NASET's Educating Children with Severe Disabilities Series

Residential Placement Options

Looks at the various residential care facilities available when your student ages out. It will also provide information on 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)
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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.

The goal of residential programs is to provide access to the highest possible quality of services that a person with certain disabilities needs, while at the same time permitting and encouraging the person to be as independent as possible.

Adult Foster Care

Adult foster care homes are provided by families who, for altruistic, religious, or monetary reasons provide a home care environment for the adult with disabilities. In this residential option, the foster care family receives government reimbursement for this service. While this living arrangement is meant to be a permanent situation, no guarantees exist.

According to Adult Foster Care Services (2003), Adult Foster Care is a licensed family setting for adults who are unable to live alone due to physical, emotional, or developmental impairments. These homes often provide 24 hour care for a small number of impaired residents. Residents receive meals, support, supervision and some assistance with personal cares and living skills, as needed.

There is a minimum room and board payment made to providers per month which is set by the State. Adult Foster Care is not a therapeutic residential facility where a resident receives awake night or nursing care assistance.

Boarding Homes

A boarding home is a residential facility that provides minimal structure and training for the adult with disabilities. These homes may provide sleeping and meal arrangements, and deal with a varied clientele with a variety of disabilities.

Family Subsidy Program

This program provides financial assistance to families to enable them to care for their children with disabilities up to age 22 at home. The Department of Human Services pays eligible families a monthly allowance for certain home care costs, such as medical equipment, respite care, transportation, and special diets. Eligibility for the program is based on the needs of the family and their ability to provide the necessary level of care in the home. The program is not based on financial need.

Free-Standing Weekend Respite

This is a community-based program for families in need of respite on a planned or emergency basis. The overall objective is to afford families a reprieve from the day-to-day care giving responsibilities. Respite provides room and board, 24-hour supervision, and appropriate recreational activities to individuals with developmental disabilities.

Group Homes

Ensuring nondiscrimination in housing means ensuring an essential element of independence and integration into the community for disabled individuals. The right to vote, to work, and to travel freely are all important aspects of an individual's life, but none is more elementary than having the freedom to choose where and how one lives. Housing is shelter, but it is much more. It's the opportunity to be part of a community. It's a chance to enjoy the social and recreational aspects of being a neighbor. It can be the independence to flourish in a lifestyle of one's own choosing. In short, housing is a basic right that we cannot allow to be denied on the basis of disability.

Senator Alan Cranston

Senate Report

CRANSTON-GONZALES NATIONAL AFFORDABLE HOUSING ACT, 1990

Until the 1950s and 1960s, our society relied upon large institutions like state hospitals, training centers, nursing homes and detention facilities to house and care for people with disabilities and addiction disorders, at-risk and delinquent children, and adults who had been found not guilty by reason of insanity. Over the last several decades, however, many of these large institutions have been closed, and state agencies have come to see group homes and other congregate living arrangements as one of the ways to provide a transition back into the community for these individuals. The passage of the Fair Housing Amendments Act of 1988 accelerated this trend for people with disabilities and children (Whitman and Parnas, 1999).

The general characteristics of group homes include:

- a home with fewer than sixteen people
- a family like structure
- similarity to surrounding homes in the community
- performance of tasks by the residents of the home to the extent of their abilities, that is, cooking, mowing the lawn, laundry, and so on.
- the expectation that the disabled individual will graduate to a more independent situation that will meet his or her needs and preferences
- The term group home has taken on many meanings. The concept has certain general characteristics, but these may vary from facility to facility. Specifically, group homes are divided into two arrangements: semi-independent living arrangements and supervised living arrangements. These options differ in the following ways:
- staffing arrangements
- level of disability
- the need for supervision

Some people with disabilities, however, live in group homes,1 either because they require a high level of support or because there is a lack of resources, such as funding for individual rental assistance or for personal care attendants, that would allow them to live independently. Group homes allow people with disabilities to be reintegrated into single- and multi-family residential neighborhoods where their needs

can be met and where they can fit naturally into the community. Well-run homes provide access to a safe, healthy living environment and the same quality of housing and community opportunities available to other families in the neighborhood (Whitman and Parnas, 1999).

Semi-Independent Living Arrangements (SIL)

These services provide intensive support and training to persons with disabilities 18 years of age and over to enable them to learn to live independently in the community or to maintain semi-independence. Persons eligible for SILs do not require daily support services, but are unable to live independently without some training or occasional support. SILs recipients live in their own homes or apartments, in rooming houses, or in foster homes. They often share living arrangements with other persons who have disabilities. The key characteristic is that the staff does not live in the facility. In some cases, they may be on call in cases of emergency.

Home Care Attendants or Personal Assistant Services

These auxiliary services are available to assist consumers in housekeeping and personal care needs; they enable the consumer to live more independently. They may be paid for by the individual or by public funds through Medicaid.

Supervised Living Arrangements

These services provide intensive support and training for persons with severe disabilities. Unlike Semi-Independent Living Arrangements, these facilities have full-time residential staff. This type of arrangement is usually provided for individuals who are not able to care for themselves and need full-time supervision.

Intermediate Care Facility (ICF/MR)

ICF/MR facilities are specially licensed residential settings for persons who require 24-hour care and supervision and are supported by Medicaid funds. An ICF/MR is a nursing home, recognized under the Medicaid program, which provides health-related care and services to individuals who do not require acute or skilled nursing care, but who, because of their mental or physical condition, require care and services above the level of room and board available only through facility placement (Insurance Glossary, 2003).

Specific requirements for ICF's vary by state. Institutions for care of the mentally retarded or people with related conditions (ICF/MR) are also included. The distinction between "health-related care and services" and "room and board" is important since ICF's are subject to different regulations and coverage requirements than institutions which do not provide health-related care and services. Group homes may range in size from small six-person homes to larger institutions. Most of them are small residences, serving under sixteen people. The ICF provides a full array of direct-care and clinical services within the program model. Clinical services include psychology, social work, speech therapy, nursing, nutrition, pharmacology, and medical services. ICF admission requires that participants be Medicaid-eligible, have an IQ below 59, and manifest deficits in basic skills such as grooming and hygiene.

Supportive Living Units (SLU)

SLUs are state-funded small residential sites, typically housing one to three high-functioning individuals. These individuals may or may not be Medicaid-eligible, are typically competitively employed, and require 21 hours or less per week individual protection and oversight by a direct-care person.

Waivered Services

The term waivered services applies to persons with mental retardation who are currently in ICF/MRs, or who are at risk of being placed in ICF/MRs unless the waivered services can be provided to them in a home or community setting. The possible living arrangements are intended to be much less restrictive and isolated from the mainstream world than the traditional ICF/MR settings. The home or community-based residence could include a person's own parental home, a foster home, an apartment, or a small group home. These services are available to individuals who would otherwise qualify for Medicaid only if they were in an out-of-home setting.

Evaluating Residential Programs

There is no substitute for firsthand observation. When you and the parents have organized your list of potential residential programs, the parents (and you, if possible) should make appointments to visit each one. Do not hesitate to ask the following questions:

- What are the entry requirements?
- How many people live at the particular residence?
- Is there a waiting list?
- How long is the waiting list?
- What is the staffing pattern?
- What other services are provided at this residence?
- What are the expectations for activities outside the residence?
- Can the resident go to a day program?
- Can the resident have a part-time or weekend job?
- What will the costs be for the specific services provided by this residence?
- How is the personal money of the resident monitored?
- Are family visits encouraged?
- What kinds of household chores will the resident be responsible for?
- Are leisure activities part of the resident's program?

Making a Residence Accessible

Whether one is building an accessible home or modifying an existing residence, the cost can be prohibitive. A home equity or other bank loan may be one financing alternative. Depending upon one's circumstances and the nature of the disability, assistance may also be obtained through medical insurance, medical and social services, income support, or vocational services from any of a number of different resources. Consumer-oriented disability organizations and rehabilitation facilities may also provide information resources on funding assistance available in the local community.

Housing Subsidies

Section 8 Housing

Section 8 refers to rent subsidy payments by the government to allow an individual to secure decent, safe, and sanitary housing in private accommodations. The income limitations for eligibility are determined by information from the local housing authorities. This program comes under the U.S. Department of Housing and Urban Development (HUD). The specific steps required in applying for rental assistance are:

1. An application must be completed and filed with the local housing authority.

2. Eligibility is then determined, based on the intended type of occupancy (elderly or disabled) and income.

3. It is up to the parent or the young person to find suitable housing on the open market.

4. This housing must be inspected by the local housing authority and meet demanding quality standards.

5. Once the housing has passed inspection, it must be determined if the landlord is interested in participating in Section 8 housing.

6. If it is determined that rent and utilities do not exceed the fair market rent, and the landlord is in agreement, the housing may be leased.

Section 202 Housing

Section 202 refers to a program that provides direct loans for the construction of housing for three specific populations:

- individuals with developmental disabilities
- those with chronic mental illness
- those with physical disabilities

These funds are intended for the construction of group facilities for those with disabilities. Parents can get further information on this subsidy from their local housing authority.
Overview of Respite Care

Over the years, there has been a growing awareness that adjustment to the special needs of a child influences all family members. This awareness has generated interest and has led to the development of support services for families to assist them throughout the lifelong adjustment process. Within the diversity of family support services, respite care consistently has been identified by families as a priority need (Cohen & Warren, 1985).

The following was written by a parent of a child with a chronic illness.
“Of the first six months of my child’s life, three and a half months were spent in the hospital. We lived in a world of intensive care, with cardiac monitors, oxygen tents, tubes in every orifice and IV’s in every extremity of my daughter’s body.

“The weeks my daughter was home were completely taken up with her care: two hours to get a meal in her, so for six hours a day I was feeding her; up many nights holding her so she could sleep on my shoulder so that she could breathe if she had a respiratory infection. Respiratory infections were frequent because of her disabilities, and many nights my husband and I would have to get our older child up, take him to our neighbor’s house and take my daughter to the hospital where she could have oxygen if her breathing got too labored. After getting her admitted, we would go back home, and get up again the next morning to get our son off to school and to return to the hospital. This after being awakened in the middle of the night with a phone call from the hospital saying that they were transferring her to intensive care so she could be watched more closely.

"Did we need respite? You bet we did! This was important particularly with a disabled and medically fragile child who needed expert care.

"During that time, either my husband or I always had to be with our daughter while the other ran to the grocery, the bank, the pediatrician for the individual's health care needs, or just to sleep for a few hours. Our friends disappeared from our lives, and our relatives lived far away. The world of normal family life in which family members live, work, and play together and take joy in each other's accomplishments, activities, and outings vanished.

"Our daughter had major surgery scheduled at six months and she would be hospitalized for at least 10 days. I approached my daughter's doctors with our family's need for a rest. Would they and the nurse's care for her for seven days while our family went away? We wouldn't leave for three days after surgery to make sure she was on the road to recovery. We felt safe leaving her in their hands, and we could truly relax.

"The week that our family stayed at the beach was the most wonderful gift during those six months. It was truly a blessing, not only for us but for our daughter, for it gave us the opportunity to stand outside the situation and view it from a distance. It enabled us to review what had gone on before, to put things into perspective, to think and plan. We were also physically restored, and we were able to go on with much more strength for the next 12 months caring for our daughter. Respite care was unavailable 11 years ago when we needed to cope with the challenges my daughter presented to our family. I had to make it happen."

All parents need a break now and then, to have time for themselves away from the responsibilities of caring for their children. This is true for families of children with disabilities or chronic health care needs too, only for these families it may be more difficult to arrange.

While respite may be a new word for some people, it is not a new phenomenon; it emerged in the late 1960's with the deinstitutionalization movement. One of the most important principles of this movement was the belief that the best place to care for a child with special needs is in the child's home and community. Families with a child who has a disability or chronic illness know the commitment and intensity of care necessary for their children. The level of dedication and care becomes part of daily life, part of the family routine, but this same commitment can make stress routine too. Parents can become accustomed to having no time for themselves. According to Salisbury and Intagliata (1986), "the need of families for support in general and for respite care in particular has emerged as one of the most important issues to be addressed in the 1980's by policymakers, service providers, and researchers in the field of developmental disabilities," (p. xiii).

Respite care is an essential part of the overall support that families may need to keep their child with a disability or chronic illness at home. United Cerebral Palsy Associations, Inc. (UCPA) defines respite care as "a system of temporary supports for families of developmentally disabled individuals which provides the family with relief. "Temporary" may mean anything from an hour to three months. It may also mean "periodically or on a regular basis." It can be provided in the client's home or in a variety of out-of-home settings," (Warren and Dickman, 1981, p. 3). Respite services are intended to provide assistance to the family, and to prevent "burnout" and family disintegration. Since not all families have the same needs, respite care should always be geared to individual family needs by identifying the type of respite needed and matching the need to the services currently available, or using this information to develop services where none exist. Once identified, it is also important for families to have ready access to that type of respite, in an affordable form.

Regardless of the type of respite program utilized, the emphasis should be on orienting services toward the entire family. The birth of a child with a disability or the discovery that a child has a disability or chronic illness is obviously a difficult time for the entire family, including siblings, grandparents and other relatives. Families need to adjust to major changes in their daily lifestyles and in their dreams. Extended family and friends will also need to adjust to these changes. These changes will take planning and time. We are accustomed to typical family life; a child with a significant disability or chronic illness is not typical. Therefore, plans for an untypical lifestyle call for creativity and flexibility. It is also important to bear in mind that the child will change as he or she grows and develops into an individual with his or her own personality and ideas.

Many families will find these changes difficult to handle. Many communities may be limited in their resources or in their interest in meeting the special needs such families present. These combined factors

can leave the immediate family with the full-time care of their child and can lead to feelings of isolation from other family members, friends, and community activities, religious and social functions. Even performing the basic necessities of daily life, such as grocery shopping or carpooling, can become difficult to impossible.

It is obvious to anyone who has lived this life that respite care becomes a vital service—a necessity, not a luxury. Parents, of course, are clearly the experts about the need and importance of respite care. Just as families differ, so will the necessity for respite care. Basically, however, all families require some relaxation, diversion, and the security of knowing that their children are safe and happy. The most difficult problem for the family with a child who has a disability is finding the quality of care and expertise the child needs.

As one parent put it, "Families need an uncomplicated, easily accessible means of arranging respite care to suit their wants and needs. When a potential pleasure becomes more trouble than it's worth, then I give it up. I always measure the event against the complications involved in making it happen. Time off is no relaxation if I spend the entire time worrying if the kids are OK. I can't enjoy myself if I think they are unhappy, and certainly I can't relax if I'm not confident about the reliability of the person watching my children. I think many professionals are under the misconception that time away from the cares of rearing a child with a disability is what I need to maintain my sanity. I need much more than time—I need the security that comes from knowing that the person I've left my son with is as capable as I am of providing for his needs. You simply can't relax and enjoy yourself and worry at the same time. It's peace of mind I need—not just time."

Benefits of Respite Care

In addition to providing direct relief, respite has added benefits for families, including:

- **Relaxation:** Respite gives families peace of mind, helps them relax, and renews their humor and their energy
- **Enjoyment:** Respite allows families to enjoy favorite pastimes and pursue new activities
- **Stability:** Respite improves the family's ability to cope with daily responsibilities and maintain stability during crisis
- **Preservation:** Respite helps preserve the family unit and lessens the pressures that might lead to institutionalization, divorce, neglect and child abuse
- **Involvement:** Respite allows families to become involved in community activities and to feel less isolated
- **Time Off:** Respite allows families to take that needed vacation, spend time together and time alone
- **Enrichment:** Respite makes it possible for family members to establish individual identities and enrich their own growth and development.

Often, we hear the question, "Who takes care of the caretakers?" Caretakers can include not only parents, but also brothers and sisters, grandparents, and extended family and friends. Respite gives caretakers the opportunity to have a rest, to take care of personal matters, to enjoy some leisure time, and occasionally to be relieved of the constant need to care for a child with a disability or chronic illness.

The child or youth with disabilities also benefits from respite care, gaining the opportunity to build new relationships and to move toward independence. In many families, it is common for children to attend day care or after-school care, interact with peers and adults outside the family, and stay with a child care provider while their parents enjoy an evening out. Respite provides these same opportunities for children with special needs.

For older individuals with a disability, respite can assist in building skills needed for independent living. Since the most appropriate living situation for many adults with a disability is in a group home or other supported environment, out-of-home respite care can enable families to test this option, explore community resources and prepare themselves and their family member with a disability for this change.

States and communities are recognizing that respite care also benefits them. On average, the costs for respite services are 65 to 70 percent less than the costs of maintaining people in institutions (Salisbury

and Intagliata, 1986). The cost-effectiveness of respite services allows scarce tax dollars to be used for additional community-based services. During the previous decade, over 30 states passed legislation for in-home family support services, including respite care, using either direct services or voucher systems (Agosta and Bradley, 1985).

With the 1986 passage of the Children's Justice Act (Public Law 99-401) and its amendment, the Children's with Disabilities Temporary Care Reauthorization Act (P.L. 101-127), respite care has gained support at the Federal level. This legislation authorized funding to states to develop and implement affordable respite care programs and crisis nurseries. Unfortunately, while this Federal funding provides relief for some families, access and affordability continue to be issues for many families in need. As Brill (1994) observes: Families soon discovered that the law fell short of providing national guidelines for respite care. Every state dispensed different versions of the services, and individual agencies devised their own criteria for length of time and funding allotments. (p. 49)

Thus, in spite of the availability of government funding in some areas, many respite care programs must charge for their services. This practice reduces expenses for providers and makes it possible to serve more families. However, charging for respite services can limit their availability to those families who can afford the fees (Cohen and Warren, 1985).
For children and youth with disabilities, their families and communities, and Federal, state and local governments, the benefits of respite care are enormous. However, the need for maintaining and expanding the levels of available respite services is tremendous.

Respite Care Suggestions for Parents

Parents deciding to leave their child who has special needs in the care of someone else, either in or outside their home, may experience a variety of hesitations. They can have feelings of guilt, anxiety, even a sense of loss of control.

Jeanne Borfitz-Mescon (1988) suggests that a number of fears and concerns are common to parents in this situation: that the child may not get as much attention, or that the care may not be as good; that something may be missed; that the caretaker or staff may not be able to comfort their child, and that he or she might be left crying. The anxiety resulting from these very normal and real concerns or fears can in fact cause parents to believe that respite is just not worth it.

It is important that a parent becomes comfortable with his/her decision and develop the trust critical to maintaining the peace of mind necessary for relaxation and enjoyment. One way to accomplish this goal is to help parents begin to think about respite care and whether their family, and their child with special needs would benefit from it. The following suggestions may help.

How to Tell if a Family Could Benefit from Respite Care

If parents are considering respite care they need to ask themselves the following questions:

1. Is finding temporary care for the child a problem?
2. Is it important that the parents enjoy an evening alone together, or with friends, without the children?
3. If they had appropriate care for their child with special needs, would they use the time for a special activity with their other children?
4. Do they think that they would be a better parent if they had a break now and then?
5. Are they concerned that in the event of a family emergency there is no one with whom they would feel secure about leaving their child?
6. Would they feel comfortable going to a trained and reputable respite provider to arrange for care for their child?

If you they answered "Yes" to several of these questions, they and their family could benefit from respite care and should investigate the resources in their community.

Many agencies and organizations have information on respite care services. (For a referral, contact the National Respite Locator Service, operated by the ARC National Resource Center: 1-800-773-5433). In

general, assist parents in seeking out groups or professionals who work with children their child's age. For example, if their child is in preschool, have them contact the school and discuss the need for respite care with the staff. If there is a parent group associated with their school, or if there is a local parent group concerned with children who have needs similar to their child's, have the parent ask them. If the child is an adolescent, suggest to the parents that they talk to the staff at his or her school or, again, identify parent groups in the area with needs similar to theirs.

The following list presents some of the types of groups parents may want to contact in seeking services. Many will be listed in the telephone book. If they experience difficulty locating the organization in their community, often a state contact can be made. Examples include:

State and Local Government Agencies
State Department of Mental Retardation
State Developmental Disabilities Council
State Program for Children with Special Health Care Needs (formerly Crippled Children's Services)
Departments of Health and Human Services, or Social Services
Department of Mental Health
State and local Departments of Education
State Protection and Advocacy Agency

Also, state and local disability support groups and agencies may be helpful in assisting parents with respite care. Examples of these include:
The Arc
United Cerebral Palsy Associations, Inc.
Autism Society of America
Brain Injury Association
Mental Health Association and CASSP
Spina Bifida Association
National Easter Seal Society
Parent Training and Information Center
Parent-to-Parent
University Affiliated Program(s)
Community Services Board
YMCA/YWCA
Churches

What Parents Need to Know when Seeking Respite Care Services in their Community

Parents seeking respite care services in their community should ask themselves the following questions. The information will be helpful when contacting agencies in their local community about respite care (Bradley, 1988).

1. What kind of services do they need? (Long-term, short-term, or both? Why?)
2. Do they prefer services in their home, a cooperative, or in an outside setting? (This will depend on the type of service they need.)
3. Can they donate time to a cooperative, or is it better for them to obtain help from a respite agency?
4. Does this agency provide the types of service they need?
5. Is there a cost for the service?
6. Is the parent able to afford this service?
7. If they can't afford the service, are there funds available to assist them?
8. Who is responsible for the direct payment to the provider?
9. How are respite providers selected?
10. Are the providers trained?
11. How many hours of training have they had?
12. Do these providers have training in First Aid and CPR?
13. What other areas are covered in their training?
14. For out-of-home care, does anyone monitor the facility for safety and health measures?

15. Will they be able to have a prior meeting with the care provider?
16. Will they have an opportunity to provide written care instructions to the provider?
17. Will they have an opportunity to assist in training the provider with reference to their son's/daughter's needs?
18. What is the policy that covers emergency situations?
19. Will they have to carry additional insurance to cover the provider while he/she is in the home?
20. Is there a policy that deals with mismatches between providers and the family?
21. Can they request a specific care provider and have the same person with the child each time?
22. Will the respite care provider care for the other children too?

Conclusion

Just as in the school setting, where the policy fosters the least restrictive educational environment, it follows that the same philosophy should be encouraged in seeking out adult living arrangements. This least restrictive independent arrangement may require utilization of many agencies, support personnel, family, and so on. Everything should be done to attain an individual's personal least restrictive living arrangement.

Further, individuals with disabilities should be aware that funding may be available to assist in making residence adaptive to personal needs--ramps, modifications in doorways or bathrooms. As a special educator, you must teach parents to explore this option with their local center for independent living.

Caring for a child with disabilities or severe health problems can be a full-time job. It is easy for parents to become overwhelmed with the care needs of a child with a disability or chronic illness. Often, families who would not hesitate to call for relief from the constant care of their typical children hesitate to call for relief from the care of their child with a disability or special health care need. That is why respite, as the word implies, is truly an interval of rest. Respite can be a parent's answer to renewed energies and a new perspective. If respite care is not available in a parent's community, help them make it happen. The best advocate for the family and the child is the parent. However, as a special educator you can also play a role in facilitating such services by having an active knowledge of what is available. One of the most important goals to strive for is family unity and well-being. It is important to remember that a parent, too, can have the gift of time that respite care represents.