NASET's Educating Children with Severe Disabilities Series

Residential Placement Options for Individuals with Severe Disabilities

Part I

This section of the series will look at the various residential care facilities available when a student ages out. It will also provide information on who should plan, how to plan, when to plan, and who to contact to ensure placement at an appropriate time.

Introduction

There may be times after a student with disabilities leaves secondary education when parents will have to explore housing alternatives other than the family home. A variety of motivations for this decision may include the following:

The physical, medical, economic, and psychological resources of some families to care for the needs of a family member with disabilities may diminish over time.

The need to foster independence and autonomy may dictate the desirability of separate housing.

Parents who are confronted with the need for residential options may face a confusing and sometimes overwhelming fund of information. A large part of this confusion is attributable to the variety of terms used to describe these available programs, i.e, group homes or community residences.

Three major factors will influence the types of service available to persons with disabilities.

First, some residential services are available only to those who are eligible for medical assistance and county mental retardation services.

Second, service options are based on the level of care needed. The family subsidy program aids families in keeping children with disabilities at home rather than placing them in a residential facility. For those who need some supervision and training to live independently but do not need care 24 hours a day, semi-independent Living Services (SILLS) may be an option.

Community-based waivered services or placement in an intermediate care facility (group home) are options for persons who need 24-hour supervision.

The third factor influencing the type of residential services available is the funding level for the programs. Unfortunately, the need for residential facilities far outweighs the availability of these resources. Some of this is due to a lack of funding, but there has also been tremendous resistance on the part of local communities to have such residences in their midst (not in my backyard). Historically, costly and lengthy legal fights have addressed this issue.

Therefore, those working with the student with disabilities must begin addressing these issues years before this need arises. Some parents report waiting five to six, or more, years for a space to open up at a facility. One of the pathways, in addition to putting their names on a list, is to get parents and their children involved in the activities of a local service provider. This will enable the family to develop an ongoing relationship with that service provider, which will be helpful when space in a facility becomes available. When parents begin their search for residential options, their goal should be to identify as many as possible. Knowing where to look will enable them to find contacts who can answer their questions.

In this section we will try to reduce the confusion caused by the different labels. In trying to unravel the many options, it is important to be as open as possible, as two group homes may be vastly different because they serve people with different levels of disability.

Raising a child with disability or chronic illness poses other challenges. As families meet these challenges, time off can become a necessity for the caretakers. In recent years, the growth of respite care services—short-term specialized childcare—has begun to provide families with some temporary relief.

The birth of a child with a disability or chronic illness, or the discovery that a child has a disability, has profound effects on a family. When parents learn that their child has a disability or special health care need, they begin a process of continuous, lifelong adjustment. Adjustment is characterized by periods of stress, and during this time, family members' individual feelings of loss can be overwhelming, shutting out almost all other feelings. Coping with uncertainty about the child's development may interfere with the parents' ability to provide support to each other and to other family members. Even when the diagnosis is clear, there are still many uncertainties—health, programmatic, and financial.

Social and community support can reduce the stress experienced by families. The support of relatives, friends, service providers, and the community can help families ease the adjustment period.

After reading this section, you should understand the following:

- Resources to Consider
- Centers for Independent Living (CIL)
- Residential Services
- Adult Foster Care
- Boarding Homes
- Family Subsidy Program
- Free-Standing Weekend Respite
- Group Homes
- Semi-Independent Living Arrangements (SIL)
- Home Care Attendants or Personal Assistant Services
- Supervised Living Arrangements
- Intermediate Care Facility (ICF/MR)
- Supportive Living Units (SLU)
- Waivered Services
- Evaluating Residential Programs
- Making a Residence Accessible
- Housing Subsidies
- Section 8 Housing
- Section 202 Housing
- Overview of Respite Care
- Benefits of Respite Care
- Respite Care Suggestions for Parents

- How to Tell if a Family Could Benefit from Respite Care
- Federal and State Agencies for Help with Respite Care
- State and Local Disability or Support Groups
- What Parents Need to Know when Seeking Respite Care Services in their Community

Resources to Consider in Beginning a Search

Every state has numerous public agencies that are responsible for meeting the various needs of people with disabilities and their families. The names of these agencies will vary from state to state, and those involved may have to investigate or cross-reference using available agencies that assist with residential resources. Parents should start their search with the following sources of information:

- Local school district's director of special education services
  Internet
- Public and university libraries
- Special education departments at universities
- Other families or individuals who may have similar experiences
- Child advocacy services
- Centers for Independent Living (CIL)

Centers for Independent Living, often referred to as "CILs" are non-residential places of action and coalition, where persons with disabilities learn empowerment and develop the skills necessary to make lifestyle choices. Centers provide services and advocacy to promote the leadership, independence, and productivity of people with disabilities. Centers work with both individuals as well as with the local communities to remove barriers to independence and ensuring equality of persons with disabilities (Department of Rehabilitative Services, 2003),

According to the Department of Rehabilitative Services (2003), CIL's are non-profit organizations, which are funded by state, federal, local and private dollars. Part C of Title VII of the Federal Rehabilitation Act provides general operations money for CILs in Virginia in the amount of over $1.3 million dollars. Additional funds under Title VII, Part B of the Act are granted to Centers under the State Plan for Independent Living. The Plan, which is jointly developed and signed by the Statewide Independent Living Council, the Department of Rehabilitative Services and Department of the Blind and Vision Impaired, provides Part B funds to Centers for systems change activities in the amount of over $450,000. General fund dollars for Center operations and Youth Transition Services currently exceed $4.5 million dollars. A portion of the State General Fund dollars were used to expand Centers for Independent Living during the last five years.

Six new consumer based Centers were established during this time period. Centers also solicit local and private funding to meet service needs which have been identified at the local level. An important source for information and assistance is centers for independent living. These centers offer programs of services for individuals with significant disabilities, or groups of individuals with significant disabilities, that promote independence, productivity, and quality of life. The centers are run by people with disabilities who themselves have been successful in establishing independent lives. These people have both the training and personal experience to know exactly what is needed to live independently, and they have a deep commitment to assisting other people with disabilities in becoming more independent.

These centers are community, consumer controlled, noninstitutional organizations. They generally offer services free of charge. There are approximately 250 CILs nationally, with at least one located in every state.

Funded by the Rehabilitation Services Administration (RSA), CILs offer a varied combination of independent living services such as:

- referral services
- independent living skills training
- peer counseling
- individual advocacy
- counseling services

- services related to securing housing or shelter
- rehabilitation technology
- mobility training
- life skills training
- interpreter and reader services
- personnel assistance services
- consumer information programs
- transportation assistance
- physical rehabilitation
- therapeutic treatment
- prostheses
- individual and group recreational services
- self-employment skills
- advocacy skills
- career options
- services to children
- preventive services
- community awareness programs

Residential Models/Residential Services

A residential program offers housing other than the individual's natural home, and it is usually designed for persons with similar needs in terms of age, independence or abilities. A residential program usually provides:

- a homelike environment with supervision and guidance as needed
- living experiences appropriate to the functioning level and learning needs of the individual
- a location within the mainstream of community life
- access to necessary supportive, habilitative programs.