapists and rearranging schedules. At the same time, parents are negotiating with the school for special education services, coordinating appointments for ongoing medical care, arranging for special equipment and becoming skilled advocates as they complete endless insurance forms and negotiate the mazes of bureaucracy. These parents worry that their other children are “short-changed” or neglected when there just is not enough time, attention and energy to go around for everyone.

"I always felt pulled between caring for our son and my other children...Looking back, they had to grow up too quickly because I couldn't always be there physically or emotionally. Even though they love their brother, I know they resented how much he controlled our life as a family." A parent of a child with TBI.

It does not necessarily become any easier as children and parents age. The usual pattern of parents being relieved of parental and financial responsibilities when adolescents become adults and leave home is reversed. In fact, it is often at this time when the physical stress of caring for an older and bigger child can force parents to consider alternative strategies. Not only do parents age, but older siblings who may have helped before now are leaving home as well. Thinking about residential care after years of caring for a child at home can be agonizing for many parents. The decision is made even more difficult by their belief that, “*No one else possibly can understand except another parent who has been through it.*”

Common Themes Among Parents

Several years ago, I had the opportunity to spend six months interviewing parents of children with severe disabilities and found several common themes. Of foremost concern to these parents was the need for additional and improved home-care services, trained staff and funding. The fact was that these parents *wanted* to raise their children at home with family. As the physical care of an older child became more difficult and was combined with parents' aging, retirement or the death or illness of a spouse, some of them eventually considered residential care. Looking ahead to the future often was painful and overwhelming, but inevitable for these families. The big question of “*Who will look out and care for our child when we no longer are able to?*” sometimes was the impetus to explore options.

"My worst fear is that my daughter will end up in a terrible place after I die. I don't want someone else making the decision about where and how she will live. I feel like this is something I have to do now to protect her future. And if I do it now, I can be there to help her adjust to living in a new place."
A parent of a child with TBI.



The shrinking window of eligibility under special education as children approach and enter into adulthood forces many parents into the realization that the adult service system is fragmented and does not carry the same entitlement protection as the law of education. Some parents considered residential care during adolescence with the hope that such a program might be better able to transition their child into adult services.

Choices for Care

What does residential care really mean? Too often, the words still conjure up images of state institutions resembling warehouses. The truth is, much has changed in recent years. Residential care options now include pediatric nursing homes, group homes, foster care and residential schools. Even so, it is not an easy choice for parents and families to make. In fact, it is very personal and many families struggle with the decision over many years, reiterating that "*Friends, relatives and even many professionals simply do not understand how difficult it is.*"

Families who have made the decision for residential care offer these suggestions for other families and the professionals who guide them. Gathering as much information as possible about the program is vital. Such information includes:

- The location and condition of the facility
- Staffing qualifications
- Social environment
- Involvement of parents
- Educational programs

As you explore the choices, ask yourself these questions:

- Why am I thinking about residential care? Why now?
- How severe are the physical, emotional and financial stresses of home care?
- What effects are they having on me, my child, spouse and other children or family members?
- How will these stresses change in the future?
- Will my child have more social, educational and recreational opportunities in a residential program?
- What does my child want?
- What do I want?
- How would residential care affect my child's brothers and sisters?

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