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ABSTRACT

The document is intended to help states and local communities locate resources to support children and adults with extensive health needs in the community. An overview article, titled "Supporting People with Medical and Physical Needs in the Community," by Bonnie Shoultz and Julie Ann Racino, identifies principles for community integration, highlights best practices in this area, and examines selected issues based on literature and experience. A second article, by Pam Walker, is titled "Family Supports for Children with Severe Disabilities and Chronic Illnesses in Maryland." It reports on good practices at three Maryland service sites and discusses key family support issues and practices. The third article, "Supporting Adults with Severe Disabilities in the Community: Selected Issues in Residential Services" (Racino and Walker), examines key issues raised by an individualized approach to supporting adults with extensive health needs. Such issues include size of setting, heterogeneity versus choice in roommates, and rigidity versus flexibility of supports. Also included are an annotated listing of 37 print resources; descriptions of services provided by six major organizations dealing with home and community-based services; and descriptions of 10 agencies, programs, and regional service systems for this population. (DB)

RESOURCES ON SUPPORTING PEOPLE WITH EXTENSIVE HEALTH NEEDS IN THE COMMUNITY

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SUPPORTING PEOPLE WITH EXTENSIVE HEALTH NEEDS IN THE COMMUNITY

PREFACE

This information package was developed in response to numerous requests by states and local communities for resources in supporting both children and adults with extensive health needs in the community. Our review indicates a wealth of written materials already available on this issue. This information package is designed primarily to provide an overall framework for reviewing these resources and to assist interested people in gaining better access to them.

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SUPPORTING PEOPLE WITH MEDICAL AND PHYSICAL NEEDS IN THE COMMUNITY

by Bonnie Shoultz and Julie Ann Racino

Center on Human Policy

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The Center on Human Policy has written a series of reports about agencies and services designed to meet the needs of people with severe disabilities. We have emphasized principles for community integration: (1) all people belong in the community; (2) people with severe disabilities should be integrated into typical neighborhoods, work environments, and community settings; (3) families should be supported to the degree necessary so their children can stay at home; (4) community living arrangements for adults should be family-scale and individualized; (5) a primary responsibility of services should be the encouragement of relationships between people with severe disabilities and other people; and (6) parents and people with disabilities should be involved in the design, operation, and monitoring of services. (Center on Human Policy, 1985).

Based on this framework, we will highlight some of the best practices nationally in supporting children and adults with complex health needs in the community, and will examine selected issues raised in our review of the literature and our experience with existing service systems.

"Medically Fragile" or "Medical or Health Needs": What Do These Labels Mean?

As with most labels, the words "medically fragile" or "medical or health needs" has a variety of very different meanings. In our experience with a number of states and local communities, we found there is no agreed-upon definition for people who have been labeled in this way. Some of the people we met fell into the categories enumerated by J. MacQueen in "Alternatives to Hospital Care" (1986, unpublished) such as people with medical/surgical problems (e.g., low-birth weight infants), terminal illnesses (e.g terminal cancer), severe intellectual disabilities, chronic medical problems (e.g., severe seizure disorder), chronic respiratory problems, and central nervous system dysfunction. In addition, we found these labels applied to people who had relatively minor health needs (e.g., mild seizure disorder), primarily physical needs (e.g., positioning, accessibility), or who had been deemed eligible for Medicaid funded services such as an "intermediate care facility" or "day treatment" program. Thus, particularly in common usage, the term "medically fragile" means very little and may be harmful in that the person so labeled is likely to be excluded from opportunities provided to others.

In many states, some people are labelled as "medically fragile" when in actuality they have easy-to-meet medical needs or are physically or multiply handicapped but don't require skilled nursing or ongoing medical care. The actual number of people with intensive medical needs is quite small when compared to the total number of people who are labelled in this way. Also, it is important to note that the medical needs of people may be very intense at times and less intense the rest of the time. Why should they have to live in a very restrictive environment all of the time?

We must also recognize that sometimes medical needs have resulted from what could be termed neglect in the person's living situation. For example, in some situations, devices such as feeding tubes are used with people who "take too long to be fed." Other people have received poor physical care (e.g., positioning) resulting in damage to their internal as well as external body systems. With proper training and care, many people can move from devices such as "feeding tubes" to eating in regular ways. For example, one nationally known consultant said she was assisting 125 people in one state to start to eat again without use of these devices.

Even if the label "medically fragile" had a precise meaning, knowledge about the health care needs of a person is not enough to know how to support that individual in the community. It is critical to integrate the health care or special needs of a person into a framework of the life of an adult or child with typical human needs. The next sections of this information package deal with this issue more explicitly. Suffice it to say that we are concerned about efforts to allow funding for children with medical needs to live in group homes when the first and foremost need for a <u>child</u> is to live with a family. We are also concerned that as the "technology assisted" and other medically complex children are now reaching adulthood, there seem to be few efforts to look at what the differences in support for adults as opposed to children may mean.

Assessment and Services Planning

Karen Green-McGowan, a well known consultant in supporting people with complex health needs in the community, has developed an assessment tool for use by health care professionals to determine the degree of "fragility" involved by an examination of each of the major body systems. (Green-McGowan, 1987) As Karen says, "Vulnerability is different than it appears. A person may look very vulnerable, but may not be and vice versa." Karen goes on to say that standardized assessments can lead to inappropriate goals. The important point is the functional relevancy (i.e., relevancy to daily life) of the assessment and the goals.

What is even more important than the specific assessment tool, however, is the way in which she integrates this assessment into a total life planning approach called functional planning (Green-McGowan, 1987). This approach has been used effectively in both the United States and Canada. Some of the main characteristics of this process include: an emphasis on the entire daily life of the person instead of a narrow "disability" focus, use of the nominal group technique to encourage participation by all people involved (including family and direct support staff), a core set of underlying values (1. People are unique. 2. Stereotypes need to be eliminated. 3. All people can learn. 4. All people have equal human value. 5. Expectations can challenge or limit. 6. Each person deserves quality services. 7. We need to understand the thoughts, feelings, needs and wants of others.), and an emphasis on what the person needs and how we can obtain it versus an emphasis on what is available. This approach has been specifically designed for use with people with complex health needs.

Other approaches to life planning can also be useful for developing supports for people with complex medical needs. For example, looking at the daily routine of a specific person can often help us identify the importance of activities beyond health and personal care needs that will make life meaningful for a person, such as work and recreation. A good discussion of an adult routine for a person with multiple disabilities is contained in "A Reconceptualization of the Role of the Direct Service Provider" (Knoll & Ford, 1987). In addition, a technique called personal futures planning (O'Brien, 1987) can also be a useful tool in creating a shared positive future vision for the life of a person with a disability: a vision based on the values of competence, community participation, choice, respect and community presence.

Best Practices for Children: Supporting the Family

The real pioneers in serving people with complex medical and physical needs have been parents and families themselves, who have found ways to bring their children home even when there was no service agency providing support. A national voluntary organization called SKIP (Sick Kids need Involved People) was incorporated in 1982 by a physician, a respiratory therapist, a nurse, and Karen Shannon, a parent, to teach and support families to care for children they call "technology-dependent" in their homes. In Maryland, New Jersey, Michigan, and Illinois, and fourteen other states, Medicaid will fund home care costing less than or as much as hospital care; this allows children who would otherwise remain in hospitals or nursing homes to live at home. As a comparison, one hospital in Syracuse, New York, stated in 1987 that its average daily revenue (this figure covers everything received by the child, such as pharmacy, room cost, etc.) for care on the regular pediatric floor was $500 per day (or $182,500 yearly), while average daily revenue in the pediatric intensive care unit is $1,062 per day (or $387,630 yearly)--far more than even the highest amount provided for home care. Home care may include 24 hour nursing care, maintenance of a respirator, feeding through a G-tube, physical therapy, maintenance of a very clean environment, 24 hour monitoring of the child's condition, administration and monitoring of medications, and any number of other things usually provided in medical facilities. It also includes attention to the child's normal needs to play, to move about in the home, and to have control over the environment.

In some states, the families helped by SKIP are families who can handle ongoing service coordination by themselves. It is likely that even these families would appreciate help in coordinating the services and resources they need, so that they could devote their energies to meeting other family needs. Today, organizations such as the Coordinating Center for Home and Community Care (CCHCC) provide service coordination for children who have medically complex needs and their families (Walker, 1988). In Maryland, Michigan, Wisconsin, and other places, some agencies provide some of the support a family (not an agency or a system) feels are needed. For example, in Calvert County, Maryland, the Association for Retarded Citizens has a Family Support Services Department that procures or provides respite care, specialized family support, and integrated day care to approximately 50 people with developmental disabilities and their families. A number of these families have a member who has intensive medical needs, such as lengthy (10-20 minute) seizures, G-tube feeding, deteriorating conditions such as muscular dystrophy or Rett's Syndrome, respiratory conditions requiring frequent suctioning, and susceptibility to other illnesses so that constant vigilance is required.

The support services in Calvert County may include daily phone and in-home consultation and support, extensive service coordination, large amounts of in-home respite care, out-of-home respite care, and purchase of diapers, medicines, braces, chairs, bathing equipment, ramps, and other items needed by the individual with the medical problems. Most of all, the agency supports the family in creatively obtaining the resources they need. The agency supports a few families for whom the goal is just to help them get through one more day, doing whatever it takes to make that possible (Bersani, 1987).

Best Practices for Children: Permanency Planning

Even with the best support services, some families cannot care for their children at home. When this is the case, the most progressive approach is one built around the concept of permanency planning. A few states provide foster care for children requiring intensive medical support, giving extra support to the family caring for the child. The state of Michigan and especially the Macomb-Oakland Regional Center has gone a giant step further by embracing permanency planning for all children with developmental disabilities, including those requiring ongoing medical care. Families of these children, some of whom have never left the hospital, are offered support services to maintain their child at home. If the child must live outside the birth family, the family is offered foster care as a temporary placement, with the goal of returning the child to the natural family.

When it is not possible for the child to return home, the agency tries to find an adoptive home for the child. The natural families of some children are no longer involved in their lives. For these children, Macomb-Oakland looks for adoptive families who will take over all of the parenting of the child. In other cases, families want to stay involved. Then Macomb-Oakland explores "open adoption," where the child's birth family can visit frequently and maintain the affectional ties they have with the child. Sometimes, a child cannot be freed for adoption. Then the agency pursues options such as "shared care" and "permanent foster care." Shared care is an arrangement in which the natural and foster parents agree to share responsibility for the child; permanent foster care is a nonlegal agreement by foster families to serve as primary parents for children until adulthood.

In Michigan, as in several other states, foster and adoptive families can receive a variety of subsidies and supports, as can natural families. Making permanency planning work in Michigan means that foster and adoptive families must be supported to the extent necessary so that they can keep the child they have taken into their home. The support makes it easier to find and keep these families, who are decent people, not saints. Macomb-Oakland staff believe, as one administrator puts it, "There's somebody for everybody. Foster families aren't interchangeable though. Some aren't good with kids with behavior problems, but they're good with medically fragile kids. You have to match the child with the family." (Taylor, Racino, Knoll, & Lutfiyya, 1987).

As a result of Macomb-Oakland's aggressive implementation of this approach in an area with a general population of two million, all but six of the children with developmental disabilities are now living in families.

Best Practices: Supporting Adults in the Community

For adults who live apart from their families, Macomb-Oakland (and some other regions in Michigan) provide medical backup services that allow people to live in homes in the community. They have found that most of the technical procedures are easily taught to lay people, and that it is safe for them to perform these procedures as long as a nurse regularly observes the performance and monitors the person's medical status. Also, as soon as they identify someone who is tube-fed or dependent on other technological devices, people are assisted to develop greater independence. A person who is tube-fed, for example, may simply require more time to eat than is given in most health care settings, and can eat independently if the staff or family members learn proper ways of assistance and give the person time to eat.

The backup support that is built in includes a physician for every 300 persons served, even though people have their own local physicians as well, and a nurse for every 48 people receiving service. The nurses may concentrate most of their time on just a few of the 48 for whom they are responsible, and monitor routine activities (such as medication administration) for the others. The physicians review the health status of the people for whom they are responsible, and get involved in problem-solving and planning for those who have serious medical problems. If someone has just had surgery or is in need of nursing care, extra staff will be provided if necessary, including LPNs or RNs.

The advantages to such a system are evident. The backup support provided extends to all the people who receive services, not just to those who require intensive medical support. It is there when and if people need it, and becomes invisible when they do not. Getting ill doesn't precipitate a crisis for the individual, because the people who support him/her can deal with his/her illness. And according to a state administrator, those who need intensive medical intervention "do a lot better in a home than in a health care facility. We are supporting many dozens of people with these needs in the community, and we are doing it well." The same administrator also notes that people are not labelled or thought of as "medically fragile," because the label makes staff and parents think they need to be cared for by health care specialists. He feels that an extremely small number of people have such an unstable health status that they need continuous 24 hour monitoring by a nurse. The community backup system provided by agencies in parts of Michigan allows almost everyone to live in a home, and to have a home to return to after temporarily being in the hospital.

Adults with medical needs who in many parts of the country were in day habilitation programs, are now working in individually tailored supported employment (Nisbet & Callahan, 1986). In addition, for people who are not working or working only part-time, agencies such as Options for Individuals, Inc. (see service section) are supporting people in integrated community experiences.

The Role of Technology

One state director recently said that we must develop the technology to support people with medical needs in the community. Technology is not the primary issue. Across the country today people with complex medical needs are living at home in the community. The "technology assisted" children, who would not have survived twenty years ago, are reaching adulthood. Through the "Katie Beckett waivers" and through the efforts of parents and professionals, children are being supported at home. At the same time, children and adults with fewer and less intense health needs remain in our institutions for people with developmental disabilities and in nursing homes because of their "medical needs." Is this a question of technology? Of course not.

It is true that technology has been going through tremendous changes today. It is also true that only a small part of what we do know is in general use. One good example is communication devices. The technology is there, but our willingness to pay for it or to use it properly is not always there. Communication is not yet perceived as a right.

Lack of Information Exchange between the Health Care and Developmental Disabilities Fields

Many of the people we work with are primarily involved with offices of developmental disabilities/mental retardation or with agencies supporting people with these labels. While there is a tremendous amount of information available in the health care area on the topics discussed in this package (e.g., home care), many of the people in the field of developmental disabilities have not had an opportunity to be exposed to it. Others do not see the materials as applicable because they are targeted to another group (e.g., children with chronic illnesses).

A good example of this lack of exchange occurred in one northeastern state where there is a major initiative to support children who are "technology-assisted." Strategies in such areas as accessing the health field, working with physicians, making the home a safe environment, and developing an individualized service coordination approach were relatively well developed (as compared to many other states) for children with chronic illnesses. However, people working with individuals with developmental disabilities <u>and</u> medical needs were generally unaware that this information existed. Moreover, this gap in knowledge flow between the fields was not even viewed as a problem; the professionals seemed to concentrate on the differences between the groups without recognizing some of the strong commonalities.

We have also found there is a distinct cadre of professionals who are knowledgeable about children with chronic illnesses or who are labelled technology-assisted and another cadre of professionals who work with children with developmental disabilities <u>and</u> medical needs. While specialization has its merits, the result for service providers may be a lack of access to the information that they need to best support people with medical needs in the community.

On a community level, some places have used a process to bring together the diverse people, including parents, who are invested in supports for people with medical needs. Through a facilitator, the group is assisted in identifying (a) the problems in their community, (b) the ones that are most important to address, (c) the ones with a high probability of being achieved, and finally (d) the issues to be targeted for change. This is a process that pulls on the existing knowledge in the community and can result in major changes without the need to wait for large scale federal or state reform.

Enabling Structures: Training, Funding and Other Supports

In order to provide flexible and individually tailored supports for people with extensive health needs, enabling administrative structures need to be in place. This section examines some of the common issues and questions raised in supporting people with complex health needs in the community. Many reports already exist recommending changes on the national level (See section on annotations). This section looks at common implementation issues at the state and local level.

One common question revolves around the training of nurses, therapists and physicians in supporting people who have both medical needs and are labelled developmentally disabled. Physician training curriculums are now available in the area of developmental disabilities (e.g., American Academy of Pediatrics, 1980). In addition, states such as Minnesota have developed strategies for training their therapists in areas such as functional life planning and assessment. The key in the training is an emphasis on envisioning positive futures for people with complex medical needs as opposed to an emphasis on technology. If medical personnel believe in supporting people in the community, the needed "technology" which exists and is accessible to them will more likely be sought out.

Regarding the training of respite workers and in-home nurses, parents often can train their own respite workers in how to best meet the needs of their child. They should be provided with assistance in doing so, if they so desire. The key to training is that it needs to be individualized to the person/family. While this is important in all training, it is of particular significance in the area of health care. Support workers, for example, do not need to be trained in all aspects of health. They do, however, need to know about the specific needs of the people they are supporting. They also need to have easy access to health personnel who can assist them with the more technical medical aspects that may arise.

Services coordination is the core that enables an individualized approach to supports to occur. In some ways, service coordination for people with technology needs can provide some learnings for the field of developmental disabilities, in general. For example, service coordination for children with "technology" needs has often meant developing new services and supports and accessing community supports as opposed to a typical casemanagement approach of fitting the people into programs. It also has often emphasized parent advocacy and families becoming their own service coordinators. The manual, The Family as Caremanager, is a good resource (Kaufman, J., 1986) on this issue.

It is important to note that coordinating services and supports for an adult is different than coordinating supports for a family. For adults, the focus is first on the adult and their choices, and only secondarily on family members or housemates. For a family, the approach is less oriented to the child with a disability and more toward an approach that looks at the interests of the family, including the child with a disability.

Throughout the country, there remain difficulties in obtaining community health care for people with developmental disabilities. These problems are an impediment to the right of people to live in the community, but can be overcome (Knoll, 1985) on an individual basis. Many of the needed changes will require work in each local community, as well as at the state and federal levels, to insure that people with developmental disabilities will have access to community health services.

The question of funding is always a major issue. What we fund and how well we fund it is usually indicative of the priorities that we have. Many of the issues of funding are really at the core questions of values.

In some states, there is a bias in the funding mechanism that discourages service providers and families from supporting people with complex needs in the community. For example, in some states, the amount of money that is available to support a person with complex health needs is similar to the amount of funds available to support a person with less complex needs. A broad base of support must be developed in these states to insure that adequate funding will be available to support children with severe disabilities to live at home with their families and adults with severe disabilities to live in typical homes in the community.

Many states also tie their funding to programs, instead of to individuals and/or families. For example, New York State develops "family support service programs" and then tries to fit the families into the programs. In contrast, places like Wisconsin tie their family support services funding to families and thus can develop supports tailored to the families (Taylor, 1986). Issues regarding supports for adults and the necessity of separating housing and support components are discussed later in this package.

In addition to state general purpose funds and grant funds, many states have used the Model 50 Medicaid Waiver (for children with chronic illnesses or technology needs) and the home and community-based care Medicaid waiver to support people with severe disabilities in the community. For more detailed information on innovative uses of these waivers, contact the Center on Human Policy.

Conclusion

This article provides the framework for the remainder of this information package on supporting people with complex health needs in the community. The sections that follow will give innovative examples of supports for children and adults and provide additional resources in the area of supporting people with complex health needs in the community.

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FAMILY SUPPORTS FOR CHILDREN WITH SEVERE DISABILITIES AND CHRONIC ILLNESSES IN MARYLAND

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In the past few years, increased emphasis has been placed on the importance of children living at home with families in the community, rather than in institutional or group settings (Center on Human Policy, 1986). In order for this to happen, particularly for children with severe impairments and chronic medical needs, it is necessary to offer families the supports they need to keep their children at home. Innovative programs in states such as Wisconsin and Michigan are providing families with a broad range of types and levels of family support (Taylor, 1985; Taylor, 1987). In Maryland, also, there are examples of intensive and individualized supports available for some families of children with severe and multiple disabilities (see, for example, Bersani, 1987).

This report focuses on some of the positive practices in Maryland in family supports, especially for families with children who have severe disabilities and chronic illnesses. It is based on visits to three sites selected by a subcommittee of the Maryland Developmental Disabilities Planning Council: the Family Support Program at The Kennedy Institute in Baltimore, the Coordinating Center for Home and Community Care (CCHCC), and SKIP (Sick Kids Need Involved People). These visits, conducted as part of the work of the Community Integration Project in Maryland in June 1987, included interviews with program staff and visits to families who receive assistance from these programs. The purpose of the site visit was not to evaluate these services, but to identify and document good practices in supporting children with extensive health needs in Maryland. A brief description of each of the sites is presented below, followed by discussion of the key family support issues and practices that were identified.

Family Support Services, The Kennedy Institute. The mission of the Department for Family Support Services is "to provide support services designed to enable families and family care providers to meet the needs of a developmentally disabled child living in the home." The Department for Family Support Services consists of three programs: the Child and Family Support Program; the Family Centered Planning Program; and the Family Support Services Program. The Child and Family Support Program provides in-home training, counseling, and service coordination for about 125 families of children from birth to 7 residing in Baltimore City or Baltimore County. Approximately 25 of these children are considered to be chronically ill or medically fragile. The Family Centered Planning Program serves approximately 50 families with children birth to 21 years of age, offering service coordination and pulling together a team of professionals and community members as a network of support for the family. Finally, the Family Support Services Program assists children from birth to 21 residing in Baltimore City, Baltimore County, and Anne Arundel County who are considered at-risk for out-of-home placement. Supports to families may include convening a team of support for the family, assisting the family with access to services or service coordination, and/or assistance with the purchase of needed services. As of June 1987, this program served approximately 75 families.

Coordinating Center for Home and Community Care (CCHCC). The Coordinating Center for Home and Community Care (CCHCC) is a nonprofit organization funded by a federal SPRANS (Special Projects of Regional and National Significance) grant. Originally established in 1983, its mission is "to create alternatives to lengthy and repeated hospitalization for children who require medically complex care." This is achieved through the cooperative effort of a "consortium" of service providers, agencies, and organizations that CCHCC is composed of, including medical facilities, community organizations, funding organizations, academic institutions, and others. CCHCC provides service coordination and case management for children who receive supports through Maryland's Model 50 Medicaid waiver. To be eligible for CCHCC services, an individual must be (1) eighteen years of age or younger; and (2) a resident of Maryland. The agency originally restricted its services to "respiratory disabled" children. However, it has now expanded the criteria for enrollment to include other children requiring medically complex care, who are not necessarily "technology-assisted." To qualify for CCHCC services, a child must have been hospitalized for 30 days or more, or be at risk of long-term or repeated hospitalization. In addition, the child must (1) be medically stable; (2) need special support in the home to avoid long term or repeated hospitalization; or (3) need specialized equipment or care in order to remain at home with minimum risk. As of June 1987, 68 children were currently being supported by CCHCC statewide; a total of 208 children have been served since the program's inception.

SKIP (Sick Kids Need Involved People). SKIP is a support and advocacy group for parents of children who are chronically ill. It is a national organization, composed of local chapters, whose purpose is to offer education, resources, and support to families. The educational component involves development of written materials for parents and professionals. Currently SKIP has a grant from the U. S. Department of Education to produce the fourth edition of a handbook for parents. In acting as a resource, SKIP identifies existing resources and builds on them. SKIP members work to "help the system help families." This involves educating professionals through participation of SKIP members at meetings, conferences, special committees, task forces, and so forth. Finally, as a source of support, SKIP's aim is to "help families to help themselves" by assisting them to identify and obtain access to needed resources.

Family-Centered Approach to Family Support

Some agencies in Maryland are taking a "family-centered" approach to supporting families of children with disabilities. These agencies try to support families on the basis of the needs of the entire family, rather than just the needs of the child with disabilities. One staff member explained that a family-centered approach might mean "looking at needs according to what the family says, versus just the priorities of the physician." From the start, the family is involved in all aspects of planning and decision-making. Another staff member commented about this approach: "We go by families' priorities...it's really family focused...I think that's one of the strengths of this program." As an organization, SKIP also stresses the importance of a family-centered perspective. The founder, Karen Shannon, emphasizes: "The family has to be the nucleus, instead of the system being the nucleus..."

Individualized and Flexible Supports

An individualized approach tailors supports to the needs of particular families. It begins by asking families what they need to keep their child at home. The types and levels of support provided vary depending upon the family's needs. Some of these supports and their application to children with severe disabilities and chronic medical needs are discussed below.

Financial Supports

Financial support is often needed by families to assist with expenses either directly related to their child, such as for medical costs, adaptive equipment, and other items not covered by Medicaid, or for more general household expenses.

One of the families receiving support from the Family Support Services Program (FSSP) at The Kennedy Institute are the Millers*--Jeff and Susan, and their two children Jan and Doug. The supports they receive illustrate some of the needs of one family and the ways they are supported.

> The Millers live in a middle-income neighborhood of row houses in the city of Baltimore. Upon entering their house, one is struck by the hominess of it--the worn but comfortable and attractive furnishings, the family photographs and momentos throughout the house, and the invitation to sit down to a freshly brewed cup of coffee. One is also immediately struck by the hospital-like bed in one corner of what would have been the dining or living room area. Next to it on the floor is a large mattress. This special bed is for Doug, the mattress for his father, who sleeps downstairs at night to be with him. As we entered the house, Cindy, the Program Coordinator of FSSP commented, "You see, this is very much a Doug house."

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*All names throughout the report, except for agency personnel, are pseudonyms.

> Doug, who is 10 years old, is labeled severely mentally retarded and has cerebral palsy. He does not walk, is blind, and often has seizures. He needs assistance with all of his self-care routines, and is fed through a g-tube. Since he was an infant, Doug has been hospitalized on the average of 8-9 times a year with repeated bouts of pneumonia, bronchitis, and various other infections.
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> It costs about $500-600 per month to maintain Doug at home (excluding the costs of his recently begun nursing care). Jeff earns $20,000 per year--not enough to cover all of Doug's expenses in addition to routine household bills. The Family Support Services Program has provided a monthly stipend of $150 per month, as well as additional help as needed for respite. The FSSP also assisted the parents in paying for some counseling for their daughter.
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> Although expenses such as utility bills and personal counseling are not directly related to Doug, assistance with them seems to have a significant impact upon this family's ability to maintain their child at home.

Above all, it is important to remember that the financial assistance needed will vary from one family to another: some families may not need any extra assistance; some may need one-time assistance with a major purchase or expense; and others may need regular, on-going assistance.

Respite

Making adequate respite available to families of children with severe disabilities and chronic illness presents a challenge. Parents of children with these types of needs are often hesitant to leave their child in the care of a stranger or someone they do not feel is adequately trained in his or her care. Within Maryland, there is some effort to provide respite for families with children who are severely disabled. For example, some families are given funds to hire their own respite provider, someone they know and are comfortable leaving their child with. Through the Family Support Program at The Kennedy Institute, Susan Miller is able to have a family friend, Betty, come stay with Doug from time to time. Betty is the only person outside of the family and Doug's nurse that Susan will leave him with; when Betty is not available, Susan will not go out. The Coordinating Center for Home and Community Care encourages families to have relatives and close friends be trained in the care of their child so these people can provide respite for either planned occasions or emergencies.

Overall, there are some positive steps being taken in Maryland to provide respite to families of chronically ill and severely disabled children. It is particularly notable that some families are able to select their own respite providers, and can pay relatives, neighbors, or friends for this type of support. However, there is still a lack of respite for families with children who are severely disabled and chronically ill and many of these families remain very isolated. There is need both for more resources directed to respite as well as an increase in amount and flexibility of funding, allowing families to hire people they know and/or those who they feel are well-trained enough to provide respite for their children with complex needs.

In-Home Care for Children with Medical Needs

To bring children who are chronically ill home to live, it is often necessary to arrange for in-home medical care. As the agency in Maryland providing service coordination for children supported by the Model 50 Medicaid waiver, CCHCC has been involved in facilitating the discharge of many children from hospitals. Prior to discharge, CCHCC convenes a meeting to develop a long-term "plan of care." Participants in this meeting include the family, the physician, the home care providers chosen by the family, a representative of the payer (whoever is paying for the home care and other medical supports, such as Medicaid or a private insurance agency), and other CCHCC staff including the financial coordinator, educational coordinator, and clinical coordinator. Before a child returns home to live, hospital staff train the parents in all aspects of care for their child. The parents then hire and train their own nurses, with assistance from CCHCC. A clinical coordinator from CCHCC visits each family within 48 hours of discharge, then once a week for the first month, once every other week for the next month, and once a month thereafter.

Michelle, who is 6 1/2 years old, lives at home with her parents and younger sister. When she was a year old, she had a brain stem infection leading to a condition known as "central hypoventilation syndrome," in which her breathing is impaired and she does not get sufficient oxygen to her brain. As a result, Michelle has had a tracheostomy, receives oxygen throughout the day, and has been on a ventilator at night since 1984. Michelle has to be tube-fed because she has no swallow or gag reflex. At night she is on an apnea monitor since she frequently stops breathing. She needs to be suctioned about every 3 hours. Through the Medicaid waiver, Michelle receives nearly 100 hours of in-home nursing per week: Monday-Friday, 7:00am-3:00pm; Sunday night-Thursday night, 11:00pm-7:00am; and Friday and Saturday night, 11:00pm-8:00am. When there are no nurses present, Michelle's parents provide the medical care she needs. Priscilla, an R.N., is the clinical coordinator from CCHCC for Michelle's family. She visits them "about once a month," and talks to them on the phone "about four times a week."

While home care for many children in Maryland has been financed by the Model 50 waiver, state developmental disabilities dollars and private insurance have also paid for some of these types of supports. There are problems with each. First, state funds for intensive in-home supports have been limited, and have not been used for such intensive home care on a routine or ongoing basis. Second, private insurance companies are hesitant to cover children with chronic illnesses. Debbie, the mother of Joe, a child who is technology assisted, related some of her family's experiences with private insurance.

> Joe, who is 6 years old, was born with cerebral palsy and "respiratory distress syndrome." Related to this, he has a weakening of the trachea, causing it to collapse, and difficulties in breathing. Debbie commented, "He has respiratory arrests all the time"--up to 25 times a day. Both parents work--Debbie in the evenings and her husband, Ed, during the day. They have 24 hours of nursing a day during the week, and nursing just at nights on the weekends.
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> The supports for Joe used to be covered by their private insurance, but this was terminated. In trying to get the coverage extended, Debbie talked about the difficulty of gaining access to the person at the insurance company whom they needed to talk to. She commented, "We weren't getting anywhere through the proper channels." She described how "we finally went running up to catch him in a parking lot...That's not the way we used to think of doing things...but that's what you have to do to get anything." Finally, she explained, "I wrote to President Reagan about our situation, and he intervened and got it (the coverage) extended for 90 more days. After this 90 days, though,

he was again terminated." Now, her husband is employed with a new company, and Joe's medical supports are covered by a new insurance agency.

Having in-home nursing up to 24 hours a day requires adjustment and adaptation of the entire household. According to Karen Shannon, of SKIP, it is something that families of children who are chronically ill and technology-assisted have to accept if they are to bring their children home from the hospital. Regarding characteristics she looks for in a prospective nurse, Michelle's mother commented, "I think it's most important that they are dependable and willing to learn." Joe's mother, Debbie, said she has fired nurses both because she did not feel they were competent and because of an "I'm the nurse" attitude. Rather than having a nurse be in control and make the decisions, Debbie prefers working together with the nurse. She commented, "you need to work as a team with the nurses." Stressing the importance of the family's relationship with the nurse, Karen Shannon pointed out that "it is important to be selective, personality-wise, in terms of nurses...you have to get nurses that you get along with and feel comfortable with." After a few years, nurses may "become like part of the family." Yet, nurses also come and go, and families must periodically find new nurses due to this turnover. At times, a family may be short one shift and the parents handle the situation as best they can, taking turns staying up nights with their child. New nurses are not always easy to find since there is a statewide shortage of nurses. Having nurses in one's home can also be invasive of privacy, and families talk about a need for time out without the nurses. One mother emphasized, "Families need to be allowed to be families."

For nurses, too, in-home nursing requires some adjustment. Priscilla, a Registered Nurse, is one of the Clinical Care Coordinators for CCHCC. As such, she visits families once every few weeks to monitor the supports they are receiving. She feels that in-home nursing is quite different from most traditional nursing practice. She explained that in this home care role, "we do a lot of non-nursing things, such as a social work role, or deal with educational issues...I think that's the most difficult thing for nurses to adjust to in this kind of work."

In summary, the in-home medical care available in Maryland has provided the opportunity for many children to live at home who otherwise would have spent much if not all of their lives in hospitals or nursing homes. One mother commented about her 6 year old child who is ventilator-assisted, "He thinks of himself as a normal child...The biggest reward of home care is they're kids, just kids, never looked at as different kids." As with other types of family supports, this type of care must also be both individualized and flexible: some families may need a few hours of nursing per week while others need up to 24 hours a day; and the needs of any one family for full-time versus part-time nursing may remain constant or vary over time. And, there is need for additional resources directed to providing in-home medical and other supports. This should include increases in the supports provided to families--not only for those with children labeled as "chronically ill" or "medically fragile," but for all children with disabilities, based upon needs of the child and family. In addition, efforts should be made to create and train an adequate pool of in-home care providers.

Social/Personal Support

In addition to supports such as nursing care, financial assistance, and respite, families of children with disabilities also need social or personal supports. Sometimes they get this through organized support meetings. For Susan Miller, the parent support group at The Kennedy Institute has been helpful, and she feels that the sibling support group was good for her daughter, Jan.

At other times, they receive support from individual people, both professional and nonprofessional. Susan also commented how Cindy, the Program Coordinator of the FSSP, has been an invaluable source of moral support. "I don't know what I would have done without her...I couldn't have done it without her...She's been a life-saver." Linda and Debbie, both mothers of children labeled "medically fragile," mentioned particular doctors who had always had "time to listen," or to let them "talk things out" when they needed to. Debbie also related how some of her nurses had continued to come on a volunteer basis when her son's insurance was terminated.

Linda and Debbie both have also received significant personal support though SKIP. While it may be difficult for parents of medically fragile and technology-assisted children to meet as a group, SKIP promotes the development of networks of "telephone friends" for mutual support. Therefore, through SKIP they can receive support themselves as well as offer support to others at the same time.

Summary: Individualized and Flexible Supports

There are a wide range of supports needed to maintain children with severe disabilities and chronic illnesses at home. These include supports provided directly to the child with disabilities, as well as assistance to the family as a whole. Further, the types and intensity of support needed will differ from one family to another, and are likely to change over time. Financial or medical support alone are generally not sufficient; families also need social and emotional supports. If all children with disabilities, including those with the most severe impairments, are to remain with or return to families, then it is essential to ask families what they need for support, and to offer individualized and flexible supports. For example, when asked about the types of support families receive, staff of the Family Support Program at The Kennedy Institute respond, "That depends on the family." And, regarding the level of supports provided, they respond, "Whatever the family needs."

A Team Approach to Family Support

Agencies providing innovative family supports in Maryland are doing so in a way that involves a team effort. The family is an integral and central part of that team. Additional team members are selected based upon the family's and child's needs and circumstances. They may include physicians, nurses, physical therapists, occupational therapists, speech therapists, nutritionist, educators, case managers and/or social workers, fundors, and family friends, relatives, and neighbors--"whomever the family identifies as being important."

> Lynne Brown, who is a year old, has trisomy 13. As a result, she has multiple disabilities, including blindness, grand mal seizures, and kidney damage. She is beginning to make some vocalizations and roll over independently. Lynne lives in a small apartment with her mother, Cathy, and her grandmother, Ellen. They receive supports from the Child and Family Support Program at The Kennedy Institute. They first contacted CFSP through a hotline. At that time, they had been receiving pressure from their pediatrician to place Lynne into an institution.
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> Initially, Lynne went for an evaluation at The Kennedy Institute. After this evaluation, the family was assigned a primary support person from the CFSP, Mary, a Pediatric Nurse Practitioner. At this point, Mary met with the family along with other relevant team members from CFSP to set priorities. They will meet every six months after this to review progress and priorities. At the outset, Mary also contacted the family physician to introduce herself and to explain CFSP involvement. Mary visits the family about once

every two weeks, possibly more often at first. Based upon the evaluation, an occupational therapist and physical therapist will visit the family once a month, at least for awhile, to train the mother and grandmother in handling, positioning, and other assistance for Lynne.

Although the pediatrician was recommending out-of-home placement for Lynne, the family has decided to keep her at home with the support from CFSP. Ellen talked about what it was like before: "With the pediatrician, everything was negative...she told us Lynne would never walk, talk, roll over, or eat regular food, but she is starting to do all of these." However, despite this pediatrician's negativity, the family has retained her as their pediatrician, since they feel she is a competent person. Also, Mary explained that she is a young pediatrician, who is really "coming along" with this family, and learning a lot from seeing them keep Lynne at home.

CCHCC also works with a team concept to help bring children who are chronically ill home. Upon referral of a family, the family services coordinator conducts a family needs assessment (including environmental needs, architectural barriers, adaptations, special equipment, etc.). Each family is then assigned a clinical care coordinator. Also, based upon the family's and child's needs. other agency staff members may be called in, including the financial coordinator or educational coordinator.

The strength of the team approaches described above is that they help provide a broad base of support and assistance to the family. It is important that the family of the child with disabilities be a central part of this team. Another key to making this type of approach effective is communication between all participants on the team. Finally, it is important that the primary function of the team be to further connect the child and family to existing community services and resources.

Case Management/Service Coordination

An essential element of family support is case management, or service coordination, for families--connecting families to various medical, respite, counseling, financial, educational, and other support services. For example, the Planning Coordinator in the Family Centered Family Planning program at The Kennedy Institute works with families to assess current services and supports, determine additional service needs, advocate for these when necessary, and plan for the future. "The goal is to have parents take over the role of coordination of their own services, and advocacy for their child." The Planning Coordinator typically visits families every two weeks, or at least once a month. However, program staff emphasize that "the frequency of visits varies with each family, depending on their needs."

The Coordinating Center for Home and Community Care (CCHCC) provides care management and service coordination for families having children considered to be chronically ill. Many of these families have in-home nursing, and therefore have to deal with the responsibilities of obtaining and coordinating nursing care in their homes. Similar to the Family Centered Planning Program, CCHCC staff members see their role as going beyond that of typical case management, to include support of and advocacy for the family. One of the primary objectives is to have families eventually become their own case managers, and advocate for the rights of their child.

Priscilla, a R.N., has been a clinical coordinator for CCHCC since the program began in 1984. She works with a total of about 25 families, 20 of whom currently have their child at home. One of these families is that of Michelle. Priscilla visits the family about once a month, but talks to them on the phone "about four times a week." When they have a turnover in nurses, Priscilla helps them find new nurses.

Case management or service coordination is a crucial element of family support. At the same time, families report that it "can be very invasive." Without careful precautions, "case management" can readily become "family management," or taking over control for families. In light of this, it is positive that the agencies in Maryland are conceptualizing their role as one of "service coordination" rather than traditional "case management." The supports provided to families often go beyond just "service coordination" to include social support for families. Also, as described in the following section, a strength of these agencies is their emphasis on empowerment of families.

Advocacy and the Empowerment of Families

The family support programs in Maryland have as one of their objectives the empowerment of families as a key to advocacy for the child with disabilities. The idea is to work with families to help them develop skill and competency as advocates. A staff member at one agency commented, "We don't do for families, we work with them." An advantage for programs such as the Family Support Programs at The Kennedy Institute and CCHCC is that they do not provide direct services. Therefore, agency personnel feel they are in a better position to advocate for services for families.

Toward this same end, one of the objectives of SKIP is to "help families to help themselves" by assisting them to identify and obtain access to needed resources and supports. The founder of SKIP, Karen Shannon, emphasized that the approach is a "hands-off" one--making recommendations and suggestions, but not telling people what to do. A parent of a child who is technology-assisted stressed the need for service coordination, especially at first, but commented that "case management can be very invasive." She emphasized that families need to be in control, to make the decisions, and acquire the skills "for handling things and figuring out how to handle them." Another parent commented, "It's amazing how much stress is reduced when you have control."

Funding Family Supports

Family supports for children with severe disabilities and chronic illnesses in Maryland are funded in a variety of ways, which are briefly described below.

Medicaid Model 50 waiver. This Medicaid waiver provides funds for in-home supports to 50 children who have complex medical needs. At first, the program served only those children who were "ventilator-assisted," but has since expanded the definition to include a broader range of children who are either "technology-assisted" or chronically ill.

Medicaid Technology-Assisted Waiver. This Medicaid waiver provides funds for children with complex medical needs who are technology assisted. The funding covers things such as specialized medical equipment, in-home nursing, case management, and in-home visits by specialty physicians.

SPRANS grant. Through the Division of Maternal and Child Health, Maryland has a SPRANS grant (Special Projects of Regional and National Significance) which funds agencies such as CCHCC as a care management and service coordination agency. This agency provides care management/service coordination to children who have complex medical needs..

Developmental Disabilities Administration (DDA). The state Developmental Disabilities Administration provides funds for family support services, which include supports to families having children with severe disabilities and chronic illnesses. There is significant flexibility in the types of supports that can be provided with these funds.

Developmental Disabilities Council. The Developmental Disabilities Council has used some of its funds to initiate or expand family support services, including supports to children with severe disabilities and medical needs.

In addition, the family support service agencies described in this report also use other available sources of support. For example, through a grant from the Hearst Foundation, The Kennedy Institute is undertaking a one-year pilot project, the Infant and Family Support Program. This program will provide supports to families with high-risk and medically fragile infants and will help identify and document the need for increased funding for this type of program in the state. Funds are also sought from sources such as the United Cerebral Palsy or the Society for Underprivileged and Handicapped Children. A one-time grant from one of these agencies might be used to help a family purchase a needed appliance or piece of adaptive equipment. Also families are assisted to obtain access to other sources of financial support that they may be eligible for, such as WIC, AFDC, private insurance, and so forth.

There are limitations attached to some of these funding sources. For example, Medicaid will only cover medical supports; yet, families usually have many additional needs. While Doug Miller receives about 60 hours of nursing a week through the Medicaid waiver, at the same time, his family receives additional financial assistance and other supports through The Kennedy Institute. Thus, it is noteworthy that some agencies in Maryland are making an effort to access any available funds and/or pool various sources of funding. It is evident, based upon the families' experiences, that a few or even multiple sources of assistance may often be necessary to meet the needs of families and their children with chronic illnesses and other disabilities.

Adequate individualized supports are available in Maryland for families of some children with severe disabilities and chronic illnesses. However, funding must be made available, from a variety of sources, to enable all children with disabilities to live at home, receiving whatever supports are necessary.

Conclusion

This report highlights the positive practices of three agencies/organizations in Maryland with respect to supports for families of children with severe disabilities and chronic illnesses. Some of the key factors in providing such supports are that: (1) the focus of support is "family-centered"; (2) the supports are both individually tailored to the needs of children and families; (3) the type and level of supports provided are based not only on financial and/or medical needs, but on social/personal needs as well; (4) a team approach to support, with the family at the center of that team, provides a broad base of knowledge and input; (5) case management is thought of more in terms of "service coordination" than of "management;" (6) the focus of support is to empower families through assisting them to advocate for the rights and services needed by their child; and (7) it is often necessary to use creativity in utilizing or pooling funding sources in order to provide needed supports for a family.

In Maryland, there are some particularly good examples of the following: (1) in-home medical supports and service coordination for children labeled technology assisted or chronically ill through CCHCC; (2) individualized and flexible family supports for a limited number of children with severe disabilities, some of whom are technology assisted or chronically ill, through the Family Support Services Program at The Kennedy Institute; and (3) organized parent support and advocacy for parents of children labeled technology assisted or chronically ill through SKIP. What is needed is that all three of these types of supports be available to <u>all</u> children with disabilities and their families.

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Supporting Adults with Severe Disabilities in the Community: Selected Issues in Residential Services

by Julie Ann Racino and Pam Walker

Center on Human Policy

Since the late 1960s, many adults with developmental disabilities have left state institutions to move to smaller residential settings in the community such as intermediate care facilities (ICF/MRs or ICF/DDs), group homes, supervised apartments or supported apartments. People with the most severe disabilities, however, often remained in state institutions or moved to a nursing home, private institution or large intermediate care facility.

In the past few years, it has become increasingly clear that all people with developmental disabilities, including people with severe disabilities and chronic health needs, can be supported in the community. The current issue is not whether a person should live in an institution or in the community, but how best to provide supports for people with the most complex needs in the community (Taylor, Racino, Knoll, & Lutfiyya, 1987).

The most exemplary practices in supporting adults with severe disabilities in the community represent a new way of thinking about "residential services." Unlike the traditional approach of establishing residential programs, fitting people into the program, and then individualizing within the context of the program, innovative service agencies are now starting with the person first and developing the supports and housing around the person. This article will examine some of the key issues raised by an individualized approach to supporting adults, including adults with extensive health needs, in the community.

Size of Setting versus an Individualized Approach to Supports

The issue of size of homes in the community for people with disabilities continues to be a key issue in some states. For example, New York State still promotes a prototype home for twelve (12) people with severe disabilities. Most intermediate care facilities, a common living arrangement for people with medical needs, have at least 8 people. In contrast, innovative service systems and agencies have already recognized the importance of size of the home to the quality of people's lives and have moved or are moving toward smaller size homes from one to four people. Examples include:

* Maryland has developed three person alternative living units across the state and supports people with severe disabilities in these settings.

* Since 1982, Connecticut has increased the number of homes for one to three people, particularly for people with challenging behaviors or extensive medical needs.

* In 1983, Wisconsin limited the size of living arrangements under their home and community-based deinstitutionalization waiver to four people, unless an exception was granted.

* Minnesota, under their home and community-based medicaid waiver, limits supported living services for adults to places where no more than six people reside and supports many adults in even smaller homes.

* Region V in Nebraska is moving away from homes of five or six people to smaller homes.

Smaller homes are particularly important for people with more severe disabilities. From the perspective of service providers, small size is valuable because it enables people with disabilities to feel more secure and to have a greater sense of control over their lifespace. It also enables staff to get to know people as individuals versus an emphasis on "group management." In interviews with innovative service providers, the general consensus was "as the problems associated with supporting a person increased, the need for the person to live with a few people or even alone, increased." (Knoll & Racino, 1988).

At the same time, it is important to realize that small size alone is not enough since it does not necessarily involve more individualized supports for people. When based on the same "model of services" as larger facilities, smaller settings can also become highly routinized and "home-like" instead of homes. The issue is not just one of size but also involves a change in the basic approach to supporting adults with severe disabilities (Taylor et al., 1987, Racino, 1988).

Heterogeneity versus Choice in Roommates

Throughout the past half dozen years there has been an increased emphasis on the importance of heterogeneity (i.e., a mix of people) in homes as opposed to people with the same type and level of disability living in the same home. Still many states and communities continue to group people on the basis of similar "needs or disabilities". It is common to find homes where all the people in the home have "challenging behaviors" or "medical needs" or "social emotional problems." This practice of grouping people on the basis of similar disabilities has often extended to even the smaller homes. For example:

> In one home, all three women - Tracy, Karen and Jeannie - used wheelchairs. Tracy and Jeannie do not speak and Karen speaks only a few words. In another home, all three people were diagnosed as having cerebral palsy and severe mental retardation. Christie and Joanne use wheelchairs, and Becky needs assistance with walking. All are either nonverbal or have very limited communication skills. (Walker, 1988)

In such homes, it would be preferable to have a group of people with a range of needs (i.e., a heterogeneous group). This could enhance people's acquisition of skills and competencies (Ford et al., 1982) as well as their integration in the community (Wolfensberger, 1972). In a recent study, most innovative service providers stressed that the nature of the grouping was as important as the size of the group. "They universally testified to the problems with the common practice of creating a specialized setting where all the most difficult people were grouped." (Knoll & Racino, 1988).

Taking an individualized approach to residential supports, however, is a "quantum" leap past the heterogeneity/homogeneity issue. Instead of matching people on the basis of their disability, either common or different, an individualized approach enables us to view people as people first and recognizes the disability as a relatively minor aspect of the matching process. For adults, the process involves supporting people in deciding with whom they will live and whether they will live alone or with others. The major decisions then revolve around issues such as the desire of people to live together, common interests, or basic compatibility.

In an individualized approach, neither the location or the number of people is predetermined. Therefore, there is greater flexibility in how many people will live together. The option of living alone, at least for a period of time, is an important one for some people. Individualized, however, does not mean that a person will always live alone or with one other person. People may also live with roommates whom they select. Because supports are not tied to a certain setting, one can live with a variety of people, including "typical" people, family, people with other labels or alone <u>and</u> still receive the needed intensity of supports. This approach recognizes the critical importance of the people we live with and the impact they may have on our lives.

Facilities versus Supports

Based on the continuum model of services, housing and supports for people with disabilities are often linked in the same setting. Thus, in order to receive the supports needed, traditionally people with severe disabilities have often been forced to reside in an intermediate care facility, nursing home, or institution. (For a full discussion on problems with the continuum concept, see Taylor, et al., 1987 and Taylor, 1988.) If they acquired more skills or if their medical or other support needs decreased, they could then move to "less restrictive settings" such as group homes. In the traditional approach, few people with severe disabilities even "made it" to group homes.

One of the most critical elements in individualized supports for adults is the separation of the components of housing and support services (Taylor et al., 1987). Separating these components makes it possible for people, including people with severe disabilities, to receive supports wherever they may live. In this approach people are not faced with the choice of living in a home of their own or receiving the intensity of supports they need; they can have both. It then is not necessary, for example, for people with medical needs to live in intermediate care facilities. They can receive the medical supports they need and still live in a home.

This separation of housing and support services can lead to greater control by the people with disabilities including choice in the type of housing and choice in the location of the home. People can live in a variety of kinds of housing, dependent on their particular circumstances, from a duplex to an apartment to a condominium to a flat to a trailer to a house and still receive the intensity of supports that they need. People, with input from significant people in their life, can also choose where they want to live, including the specific neighborhood. Thus, the location of the home can build on and strengthen natural supports as opposed to severing those ties. For example, a person with medical needs and the support people in their home may benefit from a situation where a nurse the person knows lives nearby.

Individualization within Programs versus Individualized Supports

The word individualization has been so overused in the human services field that it is difficult to know what it means. For example, we have individual service plans that typically match people with existing programs. If the person is lucky, the plans may provide for some "individualization" within an existing program (i.e., minor adaptation of the existing program to better meet the needs of the individual). From this framework, a day treatment program of 60 people and a group home for fifteen are sometimes called "individualized." If a person is "allowed" to come for a half day to a program designed as full days, that too, we call "individualization".

A truly individualized approach to supports is substantially different, since it starts with the person and their life:

First, this approach starts with getting to know the person, including the myriad aspects that make each of us unique. Unlike the typical "deficit-based" assessment, a community assessment, a less formal process of getting to know the person in a variety of community environments, may be used. The emphasis is not on screening in or out of services, but on using the assessment process to determine the supports that will be initially needed. For a good discussion of this type of assessment, see "Getting to Know You: One Approach to Service Assessment and Planning for Individuals with Disabilities" (Brost and Johnson, 1984).

Second, an individualized approach to supporting adults in the community builds on the existing community ties and relationships that each person already has in their life.

Instead of supplanting these ties, this approach looks at how these natural supports can be both maintained and strengthened, if that makes sense in the life of the person. Many of the supports that people with disabilities need are already available through "generic" or community services available to the general public. An individualized approach includes an emphasis on using these existing supports as opposed to the creation of segregated supports and services. Thus, the role of the developmental disabilities agencies is to help strengthen these generic supports (e.g., health resources) in the community. For example, many developmental disabilities agencies have located physicians and nurses within their own communities who can play significant educational roles to other medical personnel.

Third, this type of approach involves tailoring or developing supports (not programs) that will best match the person and their life circumstances. The individualized nature of the supports is typically accomplished through an array of possible supports that can be accessed by the person, in any combination. For example, individualized supports can include: dental and medical care, respite, recreation, homemaker services, transportation, attendant care/home health care, health services, home and vehicle modifications, home and community training and support, equipment/supplies, legal services, adaptive aids, leisure and recreation supports, communication assistance, behavioral supports such as crisis intervention and counseling services, and employment services. Since it is impossible to anticipate every type of support that may be needed, it is very important that the array of services includes an "other" category. Individualized supports will vary in amount, frequency and duration from person to person.

> For Mike, who has only limited verbal communication, and was having difficulty in living in a group home of eight, an individualized approach to supports meant gathering nearly twenty people who knew him well (professionals, family members, and other community members) to talk together with Mike about possible places for him to live. The outcome was that Mike and another man in the group home, both of whom had expressed a desire to live together, moved into a small house, with a support staff person living downstairs in a basement apartment. It was about a mile from the group home--close enough so they could visit friends there and use some of the same stores and other community services where they had gotten to know people. After less than a month of living in this house, Mike and his roommate had gotten to know the woman living next door, and she agreed to be a contact person or source of assistance in case of an emergency. (Walker & Salon, 1987).

Rigidity versus Flexibility of Supports

The concept of flexibility is not a new one and throughout the years some agencies and service systems have found ways to be responsive to the changing needs of people. For example, Michigan has an exceptions payment mechanism that allows for additional payments for unexpected expenses. Connecticut has made available temporary services funds at the regional level for time-limited needs such as additional staff during a period of crisis in a person's life.

This same concept applies to individualized supports, but with a new twist. Since the supports are individually tailored, flexibility means that not only can the intensity of supports be changed but also the type of supports and the way in which the supports are provided. In addition, flexibility means that supports can be decreased as well as increased without the person needing to move to a new location. This results in continuity for the person, and again builds on existing supports.

> When Lisa and Susan, both labeled severely mentally retarded and with multiple disabilities, moved into an apartment together, the residential support agency put a staff apartment across the hall from them. After a few months, this staff apartment was withdrawn when it became clear that this intensity of supports was no longer necessary. Several hours a day of staff support from this agency was still provided to these women. In addition, Lisa began to receive support from the local Visiting Nurses Association and Susan received assistance from the Association for the Blind. A neighbor down the hall in their apartment building got to know them and offered to become an emergency contact person. (Walker & Salon, 1987).

Supports for People with Medical Needs

Many of the supports that people with severe disabilities need, including people with chronic health needs, are nonmedical in nature. However, there are needs that adults with chronic needs have that require "specialized health care." These can include, but are not limited to: access to medical supports on a routine and emergency basis, availability of staff trained in the person's care, specialized medical equipment and/or home modifications, emergency medical alert systems, and support and/or administration of medications.

First, staff must be trained in the care of a specific person. In talking about people with complex medical needs, service providers often make two errors. One, staff receive general training on issues such as positioning and medications instead of the detailed person-specific training and instruction that is necessary. Two, there is often a false assumption that a nurse, a physical therapist, or other medical professionals must directly give services as opposed to teaching and supporting the staff to do so. Many procedures, such as stomach feeding, can be taught to family members and staff who do not have medical background.

Second, there must be backup systems in place regarding the health care needs of people. The Macomb-Oakland system emphasizes the importance of the availability of physicians and nurses, additional staff when needed, and a home to come back to if a person needs to enter a hospital for a period of time.

Third, in most states there is a need for developmental disabilities systems to work with professionals in the state (e.g., physical therapists, occupational therapists, nurses) regarding community supports for people whom they may not have had a chance to work with in the past. States such as Michigan and Connecticut have plans to develop a core group of trained professionals knowledgeable in such areas as functional life planning and assessment for people with severe disabilities and chronic health needs.

Agency Housing versus Home Ownership

People with disabilities are typically required to move to agency owned housing to receive intense support services. Thus, if there is a problematic situation, it is the person with a disability who needs to leave and move to a new home.

One of the key elements in an individualized approach for adults is an emphasis on a person living in a place that s/he owns or leases either alone or in conjunction with other people. Only under certain limited circumstances should an adult live in the home of another or in agency-owned housing. Ownership and leasing have both legal and personal ramifications. Ownership means that it is the person's home first and foremost. It is a place that staff, not the person, can be asked to leave. People with disabilities have seldom had the opportunity for their home to be "their castle". This approach underscores the importance of my home and the feeling of ownership.

Physical Adaptations

Although not inherent in this approach, individualized physical and other adaptations appear to occur more often in people's own or leased homes than in agency owned housing. When living in your own place comes first, doing it all on your own (i.e., process) may become secondary to getting it done (i.e., outcome). Thus, adaptations may be a necessity in one's own home in order to continue living there. Families again have been the leaders in adapting the home environment for people with extensive health needs. These adaptations can include emergency medical systems, back-up supports and a variety of medical equipment. Developmental disabilities services can learn a lot from organizations like SKIP and from independent living centers.

Consumer Choice versus Consumer Control

Current literature in the area of developmental disabilities reflects the increased emphasis on and awareness of the importance of consumer choice. Still today people with disabilities, particularly severe disabilities, have very limited choices even in their day-to-day lives. For example, it is common to visit homes throughout this country where people do not have a choice in even what they wear or eat, and do not have the opportunity to participate in their daily routines. Communication boards, used during "program times", may remain hidden and unused during the course of the day.

The approach described in this paper emphasizes the primary importance of choice by consumers in major areas of their lives. It involves substantially increased control over life decisions, including consumers hiring and firing their own support workers. Particularly for people with physical disabilities, the independent living movement in this country provides numerous examples of this approach. Options in Community Living in Madison, Wisconsin (Johnson, 1985) has extended this approach to people with mental retardation, supporting people to learn to hire and fire their workers. Even if the agency hires the workers, people with disabilities can have substantial say in who is hired and how they are evaluated.

Sometimes people say that people with the most severe disabilities cannot make choices, even day-to-day decisions about their lives. We personally have not met a person who has not had preferences, likes and dislikes. In some situations, as a stranger it was difficult to know about the person's preferences, but this changed as we started to know them. The challenge, in some situations, is to figure out what are the person's preferences. People who know the person well and see the world more from their perspective can often provide valuable insights into what would be important in a living situation. Sometimes parents or friends have told us that simply no one ever asked.

Programming Times versus Learning Skills in Natural Contexts

The traditional approach to services for people with developmental disabilities is oriented toward programming and skill development. With the addition of Medicaid funding, services for people with more severe disabilities may take on an even more medical or therapeutic focus. Yet, these programs and therapies are often not integrated into regular routines and contexts, but occur in isolation from the daily routines. Good examples, however, abound:

> As one parent said, we put his favorite cereal on the top shelf. It is a natural exercise for him each morning. Another person said, we use the prone board while cooking. Terri is learning to cook hamburgers. She does just a little, but it is something we do together.

There is a wonderful literature on partial participation of people with severe disabilities (Baumgart et al., 1982, Ford et al., 1982). The article on the "Reconceptualization of the Role of the Residential Services Provider" (Knoll & Ford, 1987) is a good resource on examining the participation of people with severe disabilities in a full and meaningful day that extends beyond basic self-care needs to community recreation and work.

Social Integration and Community Participation

During the past few years, there has been an increased emphasis on the issue of community participation and social integration of people with disabilities. Many people with chronic health needs had often remained isolated, rarely leaving the places where they lived. Today agencies are beginning to foster the participation of people with severe disabilities outside their homes. For example, one agency in Maryland periodically awards $100 to a house counselor for special networking efforts. Another agency, Options for Individuals, helps people with disabilities to connect with other "typical" people in the community and considers self-care (e.g., feeding, dressing, diapering) as things that simply need to get done as you participate in the community. Other people who were in Medicaid funded "day treatment" are now working in supported employment situations tailored to their particular needs. These situations provide an opportunity for people with severe disabilities, including people with health needs, to contribute to their communities, to have opportunities to develop relationships, and to have more opportunities/choices in their lives.

Conclusion

This article has examined some of the issues in providing community supports to adults with developmental disabilities and chronic health needs. Many of these issues are common to all adults with disabilities (e.g., the need for homes instead of facilities, the opportunity to participate in the community). The underlying values that people with medical needs can be supported well in the community and that life for people with medical needs extends far beyond their basic health care needs are central to the full integration of adults with medical needs in the community.

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Walker, P. & Salon, R. (1987). Report on Centennial Developmental Services, Inc., Weld County, Colorado. Syracuse, NY: Syracuse University, Center on Human Policy.

Wolfensberger, W. (1972). The principle of normalization in human services.

ANNOTATED LISTING OF RESOURCES ON SUPPORTING PEOPLE WITH EXTENSIVE HEALTH NEEDS IN THE COMMUNITY

This section contains a variety of resources including materials on supporting people with chronic medical needs and/or who have been labelled as "technology assisted" and materials on supporting people with extensive physical needs and/or multiple disabilities. In our review of the literature, we found that materials developed for one group (e.g., chronically ill children) were not always easily available or seen as applicable to other groups (e.g., children labelled medically fragile and developmentally disabled). In order to increase exchange across these fields, we have combined these resources into one listing.

ACCH (Association for the Care of Children's Health). (1983). Guidelines for developing community networks. ACCH, 3615 Wisconsin Ave., N.W., Washington, DC, 20016. COST: $10.00.

This booklet is based on a demonstration project which developed a network of parents and professionals as a resource for focusing regional attention on the unique needs of families with children who have a disability or a chronic illness. It also incorporates the lessons of other successful community networking efforts from throughout the country. The book outlines strategies for facilitating networking, collaboration, and problem solving among parents and professionals who seek to improve services in their communities. It is not intended to be a how-to book, but rather a frame of reference to assist groups in their planning process. It contains a list of resources, sources for additional information, and several sample needs assessment forms to help in the initial stages of organization.

ACCH (Association for the Care of Children's Health). (1984). Home care for children: An annotated bibliography. ACCH, 3615 Wisconsin Ave., N.W., Washington, DC, 20016. COST: $7.00.

This excellent resource contains brief reviews of 110 books and journal articles on home care of children with serious medical or handicapping conditions. They were selected to provide a theoretical and practical groundwork for home care development, evaluation and research. A number of citations on home care of adults are included since there is more extensive literature in this area and many of the practical issues are the same. The citations are organized into the following topic areas: general models of home care; specific illnesses or conditions; preparing, educating, and training the care team and the family for home care; terminal care; educating the child; respite care; and funding. People interested in the topic of home care are strongly urged to obtain a copy.

ACCH (Association for the Care of Children's Health). (1983). The child and health care: A bibliography. ACCH, 3615 Wisconsin Ave., N.W., Washington, DC, 20016. COST: $11.00.

This booklet presents a listing of what the reviewers consider to be the best available materials dealing with issues surrounding the involvement of families and children with the health care system. The approximately 1200 resources listed here are divided into the following areas: developmental information and resource work; children and hospitalization; parents and families in health care settings, play and the sick child; preparation for medical events; children with specific illness; dealing with chronic illness; dealing with death; ambulatory pediatrics; selected children's books; and selected films for children, families, and professionals. As with other ACCH materials, this is an excellent and comprehensive resource.

ACCH (Association for the Care of Children's Health). (1983). Guidelines for establishing a family resource library. ACCH, 3615 Wisconsin Ave., N.W., Washington, DC, 20016. COST: $9.00.

The aim of this booklet is to provide direction in forming a special family resource library. The authors see this type of a library as a source for specialized materials for adults and children to help them understand and cope with health and family concerns. The library may augment programs offering services such as preparation for parenthood, training in child growth and development, orientation to the available resources in the community, health care for children with disabilities or chronic illness, management during acute childhood illness, or assistance in dealing with educational issues. The suggestions in this book are directed to community agencies, health care providers, schools, public libraries, or anyone interested in providing this type of information service for their community. The purpose, planning, funding, and management of a special family resource library are outlined. Extensive lists of references, resources, and sources for material are provided. An appendix provides 7 samples of forms to assist in the organization of this type of resource.

ACCH (Association for the Care of Children's Health) (1984). Home care for children with serious handicapping conditions. ACCH, 3615 Wisconsin Ave., N.W., Washington, DC, 20016. COST: $9.00.

This book contains the proceedings from a 1984 interdisciplinary conference convened in Dallas, Texas with the two-fold mission of a) advancing the knowledge of parents and professionals involved in home care and b) bringing these two groups together to plan strategies that will foster support for home care in professional development and public policy. The fifteen chapters contain a wide range of information reflecting the diversity of the groups involved in this meeting. The perspective of the physician, the parent, the nurse, the therapist, and the health services administrator are all covered. A number of model programs are described. Issues such as respite, finances, interdisciplinary communication, and access to public education are discussed in depth. All in all this small book provides a great deal of useful information for anyone concerned with home care of children.

American Family Health Institute. (1986). Home care manual series. Springhouse Corporation, 111 Bethlehem Pike, Springhouse, PA, 19477.

This organization has produced a series of 32 page booklets which outline in clear jargon-free text and illustrations basic procedures in health care. The titles in the series include: Bedsores, Care basics, Cast care, Colostomy care, Comfort measures, Crutches and canes, Danger signs, Dressings and bandages, Exercises, Feeding tubes and pumps, Help for the care giver, Hospital beds, Hygiene, Incontinence care, Injections, Medications, Oxygen therapy, Parenteral nutrition, Self-help aids, Suctioning, Tips for feeding the sick, Tracheostomy care, Urinary catheter care, and Walkers and wheelchairs. These are useful resources for non-medical personnel, family members, and people with special needs themselves.

Bersani, H. (1987). Site visit report: Calvert County, Maryland ARC, family supports. Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, Syracuse University.

This is one in a series of qualitative research reports on programs and services that support people with severe disabilities in the community. The report highlights the positive practices in family supports offered by this private, nonprofit agency, including supports to some children with medical needs.

Bock, R. H., Lierman, C., Ahman, E., Weinstock, N., Alweis, M., Mitchell, F., & Ortiz, M. (1983). There's no place like home. Children's Health Care, 12 (2), 93-96

This article reports on the two years experience of a hospital-based pediatric home care service. The structure of the home care team and the process of service delivery are described. Most of the patients served in this program had multiple disabilities. The experiences recounted support the premise that home care is a cost effective health care approach. Issues to be addressed in further evaluation of home care are presented.

Campbell, P. H., Green, K. M., & Carlson, L. M. (1977). Approximating the norm through environmental and child-centered prosthetics and adaptive equipment. In E. Sontag, J. Smith, & N. Certo (Eds.). Educational programming for the severely and profoundly handicapped. Reston, VA: Council for Exceptional Children.

This article, which is technical, but clearly written, provides practical information on selecting equipment, designing prosthetics, and developing programs for people with severe physical and orthopedic impairments. The article contains numerous illustrations and case examples. The conclusion lists sources of additional information. The article is written for people involved directly in services for people with severe disabilities.

Center on Human Policy. (1987). Health care issues for children with special health needs and disabilities. Technical Assistance for Parent Programs (TAPP) Project, Federation for Children with Special Needs, 312 Stuart Street, Boston, Massachusetts.

This manual was developed as a resource for parents of children with special health needs or disabilities. The manual is designed to encourage parents to be the managers of their child's care and treatment, and to work collaboratively with health care practitioners for the benefit of the child. Section I outlines some of the key issues relating to the provision of health care and treatment for children with chronic illness and disabilities. Section II is a series of handouts that could be given to parents. Section III includes an overview of the Collaboration between Parents and Health Professionals (CAPP) Project and a reprint of the issue from Coalition Quarterly on health care issues. The last section refers the reader to additional resources.

Dixon, G. L., & Enders, A. (1984). Low cost approaches to technology and disability. National Rehabilitation Information Center, D:ATA Institute, Catholic University of America, 4407 8th Street, N. E., Washington, DC 20017. COST: $7.50

Disguised as an annotated bibliography, this report is a gold mine for disabled persons, their families, and many direct service providers. It makes accessible for the first time, in one place, the disparate and often hidden literature on low cost technical aids for disabled persons.

This is not another book recounting the wonders of the latest high-tech innovations. Rather, this resource provides ready access to the many simple devices and adaptations which meet the needs of so many disabled persons. In the past the unavailability of a central source for this information has meant that people who see these relatively simple needs have had to constantly reinvent the wheel. This resource fills that void. The book also includes 37 pages of annotated resources.

Finnie, N. R., Bavin, J., Muellere, H., Gardner, M., & Haynes, U. (1975). Handling the young cerebral palsied child at home (Second Edition). New York: Dutton-Sunrise

This is a clearly written and practical guidebook on handling children with cerebral palsy and other orthopedic disabilities. Written by medical and other health-related professionals, the book discusses movement, basic principles of handling, toilet training, dressing, feeding, speech, carrying, adaptive equipment and aids, grasp and manipulation, play and other aspects of caring for children with severe physical impairments. The book is filled with clear illustrations that demonstrate the points described in the text. The back of the book contains several useful appendices on the early stages of normal development, a questionnaire for parents, and resources in the United States (the authors of the book are from England), a glossary of medical terms, a reading list, and a list of resources for equipment and accessories. This is an excellent book for parents, foster families and direct care staff who deal with children with severe physical disabilities.

Fox, H. B. (1984). A preliminary analysis of options to improve health insurance coverage for chronically ill and disabled children. Author, 1620 Eye St., NW, Suite 300, Washington, DC 20006 {(202) 429-0160}

This technical report was prepared to assist the Division of Maternal and Child Health in its examination of alternative mechanisms for financing the cost of the care of children with chronic illnesses or other disabling conditions. It reviews the five basic models that exist to improve health insurance coverage for uninsured and underinsured populations. It further provides a preliminary assessment of these options in terms of their potential political viability as well as their potential benefits to families with children with disabilities. In conclusion, recommendations are offered regarding the optimal features of a new private health insurance program to meet these children's special health care financing and delivery needs.

Fraser, B. A., & Hensinger, R. N. (1983). Managing physical handicaps: A practical guide for parents, care providers, and educators. Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624. COST: $19.95

This book is intended to serve two purposes: a) to introduce physical therapists to the problems of individuals with severe handicaps, and b) to familiarize others with the fields of physical therapy and orthopedics. It is based on the experience of providing services to students with severe handicaps in the Wayne County (Michigan) public schools. Although it is written from the perspective of in-school services, this book is a valuable resource for any setting where people with severe physical handicaps are participating.

The presentation falls into three major sections: The first emphasizes the need to look beyond the disability and see the person. It also describes the nature of various handicapping conditions and offers one model for the delivery of physical therapy/orthopedic services. The second section describes and explains a wide range of physical handicaps. The final section discusses techniques for communication with, handling, and transporting people with severe impairments.

Gadow, K. D. (1986). Children on medication: Volume I: Hyperactivity, learning disabilities, and mental retardation Volume II: Epilepsy, emotional disturbance, and adolescent disorders. College Hill Press, 4284 41st Street, San Diego, CA 92105. COST: Volume I - $15.95, Volume II - $17.95.

These books are written to provide parents, educators, and nonmedical service providers with enough information to ask informed questions and make more knowledgeable observations of the individual receiving drug thera[illegible]. Each volume includes similar introductory material on the fundamental concepts of pharmacotherapy and carries the same appendices and glossary. When available, prevalence figures are reported for each disorder and for the use of drug therapy in the general school age population and in special education programs. Both therapeutic and side effects of the drugs employed are described, along with pattern of treatment.

Volume I focuses primarily on psychotropic drug use for hyperactivity and aggressiveness. Separate chapters deal with the use of drugs with children labeled learning disabled and with children labeled mentally retarded.

Volume II describes the use of drug therapy in a variety of low incidence disorders such as epilepsy, autism, schizophrenia, and depression.

Garwood, S. G. (Ed.) (1986, Winter). Topics in Early Childhood Special Education: Chronically Ill Children, 5(4). PRO-ED, 5342 Industrial Oaks Boulevard, Austin, TX 78735.

The nine articles in this special issue of TECSE cover a wide range of issues in services for children with chronic illness. The unifying thread of the articles seems to be an effort to sensitize professionals--especially educators--to the major concerns in this field. The lead article describes why the issue of children with chronic illness is one which merits attention. The following pieces deal with early childhood education programs, special developmental issues, parents' perspectives, research issues, fiscal concerns, professional communication, professional and organizational attitudes, and educational resources as they relate to children with chronic illness.

Goldfarb, L. A., Brotherson, M. J., Summers, J. A., & Turnbull A. P. (1986). Meeting the challenge of disability or chronic illness - A family guide. Paul H. Brookes Publishing Co., Inc. P.O. Box 10624, Baltimore, MD 21285-0624. COST: $14.95

This book is an extremely unique and valuable tool, written for all families experiencing any type of situation involving care of a family member who is ill or has a disability. It is also an important resource for professionals working with families. Filled with practical worksheets, activities and exercises, it provides information and techniques for family members to use in coping with their particular situation.

Part I, "Taking Stock," discusses methods of coping, relying upon one's value system, and various types of social and professional support. Part II, "Problem Solving," deals with family communication, problem definition, brainstorming for solutions, evaluation of alternatives, and action toward solving problems. The authors also include an Appendix of Resources, which contains a number of bibliographies on various subjects and a list of support organizations.

Green-McGowan, K., & Barks, L. S. (1985). Assessment and planning for health professionals. KMG Corporation, P.O. Box 2534, Peachtree City, GA 30269. COST: $19.95

The manual is an excellent resource covering such issues as the causes of health risk for people labelled as "medically fragile," methods of collecting information including interviewing techniques and observation of the person, an evaluation schema for the neurological, musculoskeletal, respiratory, gastrointestinal/urinary, endocrine, behavioral and nutrition/eating systems, and information on the development of health improvement goals.

The assessment methodology was developed by KMG Corporation specifically for use with people labelled as "medically fragile" in order to identify and categorize their genuine level of health risk and to focus on the management methodology of improving those risks. The manual is written specifically for health professionals and has limited applicability for non-health professionals.

Green-McGowan, K. (1987). Functional life planning for persons with complex needs. Georgia: KMG Seminars, P.O. Box 2534, Peachtree City, GA 30269. COST: $39.95.

This manual covers a variety of areas: human anatomy and movement, functional assessment, principles of 24 hour planning, adaptive equipment, environmental modifications, establishing goals and objectives, principles of team planning, and individual services planning, among others. An extremely valuable resource for planning supports for people with complex medical needs.

Hobbs, N., Perrin, J., Ireys, H., Moynihan, L., & Shayne, M. (1984). Chronically ill children in America. Rehabilitation Literature, 45(7-8), 206-213.

This article discusses the commonalities among severe chronic illnesses of childhood, reviews the definition of chronicity and severity, describes the current organization of care, costs of care and financing of care, identifies basic principles that should underlie public policy formation, and delineates the issues involved in systems change. A good resource for professionals, policy analysts, planners, and others involved in long-term policy formation.

Information Science Research Institute. (1984). Workshop on financing health care for handicapped children. Author, 8027 Leesburg Pike, Suite 102, Vienna, Virginia, 22180.

This is the proceedings of a conference held under the auspices of the Department of Health and Human Service, Public Health Service in May 1983 to respond to the special concern over health care financing that emerged as a result of the Surgeon General's December 1982 conference on Handicapped Children and Their Families. Four papers present an overview of issues in this area from the perspectives of a policy analyst, the Congress, and two groups of individuals with special medical needs. Additional papers review the problems and issues from the perspective of the providers of health care coverage. It contains numerous recommendations and strategies for moving the system toward a family centered and cost effective approach to paying for health care.

Kaufman, J., & Lichtenstein, K. A. (1986). The family as care manager: Home care coordination for medically fragile children. Coordinating Center for Home and Community Care, Inc. (CCHCC), P.O. Box 613, Severn Professional Building, Millersville, MD 21108. COST: $4.95

This workbook is an extremely valuable tool for parents and families who choose to care for their "medically fragile" child at home. Written clearly and concisely, it provides necessary and practical organizational information, as well as being an educational and informational resource tool.

Divided into four sections, Section I, the "Introduction," gives a brief review of what is entailed in a discharge plan, a very thorough needs assessment to be completed by the family, and a redefinition of "care manager." Section II, "Families as Care Managers," describes the five roles which families must assume as care managers: the role of medical manager, financial planner, educational advocate, resource specialist, and employer. Included within each topic are practical checklists and worksheets. Section III, "Maintenance of Records," explains the need for families to maintain an organized system of record keeping and delineates which information to include in an open file. Section IV, "Conversation with Families: Recurring Themes," lists those themes and concepts that the authors found to be common to families exploring the "home care frontier."

Kaufman, J., Lichtenstein, K. A., & Rosenblatt, A. (1986, November). Service coordination: A systems approach to medically fragile children. *Caring*, 42-48, 62.

In this article the role of service coordination is offered as a necessary alternative to traditional case management in services for "technology-assisted" and "medically fragile" children. The description presented here is based on the experience of implementing this role under the Maryland medicaid waiver. Within this system the coordination role includes responsibilities for screening, assessment, planning, cost effectiveness, supporting informal support systems, and on-going monitoring. The specific role of clinical care coordinator and financial coordinator are described in some detail. Issues in cost containment and determining cost effectiveness are discussed. A model cost effectiveness worksheet is provided.

Khan, N. A., & Battle, C. U. (1987). Chronic illness: Implications for development and education. *Topics in Early Childhood Special Education*, *6*(4), 35-32.

The position offered in this article is that while technological advances have assured the physical well being of a growing number of children with very complex medical needs, it is necessary to look beyond survival to the education and psychosocial development of these children. A model of early intervention which centers on the family while seeing to the child's on-going medical maintenance, educational growth, and social development is offered as one approach to meeting this need. A long term focus of this process is to smooth the movement of these children into the public school system.

Merker, E. L., & Wernsing, D. H. (1984). Medical care of the deinstitutionalized mentally retarded. American Family Physician, 29(2), 228-233.

It is sometimes asserted that community doctors are not familiar with some of the concerns surrounding the medical care of people who have a history of life in an institution where they may have been exposed to Hepatitis B or been administered massive doses of unneeded drugs. Merker and Wernsing provide an overview of the role of the community physician and special concerns as they relate to patients with developmental disabilities. They highlight the significant contribution a community physician can make in meeting the needs of these people. They outline the major "specialized" medical issues which may arise. They indicate that the family practice they are associated with has been able to meet these needs including management and reduction or elimination of psychotropic medications.

Mikol, M., Shannon, K., & Schuberth, K. (1984). Handbook for parents. SKIP (SICK KIDS Need INVOLVED PEOPLE), Inc., 216 Newport Drive, Severna Park, MD 21146

This handbook was prepared as a resource to families who choose to care for their "technology dependent" children at home. The handbook includes a plethora of practical information such as emergency and back up checklists, equipment worksheets, selected references, information on home care, documentation hints and information on SKIP. It is clearly written and would probably be a useful resource to service providers as well as to families. The revised version, Families to Families: The Home Care Experience, will be available at a cost of $7.50 postpaid.

Perske, R., Clifton, A., McLean, B. M., & Stein J. I. (1986). Mealtimes for Severely and Profoundly Handicapped Persons: New Concepts and Attitudes. Paul H. Brookes Publishing Co., Inc., P.O. Box 10624, Baltimore, MD 21285-0624. COST: $16.95.

The term Mealtimes is an apt title for this marvelously written and useful book. This book does not simply describe proper "feeding" techniques for people with severe and multiple disabilities. It shows how mealtimes can be designed to be pleasant and enjoyable experiences.

Sensitively written and superbly edited, this book is a collection of articles by professionals, parents, people with disabilities, administrators, and others. The book starts out with an introduction written by Robert Perske entitled, "A Gentle Call to Revolution." Perske sets the tone for the book in this introductory chapter by stressing the need for "dignity, kindness, cooperation, and skill." The remainder of the book is divided into four sections: Value of Mealtimes, Creative Interactions, Creative Uses of People, and Helpful Settings.

This is not intended to be a how-to-do-it handbook. Instead, the purpose is "to allow a wide range of people to speak plainly about the fresh attitudes they have developed about mealtimes and the innovative things they are trying to do."

Anyone who works with people with severe and multiple disabilities should read this book. Parents, caregivers, and agency administrators will find it especially useful.

Shayne, M. W., Walker. D. K., Perrin, J. M., & Moynihan, L. C. (1987). Health-impaired children deserve a break. Principal, 66(3), 36-39.

This article makes the case for the inclusion of children with chronic medical problems in regular schools. It points out that schools will have to examine and adapt in the areas of health and supportive services; absence and attendance policy; and life planning, transition, and career preparation in order to be truly responsive to the needs of these students. The article ends with 7 recommendations for action on the national and local scene which will positively influence the quality of life available to students with chronic health problems.

Stein, R. E. K. (1985). Home care: A challenging opportunity. Children's Health Care, 14(2), 90-95.

This six-page article addresses a number of issues regarding home care for the "chronically ill" child as an alternative to in-patient hospital care. Within the context of the article, the author raises six questions regarding home care, and proceeds to answer them with progressive, current and well thought-out discussion. Specifically the questions asked are: What is home care? Why is home care an issue now? Who can benefit from home care? What are the ingredients for a successful home care program? How should we evaluate the outcomes, and what do we currently know about these outcomes? What are some of the pitfalls of home care? Clearly written, this article appears appropriate for a wide range of readers interested in this topic.

Surgeon General of the United States. (1987). Surgeon General's Report: Children with special health care needs. Washington, DC. Department of Health and Human Services, Public Health Service (GPO # 184-020/65654).

This report is the result of the work of an on-going task force established in 1982. It recommends a national agenda to insure a commitment to family centered care for children with special health care needs. This agenda is promoted by these 7 action steps which make up the section headings of the report: 1) Pledge a national commitment to all children with special health needs and their families, 2) encourage building community-based service systems, 3) assist in ensuring adequate preparation for providers of care, 4) develop coalitions to improve the delivery of services, 5) establish guidelines to control costs of services, 6) encourage and support the development of adequate health care financing, and 7) continue to conduct research and disseminate information. Each section contains descriptions of 3 or 4 programs or services from around the country which offer examples of how that particular action step can be promoted.

Taylor, S. J. (1986). Community living in three Wisconsin counties. Syracuse, NY: Community Integration Project, Center on Human Policy, Syracuse University.

This site visit report highlights the innovative practices in community living for people with severe disabilities in Dane, Lacrosse, and Columbia Counties including: (1) county leadership, (2) setting priorities for case management, (3) family support, (4) innovative community living arrangements, and (5) the community integration program medicaid waiver. The stress throughout on individualization and flexibility particularly makes this report worth reading.

Taylor, S. J., Racino, J. A., Knoll, J., and Lutfiyya, Z. (1987). The nonrestrictive environment: On community integration for people with severe disabilities. Syracuse, NY: Human Policy Press, P.O. Box 127, Syracuse, NY 13210.

This manual outlines some basic principles of community integration, critiques the "continuum concept," describes homes and support services for adults and children with severe disabilities, discusses integrated vocational services, looks at what makes community integration work, and outlines some of the emerging controversies in community integration. Two appendices outline some strategies and resources to aid in day-to-day problem solving and describe 41 programs which are doing an effective job of integrating people with severe disabilities into the community. The manual is a good introduction to community integration and will be useful to a wide range of readers.

Taylor, S. J. (1985). Site visit report: Macomb-Oakland Regional Center, Michigan. Syracuse, NY: Community Integration Project, Center on Human Policy, Syracuse University.

This site visit report highlights the innovative practices for supporting people with severe disabilities in the community in two counties north of Detroit, Michigan. In particular, the discussion of permanency planning and specialized foster care will be of interest to people concerned about a family and enduring, stable relationships with adults for all children, including children with medical needs.

U. S. Congress. Office of Technology Assessment. (1987). *Technology-dependent children: Hospital v. home care--A technical memorandum*. Washington, DC 20402-9325, U. S. Government Printing Office (GPO # 052-003-01065-8 price: $4.75).

This report is an effort to provide Congress with the data necessary to examine issues surrounding care for the increasing number of children who are in need of on-going nursing care or medical technology in order to survive. It begins by looking at various definitions of this population and discussing how the definition affects any efforts to project long-term need for services. It offers a definition and then makes projections based on that definition. The next section examines the comparative effectiveness and cost of hospital versus home-based care. The general conclusion here is that home care can be as effective in the medical-technical realm as hospital care of most conditions and it tends to be more cost effective. However a number of potential problems inherent in "pushing" home care (e.g., placing unrealistic demands on families who are not up to them) are highlighted. The final section discusses sources of financing for home based care. There are major discussions of private insurance and a great deal of information on the range of medicaid waiver programs (at the time data was collected in mid-1986). There are also sections dealing with other programs which pay for home care. This report is essential reading for anyone who wishes to be informed on this issue.

U. S. Department of Health and Human Services. (1982). *Report of the Surgeon General's workshop on children with handicaps and their families*. Washington, DC: Author (DHHS Pub. # 83-50194).

The Surgeon General's workshop on children with handicaps and their families, held in December of 1982, provided the impetus for legislation on home care and assisted in developing programs across the country. This report discusses the workshop recommendations for strategies, presents an overview of programs for ventilator dependent children, and addresses the needs of children with other handicaps and the implications for care.

Utley, B. L., Holvoet, J. F., & Barnes, K. (1977). Handling, positioning, and feeding the physically handicapped. In E. Sontag, J. Smith, & N. Certo (Eds.). *Educational programming for the severely and profoundly handicapped*. Reston, VA: Council for Exceptional Children.

This is a technical, but clearly written article that describes handling, positioning, and feeding techniques for people with severe physical and multiple disabilities. The authors address assessment and measurement, proper positioning, task analysis, feeding techniques, precautions, and sources of additional information. They provide a step-by-step approach and offer numerous examples. The article is written for people who work directly with people with severe disabilities.

Walker, D. K., & Jacobs, F. H. (1984). Chronically ill children in school. Peabody Journal of Education, 61(2), 28-74.

This article traces the historical and philosophical determinants of current school programming for chronically ill children. It describes the range of available educational options and placement patterns for students with chronic conditions at various grade levels. The most common problems connected with these conditions are examined; these include problems confronted by the individual student as well as those the school faces as it attempts to plan and program effectively. Recommendations are made that focus on the delivery of educational services, future policy directions, and needed research.

Walker, P. (1987). Report on Centennial Developmental Services, Inc. Weld County, Colorado. Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, Syracuse University.

This qualitative site visit report describes the individualized ways in which adults with disabilities are being supported in the community in this predominantly rural county. While not specifically focusing on people with medical needs, the report highlights a new way of thinking about supporting adults with severe disabilities.

SOURCES OF INFORMATION ON HOME AND COMMUNITY-BASED SERVICES FOR PEOPLE WITH EXTENSIVE HEALTH NEEDS

ACCH-ASSOCIATION FOR THE CARE OF CHILDREN'S HEALTH

Address: 3615 Wisconsin Ave. N.W.
Washington, DC. 20016

Telephone: (202) 244-1801

Major Services and Activities:

ACCH is a multidisciplinary international organization that addresses the emotional and developmental needs of children and families in health care settings through education, research and multidisciplinary interaction. Its primary goals include: development of written and audiovisual materials which examine ways to implement a family-centered approach to care; dissemination of information through a Parent Network, various publications, and conferences; and facilitation of parent/professional collaboration and a family-centered approach to care.

Resource Materials Available:

A catalog of resource materials entitled, Educational Resources For Pediatric Care, is available by calling or writing to the above address. Included are a wide variety of extremely valuable materials: position papers, pamphlets and books, films, videotapes, filmstrips, buttons, and posters.

Membership information is also available from the same address. ACCH welcomes parents, as well as all professionals committed to family centered care for children with chronic illness or disabilities. ACCH membership benefits include: bimonthly newsletter, quarterly journal, and reduced rates for the annual conference, regional meetings, publications and employment notices.

SKIP - SICK KIDS NEED INVOLVED PEOPLE, INC.

Address: National Office
216 Newport Drive
Severna Park, MD 21146

Phone: (301) 647-0164 (Maryland number)
(202) 261-2602 (Washington, DC number)

Major Activities and Services:

SKIP is a national non-profit organization dedicated to helping families and communities to care for technology dependent children in the home. It is an organization developed by families with a primary purpose to assist other families. They help in identifying resources needed to prepare and maintain network to promote a safe home care setting. SKIP also aids families in advocating on behalf of their child in areas such as insurance coverage and financial assistance.

SKIP has 10 chapters (including the National Office and chapters in different states). Contact the National SKIP office for address and phone numbers of the other chapters and for more information on developing a chapter in your state.

Resource Materials Available:

SKIP publishes two manuals, Families to Families: The Home Care Experience and one on legislative skills.

Membership in SKIP is $10/yr. for parents (can be waived), $25.00/yr. for professionals or interested people, and $50.00/yr. for organizations.

CAPP-COLLABORATION AMONG PARENTS AND (HEALTH) PROFESSIONALS

Address:
CAPP Project
Federation for Children with Special Needs
312 Stuart St.
Boston, MA 02116

Telephone: (617) 482-2915

Major Activities and Services:

CAPP is a project of the Federation for Children with Special Needs that encourages participation from professionals and family members nationwide. The primary purpose of the CAPP Project is to increase and encourage parent involvement in the health care of their children with disabling conditions and chronic illnesses. The stated goals of the CAPP Project are:

1. The preparation of parents to assume an integral role in the health care of their children with handicaps and chronic illnesses.
2. The promotion of communication and collaboration among parents and health care providers.
3. The development of a national system to ensure parents access to information and peer support.

Resource Materials Available:

The following materials are available and may be requested by calling or writing. A fee for multiple copies may be requested.

Questions When Surgery is Recommended For Your Child
Preparing for Medical Testing
Rights of Patients (and Parents) in Massachusetts
Checklist of Items for Consideration in the Development of Individualized Education Plans for Students with Special Health Needs

Annotated Bibliographies:

- Attitudes Toward Handicaps and Chronic Illnesses and Strategies for Coping
- Communication and Partnership Between Parents and Professionals
- Personal Accounts of Disability and Illness
- Parent Involvement in Hospital Design and Policy
- Becoming Informed about your Child's Special Health Needs
- Considering Whether to Participate in Research
- Health Care Financing: Issues, Options, Strategies
- What Parents Need to Know about Case Management

RESEARCH AND TRAINING CENTER FOR PEDIATRIC REHABILITATION

Address: University of Connecticut Health Center
181 East Cedar Street
Newington, CT 06111

Telephone: (203) 665-0352

Major Activities:

This training program is involved with eight specific research and training activities, all related to the provision of early intervention for severely handicapped infants and children, ages birth to six. Training activities include: the development of an early intervention program model; provision of training and technical assistance to early intervention professionals with regard to providing integrated day care services; training and technical assistance to medical personnel, with regard to assisting families through transition from the neo-natal intensive care unit (NICU) to home; provision of family support services via a parent-to-parent network, and SKIP-Connecticut. Research activities include: a longitudinal intervention study following severely handicapped children ages birth to three; longitudinal studies of infants who have left the NICU; data collection regarding who interacts with these children; and development and implementation of a Transactional Intervention Program for infants, parents, and teachers.

This program is currently able to provide workshops and technical assistance onsite only within the state of Connecticut.

Resource Materials Available:

The Transactional Intervention Curriculum, an early intervention program for infants with severe disabilities, is presently available. Further materials regarding home care are forthcoming.

NATIONAL INFORMATION SYSTEM FOR HEALTH RELATED SERVICES

Address: National Information System
Center for Developmental Disabilities
1244 Blossom St, 5th Floor
Columbia, South Carolina 29208

Telephone: (803) 777-4435
National toll free line: 800-922-9234
for referral to agencies in the callers locales that
can provide services for chronically ill children

Contact: Kathy Mayfield, Project Manager

Major Activities and Services:

This is a computer-based information and referral system funded by the Division of Maternal and Child Health of the Department of Health and Human Services. It acts as a source of referral for consumers and professionals to tertiary and specialized service for children throughout the country with special health needs. It is expanding its services to become a national clearinghouse/resource for families of these children, rather then solely addressing the special needs of the child in isolation.

The National Information System which this project is implementing has three distinctive characteristics:

1) Free nationwide access via their 800 number;
2) human interaction between the consumer and a well trained counselor resulting in direct referral to appropriate service agencies; and
3) periodic follow-ups on the referrals to ensure appropriate referrals.

This system focuses on specialized medical, education and other health related services emphasizing diagnosis, treatment and support for children labelled developmentally disabled or chronically ill and for infants with life-threatening conditions.

Resource Materials Available:

This organization can refer inquirers to other organizations that distribute applicable written materials.

NATIONAL CENTER FOR EDUCATION IN MATERNAL AND CHILD HEALTH (NCEMCH)/NATIONAL MATERNAL AND CHILD HEALTH CLEARINGHOUSE (NMCHC)

Address: 38th and R Streets, N.W.
Washington, D.C. 20057

Telephone: 202-625-8400 (NCEMCH)
202-625-8410 (NMCHC)

Major Activities and Services

NCEMCH provides educational services to organizations, agencies, and individuals with maternal and child health interests. The center responds to information requests, maintains a resource center, develops publications on maternal and child health, and provides technical assistance in educational resource development, program planning and topical research.

Resources Available

NMCHC provides titles and publications in the fields of human genetics including topics such as pregnancy, nutrition, child health, chronic illnesses, and disabilities. Most publications are free for limited quantities.

AGENCIES, PROGRAMS, AND REGIONAL SERVICE SYSTEMS SUPPORTING PEOPLE WITH EXTENSIVE HEALTH NEEDS IN THE COMMUNITY

The following information was gathered primarily through phone interviews and is presented here as examples of supports and services for people with medical/physical disabilities. This is not meant as an endorsement of these sites, but as a way to enable you to contact other service providers or coordinators.

Coordinating Center for Home and Community Care

Address: P.O. Box 613
Severn Professional Building
Millersville, Maryland 21108

Telephone: 301-987-1048 (Baltimore)
301-621-7830 (Washington)

Contact: Joanne Kaufman
Karen-Ann Lichtenstein

Description of Supports and/or Services:

CCHCC is a federally funded non-profit organization developed to provide an alternative to lengthy hospitalization for children with chronic illness. They provide casemanagement, with a focus on the parents eventually becoming the casemanager. CCHCC does not provide direct service. Instead, it is their role to locate, coordinate, and monitor services provided to individual families and children.

A guide, The family as care manager: Home care coordination for medically fragile children, is available at a cost of $4.95. Procedure and training modules are forthcoming.

Home Care Team

Address: Children's Hospital
National Medical Center
111 Michigan Avenue, NW
Washington, DC 20010

Telephone: (202) 745-3393

Contact: Linda Maurano, Project Director

Description of Services and Supports:

The Home Care team attempts to bridge the communication and health care gaps which often exist between hospital, family, and community agency. It delivers comprehensive, homebased care to multiply-handicapped and high risk infants who need prolonged multi-faceted care outside of a hospital. The team provides therapy, nursing, social, educational, and counseling services to children and their families. The certral focus of all services is or training parents to feel comfortable as a the primary care giver. The team will instruct parents in such daily activities as feeding, positioning, stimulation activities, and the use of therapeutic equipment. The team is intended to be a interim service which fills the gap and helps the family develop skills and contact community services during the period immediately after the child returns home.

Macomb-Oakland Regional Center (Site visit)

Address: 16200 19 Mile Rd.
Mt. Clemens, Michigan 48044

Telephone: (313) 286-8400

Contact: Nancy Rosenau

Macomb-Oakland Regional Center is the state agency responsible for providing services for people with mental retardation in 2 heavily populated suburban counties north of Detroit. The policy in this region is that all children, without exception, have a right to be raised in a home and family environment. As it applies to children with extensive medical needs this policy has been achieved because it is supported by an extensive array of family support services available through the county mental health boards, the state subsidy to families of children with severe disabilities, and a special subsidized adoption program. Approximately 100 children with severe disabilities, including 30 children with very intensive medical needs, who have not returned to their birth family or been adopted are supported in specialized foster homes. These foster homes are supported by the full resources of the regional center. In an effort to insure a permanent home for every child a number of these foster providers are pursuing adoption or, if adoption or return to the birth family impossible, have been designated as a permanent home for a particular child. In addition, adults with complex medical needs are supported in community homes.

Medically Fragile Children's Program

Address: Developmental Disabilities Division
University of New Mexico
Mental Health Center
917 Vassar, N.E.
Albuquerque, New Mexico 87106

Telephone: (505) 843-2910

Contact: Shelley Carter, R.N. Program Manager

Description of Supports and Services:

This innovative family-centered support program was established by the State legislature in 1984 allocating funds to match a federal Medicaid waiver. The program provides case management; in home nursing care; speech, occupation, and physical therapy; counseling and support service to families, and environmental modification. The program is available to families with a child who has both a life threatening medical condition and a developmental disability. If resources are not available in the rural areas, the organization helps develop them. This program allows children to live at home who previously had to remain in hospitals or were placed in institutions. It helps the family develop confidence in its role as care giver and provide the support necessary to alleviate some of the stress associated with care of a person with extensive medical needs. A coalition of parents groups are primarily responsible for the development of this program. The continued presence of parents in all aspects of this program ensures that it remains committed to answering the needs of the population it was intended to serve.

Options for Individuals, Inc.

Address: 102 E. Oak Street
Louisville, Kentucky 40203

Telephone: 502-636-9198

Contact: Barbara C. Banaszynski

Description of Supports and Services:

This is an example of an agency that supports adults (who otherwise would be involved in a traditional day habilitation program or none at all) to be actively involved in the community. They assist people to build a network of support in the community, starting with environments nearest the home. They support community members in coming to know, understand and support their neighbors who have different needs but similar feelings. About a third of the people have physical disabilities. Self-care (e.g., diapering, feeding) is considered simply something that need to get done in order for people to fully participate in the community.

Recruitment Plus Project

Address: Department of Public Health
Family Health Services
150 Tremont Street
Boston, Massachusetts 02111

Telephone: (617) 727-5822

Contact: Ellen Levy, Project Coordinator

Description of Supports and Services:

The intent of this project is to recruit 25 foster and adoptive homes and 100 home health providers and respite workers. As part of this effort the project is reaching out to social services, medical professionals, and the general public to present information about the increasing potential for providing home care for severely medically involved children. As part of its primary mission the project acts as a matchmaker, connecting children with families who are able to provide them with a home. In addition the project coordinates some support services for families of children with medical needs. These services include an adaptive equipment exchange, a resource bibliography, and a training program on the medical care of children with multiple disabilities that is open to birth, adoptive, and foster parents; respite families; home health aides; interested professionals, or any potential care provider.

Region V Mental Retardation Services

Address: Region V Mental Retardation Services
2202 South 11th St.
4th Floor
Lincoln, Nebraska 68502

Telephone: (402) 471-4400

Contact: David Merrill

Description of Supports and Services:

This is the regional service agency for a 16 county area around Lincoln, Nebraska. In this region all medically involved children who live in the community are in natural, adoptive, or foster homes. State funded services throughout the entire state offer a full array of specialized services to families which assist them in maintaining a child with extensive medical needs or environmental adaptations at home. If this level of support is not sufficient the regional office can provide case management and other services including specialized in-home respite, staff support in the home, or other supports that the family may need. Essentially the same level of specialized supports are available for birth, adoptive, and foster families. The regional office maintains a liaison with community physicians to ensure that specialized medical needs are met. This region also supports a number of adults with complex medical needs in individualized community homes.

Ventilator Assisted Care Program

Address: Children's Hospital
200 Henry Clay Avenue
New Orleans, Louisiana 70118

Telephone: (504) 899-9511 ext. 509

Contact: Kathryn Ann Kirkhart, Ph.D.
Project Coordinator
Nora Steele, RN
Assistant Project Coordinator

Description of Supports and Services:

The ventilator assisted care program (VACP) was originally a federally funded project with a primary objective of providing an alternative to hospitalization for individual children requiring ventilator assistance. In addition to medical care, follow-up and an extensive array of interdisciplinary services have been available on an as needed basis at Children's Hospital. Currently, the VACAP is funded for case management service provision to inpatients and outpatients by Medicaid and the Handicapped Children's Services Program. VACP also assists local health care personnel by providing training and consultation. A number of training materials, a resource guide for living at home with chronically ill children, and various professional publications are available from VACP.

Westport Associates

Address: Westport Associates
P.O. Box N348
Westport, MA 02790

Telephone: 617-675-5710

Contact: Sheila St. Auben

Description of Supports and Services:

This agency is an example of supporting adults in homes, including at least one person with more extensive medical needs. This agency provides permanent homes for 10 individuals with severe disabilities. Everyone in the agency is intimately involved in direct service work. This agency exemplifies an effort to transform the group home model into more personalized homes with the agency adapting to the people.

Wisconsin Family Support Program

Address: Developmental Disabilities Office
Division of Community Services
P.O. Box 7851
Madison, WI 53707

Telephone: 608-266-7469

Contact: Beverly Doherty

Description of Services and Supports:

The purpose of this program is to provide families with whatever they need to prevent the institutionalization of their disabled family member. The program provides a "menu" of 17 services plus an information and referral system for the families that they serve. It also supports the counties in developing skills in supporting families.