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A Guidebook for Families

LEARNING TO LIVE WITH DISABILITY:

A Guidebook for Families

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I. INTRODUCTION

The family is viewed as the backbone of civilization, as the institution upon which society's other institutions rest, and as the source of each person's ability to relate to others and form an image of the self, or an identity. When people conceptualize a family they see it composed of a father, mother, and two or three children. In short, they see a nuclear family.

In its broadest sense, "family" refers to people related not only by blood, but by sentiment, marriage, agreement, or circumstance. In addition to the nuclear family, there are single-parent families, foster families, extended families, "blended" families, couples without children, communal-style families, and other forms of family life. This booklet is addressed to all these forms. Close friends can play a role in the support system of individuals or families as well.

The term "family," then, is meant to include people who are significant in the life of a person who is disabled, and who, even though not family members, perform functions which are thought to be what a family does — both with and for its members.

Depending on the ages of its members, the family is charged with various and complex responsibilities. Among them are caregiving, providing financial support and management, as well as physical and emotional support, helping with education, instilling values and discipline, providing for leisure and recreation, maintaining safe and sanitary living quarters, attending to health needs, while at the same time attending to members' needs for independence and self-expression.

This is a tall order for most people, who may lack the education, time, energy, experience, or willingness to fulfill all of these responsibilities at all times. Few families are capable of meeting all these needs for each family member — and the demand is even more awesome for single-parent families.

However, when one or more family members have physical and/or emotional disabilities, there may be additional responsibilities. These include:

- Helping to manage the disabled person's physical (or medical) limitations and the physical environment. Besides the home, the physical environment may include school, work site, transportation systems, meeting places, and recreation sites
- Being aware of and managing the emotional aspects of disability within the family, as they relate to the disabled person, friends, neighbors, and society generally
- Attempting to create an environment in which the disabled person can move toward maximum independence
- Becoming knowledgeable about the rights and services to which the disabled family member is entitled
- Communicating the needs of the disabled person and of the family to service providers and to society
- Monitoring the system to ensure that these rights and services are being provided and that they are responsive to the changing needs of the disabled person and his/her family.

These extra responsibilities can mean added stress for the entire family. Some common family problems resulting from these added stresses are marital discord, disturbed sibling relationships, a greater likelihood of emotional distress, drug and/or alcohol abuse, and an increased chance of family crises. No family can function in total isolation. There simply are not enough resources within a family to fulfill all the responsibilities with which it is charged. This is particularly true when we consider the family of a disabled person.

When a family member is disabled it is experienced on some level by each family member. When disability occurs in a family, changes in feelings, attitudes, lifestyle, financial conditions, energy and time expenditure, relationships, and independence may all be felt. Entire families can temporarily become as "handicapped" by disablement as is the disabled family member. They can lose the ability to cope.

The term "coping," as it is used in this context, does not only connote "acceptance"—although acceptance of disability is no easy or simple matter. Coping also means that the involved persons actively assume responsibility for their own welfare, by struggling with problems or obstacles, thus gaining the knowledge needed to solve problems.

While the impetus to solve problems stems from the determination of the people who are primarily affected, the process of coping does not require absolute self-reliance. Building self-reliance is important in that it builds internal strength. Moreover, if not taken to extremes, greater self-reliance enhances a person's ability to receive help, since it promotes equality in the relationship between the helper and the person who is helped. It affords the receivers of help the ability to choose

when and how they receive help. Therefore, coping must be considered qualitatively. It is the reach *toward* self-reliance, self-management, and greater understanding which makes living with disability a satisfying experience.

In this booklet we will provide the family of disabled persons, as well as those involved with such families, various means by which they can learn to cope more effectively with disability, and thereby minimize its disruptive impact upon the family.

More specifically, then, we aim to:

- Help families gain a better understanding of what disablement means to them
- Increase awareness of family needs relating to disability
- Help families develop the inner resources to minimize the impact of disablement
- Provide information on advocacy issues and methods
- Help families to better understand the services system
- Provide direction on when and how to seek help when the family's existing resources are insufficient.

When a family is suddenly confronted with the disablement of one or more of its members—be it that of a child, an adult, or an elderly person—it is often a confusing and frightening experience. It is confusing in the sense that so much is uncertain and much depends upon elements which are unknown or which seem out of human control. And it is frightening for the family, when the course, duration, and impact of the disablement cannot be predicted.

Society and rehabilitation professionals have traditionally focused attention on the disabled person. Families of disabled people have not received the attention they deserve. They have been largely neglected, and their feelings and needs have been minimized. In this booklet, we assume that while no family can solve all the difficult problems of disablement all the time, people working together, identifying their difficulties, sharing their experiences, and working on solutions, can manage their lives in a rewarding and satisfying way. Families can learn how better to help themselves and receive valuable help from others.

The experience of coping with disability can enhance growth, not only for the disabled person but for the entire family. It can be an opportunity to learn about one's strengths and one's capacity for understanding and developing healthy dependence and independence. It can challenge and, perhaps, realign one's values. It can also be a means by which a family can make lifelong and valuable connections and friendships with people outside the family who share similar concerns. To this end, suggestions and information will be given in the hope that

II. THE PROCESS OF UNDERSTANDING DISABILITY

Perhaps the most realistic and useful way for families to understand and endure disability is by viewing it as a *process*. The experience of disability is difficult to discuss because it changes over time. At times, the limitations imposed by disability are painfully evident, while at other times disability can seem to be no imposition at all. Because human beings can become disabled at any point in the life-cycle, developmental processes may be involved. Whatever disablement means to a family at one time, its meaning will change at a later time. Feelings, bodies, minds, and the political and technological environment will not remain static. Neither will the personal meanings of disability.

Adjustment to disability is an open-ended process of conflicts and resolutions which take place through the life-span of the affected person and his or her family. In this respect, it is identical to the processes of adjustment to any other life crises, challenges, or conflicts. But it is unique in that it may have a long-term impact on personal relationships, self-image, physical and emotional health, communication, learning, employment, transportation, and recreation. Few situations have the potential to affect as many aspects of daily life as does disablement.

Numerous factors will influence the extent to which a family will suffer the effects of permanent disability. Many of these factors will be covered more fully in later sections of this booklet. The major factors which affect how a family experiences disablement of a member are:

INNER FACTORS

- Physical and emotional health of family members
- Ability to parent well — comprising both the ability to nurture and the ability to encourage independence
- Capacity to communicate, solve problems, and organize tasks
- Willingness of family members to help each other
- Absence of other major stresses in the family
- Presence of an honest, flexible, and hopeful attitude of family members toward disablement
- Severity and limitations in functioning of the disabled family member
- Prior experience with disablement
- Ability of the family to ascertain and assert its needs

OUTER FACTORS

- Contacts (people) which a family has or is able to establish
- Awareness of resources in the community which the family can use
- Extent to which the community presents barriers, both physical and attitudinal
- Adequacy and responsiveness of the services system
- Willingness on the part of service providers to empathize with and include the family in the growth of its disabled member.

All of these factors can be changed to a greater or lesser degree through experience, education, assertion, determination, and support. A "hostile" environment inside and outside of the family can make the problems associated with disability insurmountable. Conversely, an encouraging family and external environment can further the understanding of disability and soften its impact. Viewed in this way, disablement, in and of itself, loses some of its negative power. It then becomes an issue of what people do and feel about it, how people go about the business of living with it, and how people grow despite its adverse effects.

People frequently have trouble coping with the frustration during the occasionally lengthy period in which a diagnosis is being made of their potentially disabled family member. A thousand questions will arise. "How long can this problem be expected to last?" "How incapacitating is this problem?" "What effect will this disability have on the family?" "How should the family treat the disabled person?"

During the onset, the family is not only experiencing its own feelings of worry and stress, but frequently family members are called upon to consent to treatment or testing if the "patient" is a minor, under their guardianship, or is unable to give "informed consent." For many families, this period is their first experience in dealing intensively with the medical profession or the hospital world. Few are prepared for the impersonality and long waiting periods which are often a part of clinic and hospital care.

Some families question the competency and credibility of the doctors involved in diagnosis and treatment of their relative. This is particularly true and quite justified when conflicting diagnoses are made. Problems with credibility intensify when the family is not included in the diagnostic process or is not being kept fully informed. Feelings of helplessness and dependency on the medical profession can alternately turn into resentment towards the doctors involved, or over-reliance on them to dictate prognosis and treatment. When a family member is seriously ill, hospitalized, or extremely incapacitated, trust in the medical profession is required (although it often is given with much trepidation on the part of the family).

Families are often ambivalent when a firm diagnosis is made. On the one hand, they need to know what the problem is so that treatment and/or rehabilitation can begin and a name can be attached to the problem. On the other hand, the desire not to know is strong, particularly if the prognosis is poor for the person's ability to either achieve (if disabled from birth) or regain normal functioning. Diagnosis is particularly painful for families and their disabled member when a degenerative disease process, such as muscular dystrophy, multiple sclerosis, or cystic fibrosis, is present. Such disabilities can be even more traumatic for families since some are linked to heredity, and parents are forced to consider the risk of having more children or the danger of the disease being present in, or carried by, other family members.

In those instances when the best diagnosis and/or prognosis must remain tentative, family members may find the stress of uncertainty intolerable. Or, the way in which the diagnosis is presented may paint an unnecessarily bleak picture of the prognosis for the disabled person. This can undermine the hope the family needs to carry on.

The time of diagnosis is often the time when the family is in shock and may be reacting emotionally. They are frequently unable to fully comprehend what they hear even though it has been thoroughly explained. This is the very time when a reasonable, inquiring, and less emotional approach is most needed. Sometimes it is wise to ask another adult family member or trusted friend to accompany the immediate family members to medical visits to give support. Below are additional suggestions which have helped families.

- Be prepared to present as much information as possible about onset and symptoms.
- Write out your questions for the doctor and be sure to ask them no matter how trivial they may seem to you at the time. Bring and use a tape recorder.
- Make sure the information given is understandable and acceptable to you. If you do not agree on a procedure or a course of treatment, state your objections and reasons.
- Sometimes you may want a second, or even third, opinion. It is your right to request this as a family member of a disabled person, especially if s/he is unable to make the request.
- Read and ask about the disability. Public libraries often have useful information which can aid you in becoming a more knowledgeable participant in the treatment process.
- Call the nearest organizations which specialize in the disability in question (see Chapter X for a list of national organizations). Talk to them about your family situation and inquire about the help they can offer to you now or in the future.

- Share information and feelings with your family and friends. Many of the difficulties families report having in the early stages of disability are due to the feelings of isolation from others who are concerned and who can offer support or constructive advice. Do not depend at this time on people who are themselves so distraught about the disability that they are not only unable to offer support but need a great deal of support themselves.
- If the family member requires extensive hospital treatment, and is medically fragile, ask the hospital social workers, nurses, or doctors what arrangements they have for overnight stays at or near the hospital. Some of the larger hospitals, particularly where children are treated, are beginning to provide rooms for families of hospitalized patients.
- Despite the disability, the disabled person is a *person* first. It is sometimes easy to forget this fact when so much attention is paid to the medical or functional disability, particularly during diagnostic phases. Honesty, love, and respect between the family and disabled person are the most important and most needed elements. Except where rapid and irreversible mental or physical deterioration has taken place, the person is essentially the same as before the diagnosis (or perhaps has even improved).
- Planning for the future can begin, if only tentatively. It is not too soon to look into rehabilitation programs and services. This subject will be covered in greater depth later on. However, families are often not informed of the programs available to them and their disabled family member. This can needlessly waste the family time and energy.

III. EMOTIONAL REACTIONS TO DISABILITY

In this section we will discuss some of the most frequent emotional responses to disablement. We would like to help families understand that what they have felt, or are now feeling, could be considered "normal" reactions to a difficult and stressful situation. Recognizing, understanding, and expressing the emotions associated with disablement enables greater mastery of daily inconveniences and obstacles. Therefore, because disability is first felt emotionally by the family, and emotionally and physically by the disabled family member, it is within this realm that we will begin.

DENIAL

Denial is the most common *initial* reaction to disablement. People use denial to shield themselves from the overwhelming emotional pain which full recognition of disability brings. Each family member will accept or deny the reality of disablement according to his or her capacity to understand what it means to them, their preexisting attitudes about disablement, and their emotional strength. Initially, denial protects the person from being engulfed by pessimism, despair, and frustration. Tom, a middle-aged man with grown children, said,

> After the doctor told me that my heart was in bad shape and that I would have to undergo triple bypass surgery, I went out and played three sets of tennis. My son found me at the court and really bawled me out for taking such a chance with my life. I guess he really loved me if he could get so angry with me.

While few people are quite as extreme as Tom was in this instance, denial of the disability or its potential seriousness occurs quite frequently. The father of a child who was born with club feet couldn't even use the words "club feet," until after successful surgeries were performed and his child's defects were corrected.

Disabilities which are invisible to others such as deafness, emotional illness, and disorders or diseases of the brain or internal organs, can be denied for longer periods of time, simply because they are not noticed by most people. It is therefore easier for the disabled person, and/or his family, to deny the existence of the disability on a wholesale basis.

Denial becomes harmful when the existence of the disability needs to be recognized so that treatment may be carried out and adjustments

made, or when the family isolates itself or the disabled family member solely to avoid the possibility of having attention called to the disability.

Usually, denial cannot be maintained. Eventually painful feelings of loss, anger, fear, guilt, worry, frustration, and depression occur. Since depression involves all of these feelings, often at once, considerable confusion can be experienced which compounds the difficulty family members may have in expressing their feelings or explaining irrational or puzzling behavior. Families will normally feel depressed for many months following the recognition of the permanance of disability and, as it is composed of other thoughts and feelings, chief among them being loss, anger, fear, and guilt, these other feelings will be explored in more depth.

LOSS

Any type of disability *always* involves loss, which is felt on at least two levels. The first, and most obvious, is the loss experienced on a functional or practical level. The person who is disabled has lost one, or more than one, ability to function as fully as s/he would have before becoming disabled. Since it is this functional or practical inability which is most apparent, it is this loss which is most easily identified and acknowledged. The parents of a developmentally disabled child see the child's inability to meet the normal milestones of infancy and childhood and may feel the loss of autonomy and independence as they foresee long years of struggle ahead.

For adults who become suddenly disabled, the loss of mobility, hearing, sight, or control of bodily functioning, can be more devastating than a gradual loss of functioning which is not quite so dramatic. The loss involved in childhood disablement, such as developmental disability, is most often felt by the family first, and only later in the development of the child when s/he perceives s/he is different from most other people. Loss on a functional level means that the person cannot do certain things. S/he either cannot do things in the same way as most other people can, or s/he may be completely unable to do some things.

Another level of loss which occurs with disablement is loss of a fantasy, plan, or dream for the future. For example, a person with a traumatic injury, which creates a permanent paraplegia, will experience a loss not only of mobility but of the ability to participate in athletics and to perform sexually in the same manner as before. S/he has lost an image of self as s/he was or perhaps had the potential to be. This can cause a temporary loss of self-esteem. The person's family experiences the same feeling of loss in varying degrees.

The family of a physically or mentally disabled child experiences the loss of an image of having a "perfect" child. And, since children are

seen by society as reflections on the family, parents may feel a loss of esteem from society as a result of having an "imperfect" child and, consequently, a loss of individual self-esteem. They may also have had fantasies and expectations as to what this child was to be, which do not correspond with the reality of the child's abilities.

Loss encompasses a painful constellation of feelings. Deep sorrow and grief are often accompanied by anger and rage, as well as a sense of betrayal as expressed in the words "why me?" Sometimes feelings of bitter disappointment arise. These can be turned outward as revenge onto society or other family members, or inward as self-condemnation. Fear of death, fear of emotional or physical pain, or fear of further disablement can also be felt.

The healthy expression of loss can be seen as a process of allowing these and other painful feelings and thoughts, which occur over a period of time, to be felt, acknowledged, and even discussed in a safe environment, without fear of retaliation. It is important not to hold back or bury feelings unless, after expressing them over a period of time, they have changed or have greatly lessened. This may be hard to do, not only because it is painful to openly experience loss, but because our society seems to value emotional control. This climate of suppression can psychologically harm the family if it leads to bottling up expressions of sorrow, grief, anger, and other emotions. Chronic depression can result from physical and psychological losses which have never been fully felt, expressed, or resolved.

Expression of loss generally comes about slowly, in gradual doses. Grief and sadness can reappear suddenly as memories or fantasies of what has been lost are triggered. Expecting that this will happen will help in overcoming the effects of grief. It is part of the reconstructive process.

ANGER

Anger gives many people difficulty. Frequent feelings of anger accompany physical disability, particularly in its early stages. It can take many guises aside from the full-blown yelling which most frequently comes to mind. Some of the myriad forms anger can take are:

- Frequent and mild-to-severe frustration
- Rage (with or without physical violence)
- Blame of others, or "the system" ("It's their fault!")
- Chronic resentment (reasonable or unreasonable expectations not met)
- Guilt-inducing behavior ("Look what you did to me")
- Extreme passivity ("Do it for me, I can't")
- Martyrdom ("killing with kindness" at the expense of self)

- Over-solicitude or patronizing others
- Hostility ("I'll get back at you somehow").

Anger, in and of itself, can be considered a pure emotion just as are sadness, joy, hope, or fear. It can be expressed in its pure form, or, as above, with other motives or actions attached. Or it can be felt in combination with other feelings, such as fear.

It is very difficult to adequately express and then let go of anger toward disability, particularly permanent disability, because it seems so *unfair.* We want to make sense of it and yet we can't. We want to make it somebody's fault, and indeed, in some few instances either directly or indirectly, it was! Sometimes it gives one temporary feelings of relief to focus on someone or something other than oneself. Doctors, schools, God, fate, parents, and family members are frequent targets of anger — sometimes justifiably so.

Anger can be destructive if it is misdirected, as in some of the previous examples, or if it is bottled up and turned inward as an attack on one's self. Such misdirected anger becomes self-perpetuating. It can spoil not only a person's outlook on life, but close relationships as well. Both misdirected and bottled up anger can be illustrated by this example:

> Angie is a bright, healthy fourteen-year-old girl who, because of being injured in an auto accident at five years of age, is disabled. She cannot walk without the help of braces and canes, and this she does very slowly. In all other respects, however, she is physically normal. She is still being dressed and groomed by her mother, Jean, and because she previously had refused to do household chores or keep her own room clean, she is no longer asked to do so. Instead, her mother, who also has a full-time job, cooks and keeps house with some begrudging assistance from Angie's eight-year-old brother, Jason. Angie's father, Carl, who was driving the car in which Angie was injured, occasionally berates his wife for being too easy on Angie, but for the most part avoids any confrontation of any family member, and withdraws from interacting with them. In the past year, Jean has been an extremely active, vocal, and irate member of a small group of parents who are attempting to reform Angie's school.

Among other things, this example illustrates the importance of good communication and task sharing, which in this family could not be accomplished without first uncovering the misdirected and bottled-up anger (and guilt) which hampered each family member. It wasn't until Jason became constantly ill with stomach pains that the family doctor recommended family counseling to them. Fortunately, they were able to

understand their feelings and how these feelings affected not only their family relationships, but their other activities as well.

Anger is a normal and natural response to disability — to being hurt. And it is felt by the entire family. It is important for the family to acknowledge their anger without resorting to blaming each other or using other indirect avenues of anger expression. Sometimes it is very beneficial to ask someone (who you know will not judge you negatively or reject you for feeling angry) to just sit and listen to your angry thoughts and feelings. If no one can be found who would react unemotionally to you, use a tape recorder or write your anger on paper. It's essential to express it, even if it seems irrational. After all, there's nothing rational about disablement.

FEAR

Another feeling which everyone has at some times but which becomes particularly pronounced with disability is fear. Fear of: pain, being alone, financial insecurity, total dependence, loss of love, the future, independence, or even death, can become major preoccupations for those facing the emotional stresses of physical and/or mental incapacities.

The person who becomes disabled suddenly may fear a now-dangerous outside environment which once felt relatively safe. The presence of curbs and steps, of barriers in attitudes, and of needing to make complex plans to execute what may be a relatively simple task, cause realistic fears to arise. The tendency, then, may be to retreat, at least temporarily, into an environment that is manageable and controllable.

Different fears are associated with different disabilities. For instance, people who are blind or deaf may feel that people are talking about them or playing tricks on them because they cannot see or hear all that is going on around them. Those who are physically dependent on others for basic assistance may fear abandonment by those on whom they depend, or its opposite — being engulfed and controlled by the physically needed person(s).

The person who is developmentally disabled or multihandicapped may fear greater independence. And, the impact which the prospect of independent living has on the family of a developmentally disabled adult has not been fully appreciated. The adjustment which the family must make, often without sufficient support and information, can have the same intense quality as when the developmentally disabled child was newly diagnosed.

Generally, these very deep fears diminish over time as reality, experience, and practice aid in replacing them with action. Disabled people and their families should not be surprised, though, if fears

occasionally surface. This is entirely understandable given the very real difficulties they must face in the long process of adjustment, particularly if the course of disability is uneven or downhill.

A major fear of those who have progressive diseases comes from the lack of *predictability* one faces. Hope alternates with despair, relating to one's endurance, health, perhaps one's employment, and other areas of life. How can one function with such uncertainty?

Many elderly people are beset with real and terrible fears, some brought about by financial insecurity or poverty, others by failing physical and mental capacities, and others by lack of safety in their environment, which can cause isolation.

Planning for emergencies and back-up support, as well as having some financial reserves, can go far to alleviate some of these practical fears. Knowledge of what may be expected in the course of disablement is also extremely helpful and minimizes the possibility of being caught completely unprepared for a crisis. Further, families can turn to agencies for assistance.

GUILT

Guilt is one of the most complicated and devastating of human emotions because it tends to be circular; that is, it leads to denial of guilt, anger, acting out, shame or remorse, more guilt; or other such mixed and complicated feelings. Most people accept more guilt for their thoughts and actions than is warranted and are consequently in a position of forever "paying back" for wrongs they have not committed. Others seem to have an insufficiently developed sense of guilt, are unable to accept responsibility for the negative consequences of their actions, and usually turn their guilt feelings into angry attacks on others.

Guilt which is unresolved or unacceptable to the person can stem from many sources; among them are:

- An exaggerated sense of omnipotence; that is, the person feels s/he has the "God-like" quality of being able to wish or will something negative to happen
- Parental or other influences in early years having the effect of making the child feel responsible for the "bad" things that happened to his or her parents, to him/herself or others, but for which the child was not actually responsible
- A feeling that if something is denied another person, harm will take place; this can result in failure to assert oneself, and fear of disagreement
- Failure to acknowledge or attempt to make reparation for harms actually committed can cause guilt feelings to linger
- An overly critical attitude towards one's self and others.

Actions which arise from feelings of guilt usually compound the problem, since they can result in extreme self-sacrifice. Conscious or unconscious bargains which are made (based upon unacknowledged guilt) can lead to resentment, anger, and the same circular pattern as was previously described.

It is important to uncover and analyze the sources of excessive guilt feelings. Parents, for instance, of a severely disabled child will often feel overwhelming guilt over wishes that their child had not lived. They are often unable to express these thoughts to one another, and they become deeply buried. Or they can feel that God is punishing them for past misdeeds by giving them a handicapped child. These deep feelings of shame and guilt, if not directly expressed, can lead to suppression or misdirection of anger, conversion of guilt to excessive fears and worrying, emotionally induced illness, or overprotection of the child. Disabled teenagers and adults can feel a great deal of guilt about thoughts of suicide or of otherwise harming themselves.

Families can help uncover guilt feelings, whether warranted or unwarranted, by permitting family members to communicate freely about their guilt feelings. Sometimes even bringing up the topic of guilt by such "exercises" as having family members write out their responses to statements beginning with "I feel (felt) guilty when . . .," and discussing their responses, can help.

IV. DEPENDENCY, INDEPENDENCE, AND INTERDEPENDENCE

All people are social animals, and all people are dependent. The human infant remains physically and emotionally dependent on its family longer than any other creature in the animal kingdom. Centuries ago, societies considered that adulthood was reached during the teenage years as soon as the person was able to reproduce children and to work. Emancipation occurred much sooner in the life-cycle because life spans were shortened by disease, wars, and other hardships. Today, even though children may be physically mature, they are seldom emancipated until they have reached their twenties. So, our society not only condones but encourages a certain amount of dependency on the family through young adulthood.

Society also seems to condone more dependent behavior for girls than it does for boys. The women's liberation movement has pointed out the differences in how families socialize girls to be less competitive and aggressive (at least overtly) than boys. Fortunately, families are becoming more aware of these differences in attitudes in rearing children and are accepting and encouraging variability in behavior for both sexes.

Emotional dependence on others changes and decreases with age but is always present in the healthy individual. In times of stress, we are emotionally more dependent on others for support, listening, care, and encouragement. We may also be more dependent physically as our energies are taxed and activities which had been easy are more difficult to perform.

Increased emotional dependence may last a long time, even after a crisis has passed. Adjustment to changed circumstances requires some time, patience, and people who are able to understand and respond to the greater needs for assistance.

For a disabled person, a certain amount of physical dependency is often necessary because of the limitations imposed by the environment on mobility, employment opportunities, recreational outlets, and so forth. The amount of dependency on others (or on special equipment) also will vary with the disabled person's physical or mental limitations. Some mentally retarded individuals may always require some sort of supervision if their judgment is severely impaired. A severely physically disabled person may be unable to prepare meals, turn in bed, or use the toilet without assistance. Environmental controls, assistive devices, and recent breakthroughs in communication aids hold tremendous potential for maximizing self-sufficiency for disabled people. Attendant care is

also an increasingly recognized need since attendants can help families reduce the amount of time they spend caring for their disabled member's physical needs.

However, since supportive devices can break down and supportive people can be unavailable, family members may be the only back-up people to whom the disabled person may turn. While planning for alternative supports during these periods of "breakdown" can help to prevent crises, changes within the services systems will also be necessary to minimize the risks in living independently for severely disabled and elderly persons.

But it is emotional over-dependence which is so difficult to change. Over-dependence usually begins as soon as the family begins to treat the disabled person differently than they treat other family members. They may make special allowances because of feelings of pity or guilt, or they may worry excessively about the disabled member's well-being. Sometimes a cycle of caregiving, characterized by alternating guilt and resentment, takes place. This can be very hard to modify. The term for this is "hostile dependency," for mutual hostility builds up on the part of both the caregiver and the recipient of care. Both parties battle for a sense of control over the other in an endless attempt to bolster their self-esteem. Sadly, many relationships are governed by these dynamics throughout all of society.

Over-dependence and over-protection of a disabled person can spring from other sources as well. For instance, families of disabled people can be just as vulnerable to the negative stereotypes and images of disability as is the rest of society. These distorted notions of disabled people as "pathetic victims" are difficult to change, particularly if the family has been exposed to these negative images over many years.

Another factor which contributes to over-protection is that some disabled people, at one time, really required intensive family caregiving. Consequently, patterns of relating to that person were established on the basis of a very real situation. However, if the physical needs for caregiving lessen while the family maintains its previous level of care, expecting dependency and helplessness, that family is "stuck" in an outmoded reality. If adjustments are not made, such as encouraging self-care and assuming other responsibilities, the disabled person's helplessness will often persist.

The effects of over-dependency have a doubly crippling effect on the disabled person. S/he may fear opposing the family and being assertive, for to do so might threaten relationships on which s/he depends for love, care, and, in some cases, survival. S/he may avoid taking responsibility for independent actions for fear that failure would bruise an already insecure ego. S/he may withdraw passively or become manipulative, using disablement as an excuse for helplessness or lack of initiative.

The family, in these instances, most probably has rewarded helplessness because it may view the world as cold and dangerous or because the disabled person's independence would threaten the family's shaky equilibrium. If a mother, for instance, has devoted most of her time and energy to caring for a handicapped "child" over the years, and suddenly s/he leaves, she is left without a major function which had formerly been her *raison d'etre.* She may then be faced with a marital relationship which has been unsatisfying, no career, and perhaps no marketable skills.

This dismal outcome can be prevented if the family is aware of the appropriateness and inevitability of greater degrees of independence as the disabled member matures. By gradually building toward emancipation and by anticipating that family relationships will change as a result of growth and development, family members will be able to view each other's increased independence positively.

Independence is never absolute. It does not mean that no dependencies exist. What it has come to mean to disabled people is increased freedom of choice, increased dignity, equality of status with all other citizens, and increased opportunities to develop a personally satisfying lifestyle. In short, a disabled person can expect to enjoy the independence which any other person in society enjoys to the fullest extent possible.

Perhaps a more accurate term to use when trying to describe the condition between the two extremes of total independence and total dependence is "interdependence." This term does not imply that interdependence is an intermediate step on the path to total independence, for that is an unattainable and unwanted goal. Interdependence merely recognizes what already exists in both our natural and technological environment. We all depend on each other for certain things and, at different points in our lives, some needs become major concerns which formerly were of minor concern. Interdependence implies recognizing your needs (some of which change with development through life's stages, while others endure, such as the need for love and self-esteem); risking having them met through increasing your own abilities to help yourself; and working with others who share your interests and concerns. A disabled man summed up an important insight he gained from group therapy in saying, "The key to independence is knowing when to be dependent."

Strangely, greater interdependence can be developed by recognizing dependency, if possible, *without guilt*. Here are some other steps family members can take to lessen dependency.

- Reassure yourself that other people feel dependent and you are not unique.

- Recognize that no one person can give you everything you need, and learn to expect different things from different people.
- Become as self-reliant as you can, keeping in mind that self-reliance boosts self-esteem.
- Look for *appropriate* sources of support, but beware of exaggerated expectations focused on the wrong people. Spouses cannot be expected to be parents to each other at all times.
- Have family discussions about family needs and problems. Try to redistribute tasks so that each member shares more equally in household responsibilities. For instance, your teenage disabled family member probably can be helped and encouraged to participate more fully in self-care, in family tasks, and in personal and family decision making.
- Work toward more equalized relationships based upon respect rather than guilt. These differences can be characterized by doing more with the disabled person rather than "for" him or her. And, it is also appropriate for the family to receive help and support *from* the disabled person at times.
- Explore opportunities for the disabled person and family members to learn from "modeling." Modeling means that people in similar situations (peers) share the successes and failures they've had in overcoming obstacles. Some programs such as centers for independent living offer such opportunities for peers to get together and help each other.

Remember that your family is also part of a larger system. There are many opportunities to get help and support from friends, other family members, neighbors, and professionals in the community. Don't be afraid to seek help when you need it. It's not only your privilege but your right!

Families play an important role in helping both "normal" and disabled children learn about sex. The topic of sexuality is complex and highly personal. The term "sexuality" conjures up many different things to people. To some, it means the act of sexual intercourse, while for others it connotes a life force, energy, or drives. Others closely relate sexuality to sensuality. The emotions people associate with sexuality will differ vastly and are determined not only by past life experiences, but how people feel about themselves and about themselves in relation to others.

The earliest experiences of sexuality occur in the mother-baby relationship. The baby feels sensually gratified through being touched, held, caressed, bathed, fed, and talked to by the mother and other nurturing people in the baby's life. It is upon this foundation that the baby learns about himself/herself, if only partially, and, the baby learns

about relationships with others. Sexuality, through sensuality, is present in the infant. It changes or develops complexity throughout the life-cycle of each person.

The expressions of sexuality may vary greatly from one person to another. When a person is disabled, the means by which s/he expresses sexuality will depend upon physical and/or mental capabilities, the person's self-image, their ability to form relationships, and the availability of suitable partners. In these respects, sexuality for disabled people is identical to sexuality for nondisabled people.

Disabled people are sexual human beings, just as is everyone else. However, problems with feelings about sexuality and the expression of sexuality occur more frequently with disability. In addition to the factors mentioned above (self-image, ability to form relationships, availability of partners), other factors may impede a disabled person's ability to experience sexuality in a satisfying fashion. These factors are:

- Inadequate or distorted knowledge of sexuality and human reproduction
- Feelings of fear or shame about one's body and the expression of sexuality
- Few opportunities to develop relationships, resulting in an immaturity with others.

Families can help a developing child with one or more disabilities to have a positive self-image, by being comfortable about sexuality in general, by discussing sexuality with their child according to the child's ability to comprehend what it means, by using the correct names of body parts including genitals, and by encouraging the child to respect himself/herself and others.

Many sex education programs for disabled people are now available through schools and universities, and are also being offered by private agencies. Family planning agencies are beginning to provide special services to teenagers and adults with disabilities. Counseling is more readily available to individuals, couples, or groups for whom disability-related issues present obstacles to fulfillment in sexuality and relationships.

Families can assist a disabled person by creating a healthy, enjoyable, and responsible climate about sexuality and all other forms of self-expression. When the issues relating to sexuality of the disabled person are beyond the family's capacity to resolve, or are inappropriate for the family to handle, assistance from others can be obtained.

V. PROBLEMS AND RESOURCES

A family with one or more disabled members is still a family. It is like and unlike any other family unit. But there are some unique needs of families faced with disability which other families may not have to confront as fully or as regularly. Counselors who work with the families of disabled people have noted that personal problems and issues which may have been dormant but unresolved will reappear when the family faces the stresses of disablement. It is almost a rule of thumb that the happier and healthier a person or family is before disability hits, the better they are able to cope with its effects. A teenage child of two blind parents states, "I think the effect of disability on me is not very much . . . it's more related to who the people are in the family, their personalities, and the ups and downs which normal families have." Her parents have worked hard to achieve the harmony which they now enjoy. The hard work this family had to do involved confronting, in a positive fashion, the obstacles which the disabilities of both parents posed for all of the family members. The following section describes some of the problems which disablement can present to families, and suggests ways to overcome these typical problems.

ENHANCING FAMILY COMMUNICATION

The stress families feel when faced by disability can be greatly eased by strengthening family relationships through good communication. Some ways to improve family exchanges are:

- Learn to make "I" statements. Phrases such as "I feel," "I think," tend to avoid the problems of using others to speak for you. Using "I" statements promotes individual responsibility for actions and feelings.
- Try to be objective when talking with others. Avoid "blaming" statements, or "scapegoating" of family members. Examples of blaming statements include: "You never listen to me," or "You've always hated me," and "If it weren't for you, I'd be a happy person." Statements which indict a person's character (usually containing the words "always" or "never") and which imply that the person is "bad" and always was, are extremely unproductive. Likewise, self-esteem is greatly lowered when a particular family member is consistently singled out for verbal attack or rejection (scapegoating).

- Use communication as a process of discovery rather than as a means to get back at others. If people are attacked for their openness (provided their openness does not attack others), they learn to withhold communication. This process can undermine trust between people.
- Make sure each person is heard and understood. This is particularly difficult when a person has a speech or hearing impairment. Some families unwittingly tend to exclude a person with a communications impairment, because it requires extra time and energy to carry on an interchange. Another problem occurs when families "speak for" the disabled person when the situation calls for that person to speak (or communicate) for him or herself. The extra efforts, within reason, which a family makes to encourage *full* and *accurate* communication between all of its members, and to allow each member "equal time," will pay off in building mutual respect.
- Respect and tolerate differences of opinion and feelings. It is a problem if the family requires all of its members to be the same, and if there must be consensus on all issues. If family members are truly permitted to be individuals, then they will naturally experience life differently according to their own points of view.
- Check out whether the messages given to others are received as you intended them. Watch to see whether the tone of voice and body language correspond with the spoken words. Be attuned to misplaced anger (anger directed toward someone or something other than the real source) or unwarranted or excessive anger. Look at how tenderness and love are expressed.
- Risk asking for what you want, recognizing that everyone can't get everything they want at all times.
- Learn to take turns and to compromise. Communication, like most things in life, requires give and take. Negotiate so that even if some needs are not met fully, they are at least met partially.
- Leave open the possibility of renegotiations to more fully get what you want.
- Look at who makes decisions in the family and how. Does one member impose his or her will while the others acquiesce? Or do members mutually agree and compromise? Do changes need to be made? Sometimes one person, occasionally it may even be the disabled member, will be allowed to behave as a "tyrant," dictating to and controlling other members of the family. In such cases outside guidance and intervention may be needed to help equalize relationships within the family.
- Communicate clearly according to the levels of each family member's understanding. Children are often unable to understand

complicated terminology. Mentally disabled people may require some repetition of concepts to be able to fully understand their meanings. The feeling that people around one are speaking a "foreign language" has the effect of excluding those who are not "knowledgeable." This may result in a sometimes not-so-subtle form of domination.

- Make sure that there is agreement on a time to talk and hold to it. Most important decisions require time for soul-searching, information gathering, full discussion, and planning. It is difficult to reach a major decision in a few minutes without negative repercussions.
- Admit when you are wrong. People often feel that if they do this they will lose self-esteem or the esteem of others. But experience has shown that just the opposite effect occurs.

Many families of disabled people are reluctant or reticent in discussing their feelings about the disability. This reluctance often stems from a feeling that greater emotional damage will take place if feelings are brought into the open or that the disabled person will feel personally attacked. While it may take courage to do so, as a rule, the more open the family communication is, the better the chances are of gaining needed support and strength.

TASK SHARING

Families can get into ruts regarding tasks, and this can produce much resentment. It is useful, sometimes, to reassign or reapportion tasks so that each member learns to do different things around the house and to contribute more fully to the family's functioning. For instance, parents of disabled children can take turns in providing care. Teens, including those using wheelchairs, can help to prepare meals, wash dishes, do laundry, and clean the house. Caring for pets is another task which most disabled teenagers can successfully accomplish.

Taking turns and sharing tasks build competency and give each member a sense of mastery. The skills developed in the home and in the areas of self-care can be transferred to other life situations. Occasionally, even vocations are developed through competencies acquired at home. Task sharing may require considerable patience, ingenuity, and firmness, depending on the personalities of family members and their willingness to try new things. But, most families that have followed through say it's well worth the extra efforts involved.

ROLE FLEXIBILITY AND INFLEXIBILITY

Aligned somewhat with task sharing is role flexibility. Studies have shown that the more able any individual is to handle a variety of roles

(such as those of employee, parent, child, student, volunteer), the better adjusted and more mature that person could be considered. As a child develops, s/he acquires more roles, and with them come the demand for added skills to meet the requirements of each role.

People differ in how they meet role requirements, and no one can handle all the requirements of all the family roles alone. This is why it is so difficult for single parents, for instance, to cope or flourish without outside support and relief. With disablement comes role strain, as family members are called on to perform duties and replace vital functions which may have been manageable in the past.

Sandy, a young married woman, says,

> I was so completely dependent on Jim to support me (since I had never held a job), listen to my troubles, and really to plan our lives, that when he became disabled, I was absolutely lost. I wanted to leave him, but I didn't know how I'd take care of myself. If it hadn't been for his parents, who stepped in and helped, I know I would have gone crazy, or worse. . . .

While it is true that disability in the family always occasions a sense of loss, Sandy's words illuminate some of the problems which rigidity of family roles (in this case marital roles) can cause, over and above the stresses of disability itself. Sandy was doubly unprepared for change because she was still living as a child with Jim acting more as her father than as her husband.

Another frequently observed problem springing from role inflexibility is one in which all of the caregiving responsibilities for home and children rest upon the mother's shoulders. This is difficult to remedy since traditional societal expectations have reinforced this concept of the mother's role. When there is a disabled child in the family, the increased caregiving responsibilities are often too great for the mother alone to assume. The problem worsens if she feels too guilty to ask for help, for fear that to do so would be an admission of failure. Resentment often ensues. This predicament can create emotional distance between the mother and the rest of the family which, if not resolved, can produce serious emotional and physical hardships and an overly protective attitude toward the disabled child.

Nondisabled siblings can experience the same problem. Studies have shown it is usually the eldest daughter who, through increased guilt feelings, or parental inability or unwillingness, is persistently cast in the caregiving role. Studies of siblings of mentally retarded youngsters show that they have an increased incidence of psychiatric disturbance characterized by poor peer relationships, temper tantrums, and depression.

Virtually any family member can fall prey to the problems inherent in assuming the lion's share of responsibility for one or more disabled family members. It is hard for the family to change this situation because the member who assumes this responsibility is usually the one for whom it comes most naturally and because that member is performing a vitally needed function. It also offers increasing rewards, because as time passes, one becomes more expert in fulfilling this role.

There is danger that the individual growth needs of the person assuming the caregiving role will be sacrificed, or underdeveloped. The child who must be mother, the mother who may only be mother, the father who may only be child, all have one thing in common. They have few opportunities to develop themselves as separate and unique people outside of the roles which they perceive are required of them. The resulting problems can require outside intervention, to help families adjust so that all family members can be allowed greater possibilities for self-development.

STRESS MANAGEMENT (HALT)

Members of Alcoholics Anonymous use an expression which is meant to alert the recovered alcoholic to a situation which could be dangerous to continued sobriety. It is, "Don't get too Hungry, Angry, Lonely, or Tired," or HALT.

Families under stress can find themselves in all those situations, and it is a warning signal to use in assessing whether basic needs are being met. Emotional and physical crises can be averted if the family remains aware of these basic needs. People in stress often forget to eat or may have sleep disturbances. They may be more irritable or weepy, which makes it harder for them to reach out for help. This can cause further isolation and loneliness. Action needs to be taken. Take time to nourish yourself and rest, even if you can't sleep. These are essential bodily needs. Improvement of general physical health can greatly minimize the effects of stress and alleviate much emotional vulnerability.

Here are other steps you can take to better cope with stress.

- Get out of your accustomed environment if you can, if only for a short break. Choose an environment conducive to alleviating the stress you feel. For instance, if you are anxious and tense, choose a serene place in which to unwind. If you are lonely and depressed, choose a place in which you can be with people.
- Try some physical activity. Use the many recreational outlets available (the object here is to release the tension inside).
- Relaxation techniques are often very useful in times of stress or even as a daily practice. Yoga and meditative exercises can greatly benefit your health. The basic relaxation technique involves

alternating tension of muscles (for five to seven seconds) and relaxation of muscles for twenty to thirty seconds. Focus on different muscle groupings beginning with facial and jaw muscles and slowly moving down the body to the feet. Yoga and meditation practices cannot be covered in sufficient depth here, but these and other useful relaxation techniques are contained in *The Relaxation and Stress Reduction Workbook,* referenced in "Further Reading and Resources" at the end of this booklet.

- Communicate your worries, tensions, and problems. Choose someone who is a good listener and who is in a position to help you.
- Try to discover what is causing your stress and consider these questions:
  A. Have I tried all that I can to alleviate the stress?
  B. Is the source of stress beyond my power to change?
  C. Can I accomplish change by joining with others to work toward a remedy?

Sometimes families of disabled people, or disabled persons themselves, aren't able to separate problems into the elements unique to their circumstances or common to many families in their position. Isolation of the family makes this process much more difficult. Now, with help more available, it is most important that families become aware, informed, and engaged with others in their situation and with those people who have been trained to help.

OTHER QUALITIES TO ENHANCE COPING

Families who seem to adjust well to disability have certain qualities in common. Some have had to work very hard to develop these qualities, while for others they came more naturally. These qualities are:

- *Assertion of self and of one's own needs.* This is *vitally important* when one is in a dependent position, relying on many other people or systems for finances, medical care, education, or other help. People can be trained to be assertive (as opposed to being aggressive) through formal training or advocacy awareness workshops. Assertiveness is based upon recognizing the legitimacy of your needs and rights, and it is an essential ingredient of taking responsibility for self-management.
- *Resourcefulness.* This quality can be developed in many ways, such as by having an inquisitive attitude toward life in general, asking questions when information is needed, sharing your experiences with others, reading to obtain more information, and asking for assistance.

A key word to think of in relation to resourcefulness is "sharing;" that is, that a part of getting is also giving. Families can share their knowledge of the system to help each other, and knowledge of the system aids in more effectively utilizing available services.

Another important aspect of resourcefulness is the ability to develop contacts which can be useful in raising funds, providing physical care, or other types of concrete assistance. Sometimes a contact you have made within a service delivery system, or with a legislator or influential person in the community can make things happen for you when you alone were unsuccessful.

Keep resource files with business cards, program information, records of correspondence, newsletters, articles, meeting notes, and names of people to contact for various services. Seek out other parents or families which share your concerns, ask them for their phone numbers and addresses, and keep them handy. You could have the beginnings of a good community coalition.

- *Patience*. An often-overlooked quality which can ease much tension is patience. It seems to come quite easily to those who recognize and accept the fact that major change doesn't happen very quickly. Physically disabled people and their families are acquainted with the extra time and energy it takes to perform most tasks, to get from one place to another, to communicate, and to wait for medical appointments. They know that planning is required to avoid either rushing or missing appointments.
- *Sense of humor*. Some families have reported that humor has saved them when life seemed pretty tragic. While some people feel there is nothing particularly funny about disability or the predicaments disabled people face, others have been able to accept their disabilities and to even joke about them. Geri Jewel, a commedienne with cerebral palsy, has a comedy act in which she incorporates jokes about her disability. Because of her uncoordinated movements and slurred speech, she was sometimes mistaken for being drunk. So she had a teeshirt made which said, "I don't have cerebral palsy, I'm drunk!" While humor doesn't have to involve disability itself, the ability to laugh and joke does suggest acceptance of the situation and the pleasure of the moment. Psychologists suggest that humor is very therapeutic, and many people agree.

PROBLEMS WITH ALCOHOL AND DRUGS

Though substance abuse is a nationwide problem affecting literally millions of Americans, it seems to occur more frequently (though there are no accurate statistics) among disabled people and their families. The

causes of substance abuse could be many and are open to speculation. Some feel that chemically-dependent people have a susceptibility or predisposition, which may be hereditary, to the effects of stimulants and depressants and can thus quickly become physically addicted to them. Others feel that environmental factors such as family or group abuse of alcohol and drugs, and life pressures and stress, are the most important causal factors. Other suspected causes are emotional problems such as chronic depression, or other mental health problems. Probably all factors have some validity as causes.

Disabled people may need to take more medications for physical pain, muscle relaxation, and sleep disturbances. Thus they are more likely to depend on medications even after the original need has diminished. Physicians will frequently prescribe these medications for emotional distress, or because a patient frequently complains, and the physician does not know what else to do.

Depression, isolation, and the lack of satisfying relationships, which some disabled people or their family members experience, can make them wish to alter reality as a "solution." Indeed, lack of adjustment to disability itself can precipitate overuse and abuse of alcohol and/or drugs. Becoming or being disabled may produce thoughts of suicide, and chemical addiction is slow suicide.

The attempt to withdraw (or even the thought of withdrawal) from the depended-upon substance may be met with resistance, fear, anxiety, and even physical symptoms. However, continuing to overuse drugs (including alcohol) damages relationships and self-esteem, increases emotional isolation, and may interfere with work. Alcohol abuse eventually causes physical damage to the body, or even death. Section 504 of the Rehabilitation Act considers alcoholism and drug abuse as disabilities in and of themselves. Substance abuse coupled with physical disability, then, is a double handicap the family must face.

Fortunately, much help is available for those who suffer from the diseases of alcoholism and drug addiction. Families can help by recognizing that substance abuse is occurring, and that alcoholism and drug abuse are very serious problems. Don't be afraid to talk to the family member with the problem and offer your support for getting help. Write for more information about the problem if necessary (see the resource list at the end of this booklet).

Discuss the issue of getting help, as well as the treatment possibilities, with family members. Your family physician may be able to steer you to proper treatment. It may even be wise to have a physical exam prior to treatment, as hospitalized detoxification may be the only safe means of withdrawal from the substance. But physical withdrawal is only the first step in treating substance abuse. A counseling or self-help program must be started immediately and must get at the causes

of the person's need to drink or take drugs. A more positive means of coping with life must be found to substitute for the destructive use of alcohol or drugs. A variety of treatment approaches are available. They are:

- Alcoholics Anonymous — This was one of the first self-help groups and is the largest program available today for alcoholism. AA is a voluntary fellowship of alcoholic persons whose sole purpose is to help themselves and each other to get sober, stay sober, and mend their lives. Narcotics Anonymous uses the same steps and principles as AA. Al Anon family groups have been set up for the spouses and friends of alcoholic persons. Alateen helps the children of alcoholic individuals understand drinking and related problems at home and outside the home.
- Counseling programs — These are staffed by specially trained substance-abuse counselors, often persons who have themselves recovered from alcoholism or drug abuse.
- Psychotherapy — Individual and group psychotherapy can help individuals to better handle their problems by building trust in another person.
- Family therapy — This treatment approach is gaining acceptance as marital and family relationships are recognized as being profoundly affected by substance abuse, and as families are seen as capable of promoting recovery and building healthier relationships.

Most recovered alcohol and drug abusers can regain functioning abilities which were lost prior to recovery. Indeed, many contribute significantly to their communities and families. But they have learned that they must refrain entirely from taking in the offending substance "one day at a time."

RELIGION AND FAITH

While it may be controversial to discuss, religion is nonetheless a potent force in some families, and it can have either a positive or negative impact. When disability occurs in a family, members try to make some sense of it, to answer the question, "Why me (or us)"? In some cases, medicine cannot give the answer as to why a disability has occurred. Some families seek spiritual answers to such questions.

Many people believe that human beings are not only composed of mind and body, but of spirit as well. Religious families have received considerable emotional (and sometimes financial) support from their affiliations with religious groups. Religion provides them with a framework of spiritual values; it offers a community of people with whom to share concerns and resources; and it can add meaning to their lives.

Religious affiliation and faith can be important resources for some families. Indeed, it has been noted that some families who before had no particular feeling or need for religion became very active in it because of disablement. While spiritual growth seems very conducive to emotional and physical well-being, strong words of caution are needed. The cases of actual faith healing are few. If a family expects its disabled member to be permanently cured of a permanent disability, they are most likely to be bitterly disappointed.

Some disabled people report that they have had dreadful experiences with adherents of certain religious groups. One woman reports:

> In my experience, religion offered no more satisfying explanations/answers to "why me" questions than medicine. In actual fact, much of the hassles of attitudinal barriers are the direct result of, or are easily derivable from, religious absolutism. This ranges from being accosted in public places by those who insist that I "believe and be healed," to avoidance (of me) by those who sense "evil" in disability.

Each family must carefully consider the physical and psychological effects which attempting to "cure" a permanent disability might have on the disabled person and the family. The desire for a cure can stem from a wish to deny the disability entirely and may prolong the grief process or prevent the seeking of medical care.

The endless, sometimes worldwide, pursuit of medical remedies may have as negative an impact on the family as the search for supernatural cures. The reasonable person must, at some point, decide that what can be done *has* been done, or *is* being done. This permits the process of living with disability to advance.

A man who had had lymphomatic carcinoma for fifteen years said, "I'm not dying of cancer. I'm too busy living with it." Religion and medicine can be balanced in a healthy way. Most medical practitioners will respect the religious beliefs and practices of their patients. They will often accommodate families' needs and preferences for treatment and will devise ways to uphold religious practices while providing treatment.

It is understandable that any remedy which has the potential for alleviating or curing a disability will be sought, particularly while the family is grieving over the disability. Physicians admit that there is much which is not yet understood or scientifically provable about disease and disability. Yet much is already known about the diagnosis and remediation of disability, and medical practices have been developed to minimize the risks to the patient.

THE EXTENDED FAMILY, NEIGHBORS, AND FRIENDS

Disability is somewhat like death or divorce in its impact on relationships outside the immediate family. People go through many stages to either broaden the numbers and kinds of relationships they develop, or to narrow their relationships to the "tried and true." This depends a great deal on the temperament of the family, how they have emotionally and physically coped with disability, and how they see themselves in relation to the community.

Most people genuinely want to help a disabled person (or their family), but don't know what to do. Unless they have directly experienced disability, they tend to have a variety of reactions to a disabled person, many of which are awkward or unwelcome.

Families are particularly sensitive to the reactions to disability of friends, neighbors, other family members, and strangers. Feelings of rejection, disappointment, and exclusion by those outside the family are frequently heard, particularly in the early stages of disability. The family then tends to close up and limit itself to situations and people who are "safe." For some families, this can be a period of retrenching while relationships are sorted out and decisions are made as to which relationships need to be saved and how, and which should be let go. As one disabled woman put it, "You really find out who your true friends are."

Some families never move out of this stage and remain isolated. This is unfortunate because they frequently are unable to obtain the help they need when they need it, since they have closed off their resources along with the hurt from which they are attempting to shield themselves.

You will need to decide how to handle cruel or insensitive remarks if they are made. Naturally, the time and energy the family spends on correcting misperceptions or rebuffs from others will depend upon how important the person (who is insensitive) is to the family, or how frequently the same or similar problems arise.

Some methods of handling these troublesome situations are:

- *Family role playing* — Compile a list of the most frequently encountered difficult or hurtful situations. Have family members take turns in playing the rejecting or avoiding person, while another member plays the person who is being rejected or avoided. Devise responses which can be used comfortably by each family member in these situations. Rehearse these responses until they feel spontaneous and can be employed almost automatically.
- *Confrontation* — By saying something such as, "I sense (my) disability makes you uncomfortable. Why is that so?", attention is

deflected back to the source of the problem, i.e., the feelings, behavior, and attitudes of the other person. This enables a more honest interchange which could change the other person's awareness.

- *Simple explanation* — Sometimes people ask naive or blunt questions. These merely require a simple, explanatory answer. For instance, an answer to a question such as, "Why can't she walk"? could be "Because her disability makes her legs so weak that she needs help in getting around." The specific disability need not even be mentioned unless it must be known or you wish it to be known.
- *Ignore the situation* — Some situations are either too minor or offer too little possibility for positive change. The best response to such situations is to turn your back. Chalk it up to the ignorance of others, and don't waste your time or energy on attempts to change this ignorance.
- *Drop the "rejectors"* — If reasonable attempts have been made to form a relationship with another, based upon understanding and respect, and disability continues to be a major obstacle in forming or sustaining a satisfying relationship, then it's time to question its continuation. It is healthier to seek out those whom you accept and who accept you, rather than staying with those who reject or exclude you.

Most families find it getting easier to cope with the outside world and the complicated world of close relationships as time goes by. The more open and comfortable the family is about disability, the easier it becomes to handle insensitive remarks, avoidance, uneasiness, or hostility from outsiders.

It is possible to educate those around you about disability in the course of your daily living. If it is very difficult to go to others' homes, invite them to your home. Sometimes you need to talk about your disability or that of your loved one, and express what you need directly and openly, since others can't guess what you're feeling. Neighbors, extended-family members, and friends can be very helpful. You might be able to devise a cooperative system of child care, or back-up plans for emergencies. If they drive and you don't, they might be able to take you to your appointments or do your shopping in exchange for other favors or paid work you do for them.

Sometimes people outside the family are more helpful than those in the family because they aren't as emotionally involved in your day-to-day struggles. They might be able to offer emotional support or bolster your spirits when you are low. Some have become so involved in helping the family that they are excellent advocates and may accompany parents to school meetings or doctor visits where support is

needed. They also may be willing to lend money to the family when short of cash.

As people with disabilities participate more in the everyday lives of nondisabled people, the "images" of disability become more crucial. Negative images and stereotypes of disablement are being challenged and changed not only through the media, but through interaction between disabled people, their families, and others in society. Thus, the potential increases for everyone to view people with disabilities as *people first*, with their disability being of secondary importance. As Wilfred Sheed wrote in his editorial "On Being Handicapped" (*Newsweek*, August 25, 1980), "Any affliction within reason can be gotten used to in time. Being treated funny cannot."

FINANCES AND PUBLIC FINANCIAL ASSISTANCE

Unless a family is wealthy, disability can be financially draining. Since public assistance monies are unobtainable unless a family's income is near the poverty level, disabilities often affect middle-income families the most. Family standards of living sometimes rapidly decrease as medical bills increase.

It is important to determine your financial needs for treatment of the disability. If your family does not have a social worker, call the nearest hospital and speak to the social worker there about what financial and program resources are available to you (this will depend on the disability your family member has, his or her age, and the family income level). The dollar amount of public assistance to disabled people varies from state to state, due in large part to the money each state is able to match with the federal grants. If the hospital social worker is not familiar with programs and other potential sources of financial assistance, *don't give up.* Ask for a referral to a public or voluntary agency for the information you need.

The public agencies which offer specific programs for disabled people nationwide or which provide financial resources for income maintenance (money on which to live) and purchase of services (programs for disabled people) are listed below.

- The federal Social Security Administration (SSI, SSA, SSDI) provides money to disabled children of low-income families or disabled adults over age eighteen who are living independently, who are in an out-of-home placement, or who are full-time students and unable to work because of their disability.
- Medicaid provides medical insurance for low-income disabled people; eligibility for SSI automatically qualifies the disabled person for Medicaid.

- County or state departments of social services provide AFDC (Aid to Families with Dependent Children) monies to families with children until they can earn enough to support themselves; they also administer homemaker-chore or in-home support services for disabled people. Food stamps may also be available to families, depending on state regulations and family income.
- Services for developmentally disabled persons vary from state to state and are financed by both federal and state governments; services can include, but are not limited to, free diagnosis and evaluation, lifetime case management for those who require it, and purchase of services for the developmentally disabled individual.
- State crippled children's services (CCS) provide medical and social services, purchase of equipment, and payment of surgeries for those who are financially eligible, and outpatient therapy for orthopedically handicapped children up to age eighteen.
- State departments of vocational rehabilitation provide a variety of services aimed toward eventual vocational placement, including testing and evaluation, purchase of equipment, financial support for training and adult education, counseling, and job placement. In addition, new "habilitation" programs are starting which will provide independent living skills training to developmentally disabled and severely handicapped persons.
- CHAMPUS is a federally funded program which provides health, rehabilitation, and mental health services to military personnel and their dependents.

For more detailed information about financial resources for disabled persons, see *Financial Resources for Disabled Individuals* by the Institute for Information Studies, another publication in the Emerging Issues in Rehabilitation series.

Many middle-income families do not financially qualify for cash support programs. Medical or health care plans may be offered as benefits through employment. It is vital to have major medical coverage, but some families have found it difficult to obtain for their disabled family member if s/he has a "preexisting condition" at the time of a new application. If the disabled person is a teenager, and you face the potential problem of exclusion from coverage, you may want to prevent this by obtaining separate coverage for him or her *before* s/he reaches age twenty-one.

If your family receives public assistance in the form of income maintenance or supplemental income for disability, here are some simple practices you can apply which could determine whether you receive the assistance to which you are entitled or are stranded while your case is mired in red tape.

- Keep records of all signed agreements and correspondence you receive regarding your case. Any phone calls or conversations should be logged with the date of the contact, who you spoke to, and what was determined. These logs should be kept with your other case correspondence.
- If an action is to be taken, make sure you understand *why*. If you are required to make an appointment or supply the agency with information by a certain date, do so, or your benefits could be cut.
- Make sure you know of appeals procedures for clients. This is necessary whenever you deal with bureaucratic agencies. Identify the final arbiter(s) in appeals cases and how long it may take to render a final decision.
- If your caseworker cannot answer your questions sufficiently and resolve your problem, or if s/he treats you with disrespect, notify the supervisor and try to solve your problems that way.
- Report any change in income, either upwards or downwards, immediately. While some clients use the fact that public assistance payments only provide for living at a subsistence level as a reason for not reporting additional income, the penalties for governmental overpayment can be severe, ranging from simply paying the overage back, to denial of assistance eligibility, to criminal fraud charges.
- Realize that for recipients of SSI, any major life change, such as becoming a full-time student, moving from residential care to independent living, or getting a job, will automatically bring a redetermination of eligibility based upon the need to assess the financial situation or severity of handicap. While this determination is taking place, payments may be held up, sometimes for months. Prepare for this by notifying your caseworker well *in advance* of the change, if possible.
- Get as many brochures about the service as you can and study them carefully. More than likely, you will not be given complete information by your eligibility caseworker.
- Families receiving AFDC (Aid to Families with Dependent Children) who have a disabled child living at home who is eligible for SSI should weigh the benefits of applying for SSI for the child. SSI income is considered part of the total family income, thereby decreasing the amount of AFDC benefits a family receives. In addition, the family may be receiving an allowance for food stamps which will probably be decreased if the child is on SSI since the income from SSI *includes* a food allowance. But, if the child needs ongoing medical care and the family is *not* eligible for any Medicaid coverage, SSI for the child should be sought, since it automatically would cover the child under the state's Medicaid plan.

Disabled adults who wish to or who can actually work are in a bind with regards to SSI and department of rehabilitation goals and practices. The purpose of SSI income maintenance is to provide money and medical benefits (homemaker/chore or in-home support services may be added) for aged and disabled people who *used to be* considered unsuited for substantial gainful employment. On the other hand, vocational rehabilitation efforts now focus on more severely disabled people, some of whom are proving themselves capable of competitive employment when given training, education, and opportunities. The "bind" comes when a severely disabled person is newly employed and the income does not match the benefits received while *not* working. This creates a work "disincentive," and characterizes the dilemma which many permanently disabled people face when considering whether or not to join the work force. Vocational counselors need to follow up closely on their clients who could be in this position and intervene *before* the disabled person becomes jobless and moneyless.

If your family is destitute and is not in *any* public assistance program, General Relief is available and may be applied for at the nearest office of the county department of social services.

Some social service agencies, such as Catholic Charities, Lutheran Social Services, Jewish Welfare organizations, and the Salvation Army, plus some other non-religiously affiliated agencies, such as United Fund and Easter Seals, will lend or give money to needy families on a limited basis. Sometimes use of the money is restricted to the purchase of food or clothing (or medical care or equipment in the case of some Easter Seals chapters).

Some fraternal organizations fund projects to assist people who belong to a certain disability group. For instance, the Lion's Clubs fund medical and surgical care for blind individuals. The Elks sponsor programs which provide in-home therapy services to children with cerebral palsy living in rural areas (in California, Hawaii, and Arizona). The Shriners' cause is orthopedically handicapped children. Find out which fraternal organizations in your community contribute to charitable causes. It may be that they would be willing to temporarily sponsor your family's special needs or extraordinary expenses if there are no other means available to fund them.

COUNSELING SERVICES

From time to time, all families may find themselves under increasing stress and exhibiting more irrational behaviors. Marriages may become very unhappy, pressure may be applied by in-laws, or serious long-term problems may exist, such as emotional breakdown. Without enumerating all the troubling possibilities, when it is clear to the family or a family member that their "inner resources" are insufficient to resolve major problems, options can, and sometimes must, be taken to get help. These options for help can be informal, such as networks of professional and nonprofessional people, or formal, such as counseling or psychotherapy. The next several paragraphs will discuss counseling and therapy options, the networking model, and how families can more easily gain the help they need.

A variety of counseling is available in most urban areas, with decidedly fewer options available in rural areas. The quality of services can range from excellent to poor, and quality sometimes has little to do with geographic location.

A surprising number of families who need psychotherapy or counseling will make their selection from the telephone book or because they like the sound of the center's or therapist's name. Occasionally, these methods of selection will work out. But there are means by which individuals and families can make a more educated choice by knowing more about the field of mental health and getting relevant questions answered over the telephone prior to the initial visit.

Many individuals and agencies offer counseling or psychotherapy services. A partial list of the major types of services follows:

- *Community mental health clinics or centers* — Currently, there are over 300 centers nationwide which are federally and locally funded, and which operate on a sliding-fee schedule based upon the individual's or family's ability to pay. They generally offer short-term (six-twelve weeks) individual, group, or family treatment. They emphasize serving chronically or acutely mentally ill people who are "at risk" of hospitalization or institutionalization. Those with physical or mental disabilities or disability-related dysfunctions are generally given lower priority for services.
- *Family clinics, child guidance clinics* — These are often privately operated or nonprofit and are staffed by a variety of professionals. Services commonly provided include family counseling, child therapy, family groups, and when indicated, individual therapy. Many operate on a sliding-fee scale and will offer longer-term therapy.

- *Agencies specializing in disability* — Some will offer short-term counseling by staff professionals. Parent groups and training are often provided. Possible limitations for some families are that counseling is not as intensive or sufficiently lengthy to resolve major family or individual problems.
- *Peer counseling* — Though a new service concept and not available in many areas, disabled persons or experienced family members are trained to counsel other disabled people and their families. Such services are generally offered at a low cost, on a sliding scale or free, and can be long-term, depending on need. "Rap groups" are often available, many at no cost. This service has been pioneered by centers for independent living.
- *Private-practice psychotherapy* — This is probably the most expensive treatment available, but many insurance policies will cover a percentage (some up to 100 percent) of costs. The benefits of this method are the professional accountability of therapists, the ability to handle deep-seated problems, and the availability of long-term treatment. Treatment is generally personal and unbureaucratic, and confidentiality is more easily kept. Individual, group, and family therapy is generally available but may depend on the preferences of therapists.
- *Paraprofessional counseling* — This is akin to peer counseling in the respect that paraprofessionals do not generally hold advanced degrees. They are unlicensed or uncertified people who counsel under the supervision of a licensed mental health professional. This category could include students who are working toward an advanced degree or mental health licensure, or ordinary citizens who wish to help others.

The mental health or counseling field can be confusing to those who have never been exposed to it, not only because of the many types of services and their benefits and limitations, but also because of the variety of disciplines and degrees of the professionals. Also there are various theories to which different therapists may adhere, various levels of experience and competence, and, of course, each therapist has his or her own personality. All of these factors should be considered when selecting the type of help you will receive.

In most states, health professionals are licensed or certified after they have acquired a certain number of clinical hours under supervision and after they have passed qualifying exams. This protects the consumer of services more fully from malpractice, not only because of the advanced training and experience necessary to qualify for licensure, but because of certain ethical and legal standards of practice which must be upheld.

If you, your family as a whole, or a member of your family needs counseling, consider the following factors.

- What money are you able or willing to spend for treatment? Remember, some insurance plans will cover partial or full payment. Medicaid, Crippled Children's Services (CCS), and CHAMPUS will also cover a limited number of visits. Bear in mind that some insurance will only cover licensed or certified professionals, such as psychiatrists (M.D.'s), psychologists (Ph.D.'s), and in some cases, clinical social workers and certified marriage, family, and child counselors.
- From the various types of counseling available in your community, which best suits your needs? Consider this in relation to what you can afford and what you expect to gain.
- What other resources can the therapist or center provide in addition to counseling? Some are: hospitalization resources, medication assessment and prescription, psychological testing, child therapy, group therapy, referral to other services, or sexual counseling. Sexual readjustment following the disablement of a marriage partner is a common source of concern, and many publications and services are now available to help in this area (see "Further Reading and Resources").
- Can you get a referral from an agency for services? Sometimes agencies have access to knowledgeable professionals or programs which you may not be able to obtain independently. They may even be able to pay for treatment for their clients if counseling is a part of the rehabilitation plan.
- Can you get recommendations from friends? Sometimes "word of mouth" is a very good method of selection, since others may have more direct experience with the service than you do.

Selecting counseling assistance can sometimes be a matter of "shopping around." You want to select a counselor who is empathetic and objective and with whom you can establish a good working relationship. You will want to know about his or her familiarity with disability-related needs and problems. This is important for you, since s/he will need to be able to objectively assess how to help you adjust to disability and its stresses. S/he will also need to assess whether there are other significant personality problems which could hinder adjustment.

A service model which may or may not include counseling or psychotherapy is "networking." It has been gaining more attention recently as service providers realize that financial resources for more expensive and specialized professional care are decreasing. Networking,

which is sometimes referred to as "the continuum of care," emphasizes training people to live as self-sufficiently as possible. It stresses creating links to new, nontraditional forms of care to meet the range of predictable human needs. These links, or networks, include social service agencies, churches, schools, neighbors, families, and friends. Services are often delivered without fee.

The networking concept of self-care is very clear. It assumes that most people who need human development services can be helped to care for themselves. Thus, investment is increasing in activities such as parenting education programs, self-advocacy, and independent living projects for disabled paople. And, benefits can come from other "nonservice" resources for self-help, such as tax credits for child care allowances and for renovation or modification of homes to make them accessible to the disabled homeowner.

The unifying theme in the preceding sections of this booklet is that families of disabled people and they themselves have much in common with other families, but they also have unique problems. There are ways to understand these unique problems and, through understanding, to build self-reliance and interdependence. Assistance can be sought along the way to prevent severe family disruption and to provide alternatives for family members in achieving greater satisfaction.

VI. USING AGENCIES EFFECTIVELY

In this section, we will discuss some of the ways families can receive help from rehabilitation and related agencies and professionals. We will suggest ways to gain access to services and programs. Mainstreaming in the schools and out-of-home placement will be covered, since both situations require families and agencies to interact, and both situations are inherently stressful.

Many families are thrust into the rehabilitative services system only because of their disabled family member. Most know little or nothing about what services are available to them (or in some cases *not* available to them) until they need them. They may know little about the legal guarantees for equality of access to public buildings, employment opportunities, or education, even though the issue of civil rights for disabled people has been publicized. Many families don't know which agencies to contact and are frustrated to find that it is often through informal means that they get to the programs which suit their needs. These problems can be greatly alleviated if families learn how to enter the system.

ENTERING THE SYSTEM

Many families complain that months, even years, can go by without their hearing about nearby programs which could have helped them. New programs are continually being formed, and established programs change; some programs close entirely. It is no wonder that families have such difficulty in finding out what is available to them at any particular time.

To help families enter the service system, information and referral (I & R) programs have been set up to act as resources for families or disabled individuals who cannot know of all the services available to them. In large metropolitan areas, though, it is often impossible for the generic (meaning they have access to information in all categories of services delivery) I & R services to keep up with new programs, program changes, or closures. Sometimes follow-up, which is a key ingredient in successful referral, is not provided or is inconsistent.

Another problem families may experience is in knowing which information and referral service to call. "Hot lines," for instance, offer people in crisis immediate relief and assistance with their problems, but they are not appropriate sources of referral for most disability-related programs. Families can easily be turned off to further inquiry if their *first* contact in trying to obtain information is inappropriate or inadequate.

Again, common sense, assertiveness, and persistence can pay off. If you refer back to the previous section you will find that many of the suggestions made there will apply equally in using I & R and other services. Learning the following skills can help you find and use appropriate programs.

- *Identify the services you need.* Families sometimes have trouble here because they don't know what services are available or cannot anticipate their needs until a crisis occurs. Some families tend to *underestimate* or *misperceive* their needs. Others may call on information and referral services for moral support or guidance, which is not always available. Charting or listing the emotional, recreational, and physical needs of the *whole family* can help greatly in clarifying what you're asking for.
- *Review the "contacts" (agencies, doctors, friends, neighbors, hospitals) which you have already made.* Ask them to investigate possible resources for you, but be sure they have all the facts they need to do this. For instance, they may need to know if you can pay for service, if your insurance will cover the cost of services, if transportation is needed, etc. Any other pertinent facts should be provided by the family to the person who makes inquiries for you. Remember, when you enlist the help of others, they can become part of a team effort, but they need to be informed of any facts which have significant bearing on your abilities or inabilities to access services.
- *Target the agencies you wish to call.* Some generic or multipurpose information and referral services are excellent clearinghouses for linking people to services. These services may be provided by United Way/United Fund, departments of social services, or even offices of local elected officials. Some of these services may use volunteers who are trained to help with specific problems. And some of the larger I & R services have procedures to assist families in thoroughly considering all of their needs and statistically recording these services needs for use in planning and coordinating of services. Often, though, you may wish to bypass the large I & R agencies and go directly to the agencies set up for specific disabilities or for disabled children or adults in general. Phone numbers can be found in the telephone book, or if none are there, their national offices can provide you with information and refer you to the office closest to you. (See the resource list of national organizations.)
- *Nurture the good contacts you've made.* If you've found an agency which seems particularly responsive to your needs, or a particular person who has helped you, stay in touch with them. A way of

keeping them involved in your progress is by giving feedback as to what was or was not useful. By giving feedback, you begin to establish a relationship which leads to the expression of feelings and thoughts. Words borrowed from science, such as "system" and "feedback," tend to diminish the importance of that which is truly helpful to people, namely relationships. We often forget that people who help others may experience the same feelings of anger, helplessness, and frustration as you do when their efforts to help you are thwarted. Conversely, they feel good when they successfully help you resolve a problem.

Helping is a two-way street. By expressing your appreciation of the efforts of others to help (if deserved), by asking questions and giving feedback about what has or has not helped, you make the relationship between you and the one who helps you more mutual, equal, and personal. And, you become more knowledgeable and self-reliant in the process.

- *Devise a plan for follow-up.* A major obstacle to success in the service system is the lack of coordination and communication between consumers and providers, and between providers and other providers. This hampers entry and exit from services, day-to-day provision of services, and planning efforts which seek to identify areas of unmet need. This problem becomes more acute with services considered to be "brief contact," such as information and referral, but it also hampers the effectiveness of long-term services.

  It is important, then, to plan for follow through, and to do your part in keeping helpers informed of the effects of their efforts. If an agency gives you a few potential resources to contact which do not turn out to be successful, call the agency back and tell them why the resources didn't help. Often, the referring agency can intervene to find out why the resources were inappropriate and make a more appropriate referral for you. If an agency agreed to call you within a specified time and they don't, call them. Unfortunately, in many instances the "squeaky wheel" principle often operates. Agencies need to know that you are motivated to get the help you need.

Sometimes an in-person meeting is the best way to get what you need. It gives you the opportunity to make the actuality of your situation real to the agency person, and it helps form a potentially ongoing partnership with people who can be valuable future allies. Many agencies are beginning to serve people in their homes, as outreach efforts increase and the needs of people who lack transportation or who are homebound are being recognized.

AN OVERVIEW OF PROGRAMS AND SERVICES

Historically, the disabled person's service needs have been the focus when programs have been created or when individual program planning has taken place. This has been based upon the "diagnostic-prescriptive" model which comes from medicine and which seeks to diagnose the problem (the disease or disability) and then to prescribe the treatment to alleviate it. Treatment was aimed at curing the disease or managing the condition through medication, therapeutic treatments, surgery, or therapeutic programs. The concern was the person with the disability, and the remedial measures which were applied to him or her.

Families were often ignored in the treatment process and were expected to fulfill their obligations by transporting the disabled person to programs and office visits, and by providing all the other caregiving as well. While services for disabled people are still the most important components of the system, and families do play a vital role in enabling the members of their family to maximize their abilities, families are beginning to speak out for what they need to help them to manage better.

Some agencies have traditionally been willing to serve the entire family. This is true of the voluntary agencies started by groups of parents of disabled children who began services where none had existed. Examples of such groups are the United Cerebral Palsy Association and the National Society for Autistic Children. These organizations, large and small, retain a family orientation and local chapters and affiliates of many of them can be found in all sections of the country.

Larger (generally governmental) agencies are often very restricted in what services they are permitted to provide to family members other than their disabled client, even though the family needs are disability-related. These restrictions stem from both funding limitations (insufficient money to adequately provide services to each disabled client, let alone to the family) and attitudinal limitations (the family is perceived as removed and distinct from or sometimes working against the plan for the disabled client). Occasionally, some agencies resist including families as fully as possible for fear that families might complicate matters too much or take away from the "professional" nature of the service. Sometimes this approach is justified, particularly if there are scarce resources for providing more sophisticated services requiring highly trained people. Some families have so many problems that it is beyond the scope of any one agency to help completely. These families need to consider whether they can reasonably expect all their problems to be tackled through services aimed primarily toward the disabled consumer and disability-related issues. Such families might

consider the "networking" idea of formal and informal services, such as psychotherapy or counseling, respite care, and family education and support groups.

In most cases, however, families could and should participate more fully with agencies. Some of the bad experiences agencies report about families, such as failing to follow through, removing the disabled person from the program, and even seriously disrupting treatment, can be directly traced to the family's involvement in the helping process being discouraged. Studies are currently underway to identify the role of the family in the rehabilitation process, and to discover the most effective ways to involve family members and significant others in programs.

Parents and family members are now legally afforded more opportunities to participate than ever before. And there are many more types of comprehensive programs and services from which to choose at all points in the life cycle of the disabled individual. During the last decade, we have witnessed the rise of infant and preschool programs which help families of young children to meet their childrens' developmental needs and which support families through the early, difficult years before public education formally begins. Day care programs have begun to serve handicapped youngsters in either specialized settings or, in some cases, along with other nonhandicapped children.

School programs and private agency programs are now beginning to assist disabled teenagers to prepare for independent living by teaching them such skills as home management, use of community resources, forming and maintaining relationships, career planning and preparation, personal grooming and hygiene, financial management, use of leisure time, and many of the other skills necessary for successful independent living.

The hard fought struggle for independent living for severely disabled adults has become more fully realized as programs like the Center for Independent Living in Berkeley, California, have demonstrated that with some support services, many disabled people can work, live in their own communities, and make outstanding contributions to society.

Services, books, magazines, groups of people, laws, agencies, and programs to assist families to learn more about disability management are increasing. Organizations to protect and advocate for the rights of disabled people are also proliferating.

Families are assuming more and more responsibility in the case management of their disabled members. Agencies are realizing that most families can provide the expert care and supervision which agencies are unable to provide, and that *with training* families can learn basic principles of case management with the agency's resources available to them. This family management model uses agencies as

allies or consultants in the services process. It has the great advantage of strengthening families and maximizing the usefulness of agencies.

A GLOSSARY OF TERMS

A new vocabulary is being used, as a "shorthand" language, to depict positive and progressive concepts, to replace older notions of disabled people as incapable of leading meaningful lives or as shut away from society. Awareness of these terms is useful, not only in conceptualizing your family's attitudes towards disability, but in helping you become more effective in the services arena.

- *Mainstreaming* — This process involves moving a disabled child from a special educational setting to a "regular" school setting. It can also mean that the disabled person joins the "mainstream" of life or is assimilated into the world of nondisabled people.
- *Normalization* — For those who are "developmentally disabled" (includes such disabilities as mental retardation, cerebral palsy, epilepsy, autism, and other neurological disorders), social segregation is often more pronounced. Some of this segregation is caused by the practical difficulties a family encounters in attempting to bring their child out into the public. But more often social stigma is the main cause. Disabled people, and not just those with developmental disabilities, have often been deprived of experiences (educational, cultural, interpersonal, recreational) which would help them to learn and mature. "Normalization" involves a concerted effort to expose the disabled person to as many opportunities as s/he is capable of using to remedy the effects of environmental and educational deprivation and to enhance development.
- *Barrier-free* — This phrase describes an environment in which the barriers in attitude, communication, transportation, employment, education, mobility, travel, and recreation have been removed — thus enabling the complete integration of disabled people into society.

PLACEMENT ISSUES

Of the many stress points in the life cycle of families of some disabled people, those which seem to be most difficult are the times when out-of-home placement is being contemplated, or a child is being considered for mainstreaming into the regular classroom. At these times families need expert guidance from agencies, accurate assessments of the functional potential of the disabled person, and a thorough understanding of all the alternatives which should be considered. Any

decision which requires a change in living arrangement, such as independent living, entry into a new school setting, or a move to a new community, can cause the family to feel anxious about the impact the change will make on the disabled family member and the entire family.

MAINSTREAMING

The benefits of mainstreaming children from special educational settings to regular classrooms have recently been emphasized. Many parents are eager to see their children interact and learn with nonhandicapped children. And, in their eagerness to take advantage of these new opportunities, they may not be able to clearly assess the potential drawbacks to mainstreaming or what effect it may have on their child.

Families are most frequently concerned about the following questions.

- Is the child emotionally ready to adjust to a new school setting?
- Is the child educationally at grade level or above, or will s/he be placed behind peers?
- Is s/he able to relate to others and form friendships?
- What extra support services or equipment will be available? Are those services adequate for his or her needs?
- How do the mainstream principal and teachers feel about mainstreaming your child? Can you or perhaps the special education teacher help to make their attitudes more positive?
- Have you worked out a plan for taking care of your child's special physical needs while at school? Who will provide assistance?
- How well does your child understand his or her disability? How is it explained to others? How does s/he accept her or his limitations?
- What architectural barriers exist at the school and what arrangements have been made to physically accommodate your child?
- What physical education or therapeutic services are offered and what arrangements are required so that s/he can obtain them?
- How will your child be transported to and from school?
- What arrangements has the school district made to pay for these services for your child in the regular classroom?
- How much do the mainstream teachers know about formulating an individualized education plan for your child?

Considerable fighting and confusion can be eliminated if your family can base its decision on having adequate answers to the above questions. Undue stress can be placed upon a child who is not prepared for the real changes likely to take place with mainstreaming.

Families can avoid some unnecessary hardships by thoroughly planning for these changes well in advance. Special mainstream counselors are available in some school districts to assist families of disabled children in getting the help they need at school and at home. Enlist as much assistance as you need to make mainstreaming a successful experience for you and your child.

OUT-OF-HOME PLACEMENT

Probably no decision a family makes concerning its disabled member is as difficult as the decision to place that person in out-of-home care. It is equally painful regardless of whether a child, an adult, or an aged family member is being placed.

Generally, the family member is emotionally, behaviorally, mentally, or physically so handicapped that the family is unable to adequately care for him or her at home, and community resources are insufficient to meet continuing needs. Families often experience a sense of profound guilt and failure. They feel they have not tried hard enough and that they are somehow to blame for renouncing their responsibilities. Families are often divided over what plans to make.

There are agencies in almost every state which have been specifically created to help families with out-of-home placement. Centers for the developmentally disabled provide these services, as well as offering lifetime case management for the developmentally disabled person. Families need support, guidance, and information when they contemplate placement. They need to have someone within the services system searching for them. They need to know that the residential arrangement they are choosing affords the greatest possibilities for growth and rehabilitation and protects the rights of its residents.

New forms of out-of-home care are becoming available, such as group homes with house parents, congregate living or shared apartment arrangements, or foster care homes, providing smaller scale environments which are more home-like. Families should consider whether such homes are appropriate for the disabled person, or whether they might be in the future. Temporary placement or respite care may be a solution for families who are uncertain about out-of-home placement or for those who are unable to obtain it readily.

We have explored some of the ways agencies and their programs can help families to better cope with disability. Agencies can and do provide many vitally needed services to disabled people and are increasingly involving families in program planning and follow-through at home. They are providing training opportunities for parents to get involved in advocacy and case management.

Legislation mandates that parents be involved in educational program planning for their youngsters, but this principle of parent involvement applies to other opportunities for program planning for services outside of school. Appeals procedures are now provided by all governmental agencies, and many private agencies are adopting their own appeals processes. Agencies can be important parts of a family's network of services if used wisely.

VII. ADVOCACY AND CONSUMERISM

Some disabled people and their families may have neither the desire nor the resources to become active advocates (broadly defined as those who attempt to change the system to get what is needed for disabled people as a group). It is useful, nonetheless, to begin to understand the processes of consumer advocacy, in the event you do decide that the best approach to a particular problem is through working with others.

ADVOCACY AND UNMET NEED

The initial step in any advocacy process is the recognition of a major and continuing unmet need. For some families, unmet needs could include lack of information, support, or training in how to manage disablement. Or, it could include lack of trained people to directly assist the family, such as by providing physical care for their disabled member, providing specialized training or teaching, or providing specialized equipment or assistive devices.

Below are other pressing, unmet needs which are felt by many families of disabled people.

- Non-English speaking families and others from ethnic minorities are often inadequately served and suffer greater obstacles in gaining services. They may have difficulties incorporating new information and attitudes toward disability which the dominant culture has recently adopted. They are often economically disadvantaged, and hence more stressed and survival-oriented than families that are freer to pursue their other needs. Bilingual volunteers and staff are urgently needed to translate written materials and to interpret programs and verbal interactions to families. Agencies have a responsibility to make every possible accommodation to serve disabled children, adults, and their families from all ethnic minority groups.
- Rural families sometimes need to go to greater lengths for assistance. Information and referral services may be harder to access. Highly specialized or technically sophisticated programs may be so far from home that they are too expensive for most families to afford when travel expenses are included.

  Citizen advocacy is urgently needed in many minority and rural communities to improve existing programs or to start new ones closer to home. Agencies which provide generic services could be urged to add programs for disabled people. Elected officials are

often supportive of community groups wishing to begin new programs, and can help them obtain grants for start-up costs. Many rural and minority community needs are still considered to be high priority for governmental assistance.

- Perhaps the greatest barrier to getting needed services is transportation. The availability of a family car to make up for the lack of accessible public transportation, cooperative carpooling, and van transportation systems can spell the difference between complete independent living, endless chauffeuring, or not using services at all.

While advocates continue to pressure transportation districts to realize the dream of making all forms of public transportation accessible to disabled users, much can be done informally through networks. Some suggested steps are:

- Ask agencies serving disabled people in your community to help organize lists of available transporters and to coordinate carpooling or borrowing of vans and buses for group or individual trips. Qualified drivers may also be needed. You may need to check into insurance regulations.
- Identify all the agencies which do transport disabled people. Sometimes they will authorize use of their vehicles when they are not in operation. Look into agencies serving elderly people. Some will coordinate occasional trips or some will transport disabled people on a daily basis. Taxis, jitneys, and other forms of private transportation may be able to give you special rates for daily trips. Sometimes public agencies subsidize the cost of transportation if there is no other means to get their disabled clients to programs.
- Call agencies which have volunteer programs to see if you can start a transportation program. Church groups often have buses or vans which could potentially be used.

CIVIL RIGHTS AND CONSUMER ACTION

Few really appreciate the rapid advances of the last decade in the legal arena. These advances have made real changes in people's lives, and have the potential of ending discrimination against disabled people if diligently applied.

In his statement of April 28, 1977, Secretary of Health, Education, and Welfare, Joseph Califano, Jr., said:

> Today I am issuing a regulation, pursuant to Section 504 of the Rehabilitation Act of 1973, that will open a new world of opportunity for more than thirty-five million handicapped Americans — the blind,

> the deaf, persons confined to wheelchairs, the mentally ill or retarded, and those with other handicaps.
>
> The 504 Regulation attacks the discriminations, the demeaning practices, and the injustices that have afflicted the nation's handicapped citizens. It reflects the recognition of the Congress that most handicapped persons can lead proud and productive lives, despite their disabilities. It will usher in a new era of equality for handicapped individuals in which unfair barriers to self-sufficiency and decent treatment will begin to fall before the force of the law.

Those are stirring words. But the last few years have shown (witness the civil rights movement for women and ethnic minorities) that change occurs slowly. It is necessary to use civil rights laws to challenge discrimination, and before laws are implemented and enforced the public needs to know what the laws will guarantee.

The two most important pieces of legislation with which disabled persons and their families need to be familiar are Sections 503 and 504 of the Rehabilitation Act of 1973, and Public Law 94-142, the Education of All Handicapped Children Act. They not only provide the legal basis for access to programs and mandate program provisions, but they ensure that programs respond to the individual needs of disabled persons.

Section 504 states that:

> No otherwise qualified individual in the United States . . . shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

Section 504 regulations pertain to all governmental programs and agencies, including elementary and secondary schools, colleges, hospitals, and other health care providers.

The term "handicapped" includes people with such diseases or conditions as speech, hearing, visual and orthopedic impairments; cerebral palsy; epilepsy; muscular dystrophy; multiple sclerosis; cancer; diabetes; heart disease; mental retardation; emotional illness; and specific learning disabilities, such as perceptual and developmental aphasia. Physical or mental impairments do not constitute a handicap, however, unless they are severe enough to substantially limit one or more of the major life functions.

Beyond the broad entitlement to freedom from discrimination, "503" and "504" require government-funded programs to be physically accessible to disabled people and to have affirmative action plans. The

regulations also require the development of public transportation systems for those whose mobility is impaired. These regulations are enforced by the Department of Health and Human Services (formerly HEW).

The basic provisions of Public Law 94-142 are that:

- No handicapped child can be excluded from a public education because of disability
- Every handicapped child is entitled to a free, appropriate, public education, regardless of the nature or severity of handicap
- Handicapped students must not be segregated in public schools but must be educated with nonhandicapped students to the maximum extent appropriate to their needs
- Evaluation procedures must be improved to avoid the inappropriate education that results from misclassification
- Procedural safeguards must be established so parents and guardians can object to evaluation and placement decisions made regarding their children
- State or local education agencies must locate and identify unserved handicapped children.

In most instances, school districts must provide, at no cost to families, transportation to and from educational programs; such "related services" as occupational, physical, and speech therapies; and a recreational or physical education program for each student. The IEP, or individualized education program, is the mechanism to ensure that all aspects of the child's educational program are being considered and that goals and measurable objectives are established for the child.

Parents are required to approve and sign the IEP for their child. If they do not agree with any part of the plan, there are "due process" safeguards which enable the family and the school to arrive at the most desirable and feasible plan for the child. Among these due process safeguards are informal hearings, fair hearings (sometimes involving the local and state educational officials), and formal complaint procedures (used when educational practices or policies deny the rights of a child to the educational program most appropriate to his or her needs).

Despite these recent breakthroughs in legislation, which require society to rethink its old beliefs, develop new attitudes, design programs which incorporate these new attitudes, and at times make substantial changes in the environment, there are factors which inhibit the realization of these goals for disabled people.

CONSTRAINTS

One of the major constraints is ignorance, or an inaccurate or incomplete understanding of the legal rights of disabled people. The previous brief descriptions of Sections 503 and 504 and Public Law 94-142 were not meant to include all the provisions of these acts, and there is much additional federal and state legislation which pertains to civil rights and programs for disabled individuals. It is very difficult for families to be really effective advocates if they are not well informed. School districts are required to inform parents of their "due process" rights and of the mechanisms of appeal for disagreements about the child's educational placement and program. Disability law groups, such as the Western Law Center for the Handicapped in Los Angeles, the American Civil Liberties Union (ACLU), and other public legal agencies can help families and parent groups obtain legal information. They may even provide free consultation to aid you in your advocacy efforts.

Fear of assertion, of reprisal against the disabled person, or of being intimidated are also major stumbling blocks to meeting needs. It is particularly important in these instances that families obtain outside help, either from a knowledgeable advocate, another parent (or parent group), or a good friend who can offer support and guidance. Sometimes a person within the system, such as a health professional or "ombudsman," can give good advice from the "inside" on ways to settle disputes. Make sure your resource person is knowledgeable and can offer constructive direction.

In a period of budgetary austerity such as we are presently experiencing, there are financial constraints in implementing laws and programs which protect the civil rights of disabled persons. Unfortunately for disabled people, when financial cuts are made, not only are services cut or at least not increased, but law enforcement begins to erode. For instance, the Department of Transportation may now be weakening its commitment to enforce accessibility requirements for public transportation (a "504" provision), and most local transit districts will not voluntarily incur the extra expense of providing accessible buses for their passengers.

Some state Architectural Barriers Compliance Boards may weaken the enforcement of minimum requirements for the removal of architectural barriers in historical buildings. Some school districts are out of compliance with Public Law 94-142 regulations at present, and if money is cut from these programs, there is little hope that these districts will be able to fulfill their legal responsibilities to disabled students in the near future.

Whether families are active advocates and work with others in the system depends a great deal on their resources, skills, and needs. Some

families are so burdened with day-to-day struggles that they have little time or energy left for political action. Others are ambivalent about challenging the adequacy of the services on which they depend and are reluctant to "rock the boat." There may not be an organized group to help prepare and train families to be effective advocates. Not all families of disabled people can be active politically. But knowledge of new *attitudes, rights*, and *power* which disabled people and their families can exercise help to foster more responsible and vigilant consumer involvement. By being watchful regarding your family's needs and knowledgeable about the treatment and services to which you are legally entitled, you can do much to benefit the family without formally entering the political arena. (See the next section on organizing an advocacy group if you want to become more politically involved.)

Families who have successfully navigated the services system may wish to volunteer on agency advisory boards or committees to help services more fully meet the needs of families faced with disability. Most programs now require consumer participation (disabled people are considered "primary" consumers; family members are termed "secondary" consumers) and families have been, are, and will be very influential in planning, setting policies, and monitoring programs which affect the lives of disabled people.

Some areas which need consumer involvement are:

- Health services
- Mental health services
- Communication
- Transportation and travel
- Housing
- Education
- Architectural barriers
- Child care
- Recreation
- Legislation
- Employment.

You probably have firsthand knowledge in all of these areas through your family experience with disability. And it is very difficult to think of any community in the country in which all of these needs are adequately met for the disabled population and their families.

Whenever possible, disabled people ought to represent themselves. However, sometimes due to age, severe physical and mental limitations, lack of transportation, or living out of the home, disabled consumers are unable to do so fully. It is incumbent on the family, then, who knows the disabled individual best, to become advocates.

The needs of the family as a whole, aside from disability, have to be considered. Greater attention needs to be given to the education of the general public (which is unfamiliar with the daily living problems of families with disability). Though families can be heroic, they are still ordinary people who sometimes struggle more than necessary to get help, support, and services.

THE ADVOCACY GROUP

Unless an effective advocacy group is already in operation, many families get bogged down in trying to organize a group of their own. They may know of a few other families who are willing to work on the issues, but they may not know how much interest can be generated in their communities to work toward advocacy goals, nor what means are available to help them organize, nor what to do after issues have been identified.

Sometimes it is good to start small. The preliminary work of the group might be devoted to investigating problems and issues, looking for support groups or interested people, soliciting help from advocacy agencies, and using individual persuasion to attempt to solve problems.

Consumer advocacy groups can take many forms: A small parent group may come together to solve relatively simple problems in the school, or coalitions of existing consumer organizations may be established to change public attitudes, create legislation, alter service delivery systems, or monitor the implementation of legislation. For more details on advocacy and lobbying, see *Lobbying for the Rights of Disabled Persons*, another book in the Emerging Issues series.

In addition, Frank Warren, in the excellent monograph *Planning for Action*, available through the United Cerebral Palsy Association, makes the following suggestions to consumers who are attempting to develop an effective advocacy organization.

- Meet regularly.
- Encourage those with the greatest commitment and the keenest understanding of the problem to exercise their leadership ability.
- Establish a means of regular communication between members. A well-written newsletter can instill enthusiasm, impart valuable information, enlighten the membership, encourage action, and provide a constant link with members who may not be able to attend all meetings. Best of all, it is inexpensive.
- Don't bite off more than you can chew. A problem solved well gives credibility to your organization and a sense of accomplishment to members.

- On the other hand, don't whittle your goals down to the point that they are worthless. Work toward an ideal, and measure your accomplishments against it.
- Don't give up in despair when members of your group fall short of the commitment you think they ought to have. Remember that every member has a different level of commitment to the cause, depending on the circumstances of his or her life. Rejoice in the participation that you get, and move on.
- Don't turn your organization into a vehicle for personal gratification or ego satisfaction. Give credit where credit is due, and dole out praise and encouragement in large quantities.
- Once you have found your consumer element, identified a common problem, and begun to meet, then it is time to assess your group's goals. Start with an ideal. Don't be awed by the task ahead of you. Take it one piece at a time. Share responsibilities.
- Examine existing approaches. It is likely that most of the things your group needs are already being provided to others through existing systems from which your people are excluded. If such is the case, and if these systems are funded by tax money, there is no good reason why they cannot be altered to serve your people as well.
- Think long and hard before you decide to establish a separate system to meet your consumers' needs while another parallel system is serving others but excluding you. Sometimes this has to be done if your people would clearly be inadequately served and if their special needs would be lost in the larger system. The goal should be to get your group's needs met in an appropriate fashion by existing agencies and systems.
- It is of the utmost importance to gather all the information you can before taking action. Study the alternatives and work towards solving your problem in the appropriate manner.
- Use your organization and communication systems to inform your people about the possibilities.
- Do not hesitate to use the requirements of Sections 503 and 504 to move organizations receiving federal funds toward serving your needs.
- Be sure your goals will meet the real needs of your consumer group. Then go to work!

Advocacy groups ought to be as democratic as possible and allow all members to contribute their thoughts and actions to the total effort. Group members must be supplied with accurate information upon which to make decisions. And, make sure a structured format is used to ensure that the group keeps to the task at hand.

The "action planning" model can guide groups who want to organize for action, develop coalitions, strengthen existing organizations, develop and operate programs, and advocate for new laws. This model consists of the following steps.

- Have your group list its needs, in order of importance.
- Set basic goals by translating the highest ranked need statement(s) into goal(s).
- Determine the objectives which must be met to attain your goal(s).
- Determine strategies to meet each objective.
- Identify responsibilities and decide who will carry out each of the strategies.
- Establish time lines for specific actions.
- Decide how the action will be reported.
- Decide how you will monitor the success of your strategies.
- Monitor and evaluate the success of the strategies and develop new strategies until your goals are achieved.

There are some other, less formal means to effectively advocate for change. The possibilities are limitless for influencing policy makers, community leaders, and the general public to support your cause. Your choice of approaches depends only on the *time, creativity*, and *energy* of your group. Some of these approaches are:

- Focus media attention on your cause by using an articulate spokesperson or feature story to dramatize your need in human terms. (See *How to Make Friends and Influence the Media*, another book in the Emerging Issues series.)
- Write letters or send telegrams to elected officials who are in decision-making positions about your group's concern.
- Write to governmental regulating bodies or "watchdog" groups such as the American Coalition of Citizens with Disabilities, and inform them of your group's efforts. Ask to be put on mailing lists of local and national advocacy agencies, or other agencies serving disabled persons (see the list at the end of this booklet).
- Be available and prepared to testify at governmental hearings related to the issues you have identified.
- Demonstrate your group's grievance in public, if necessary.
- Join with agencies and groups who support your common issues. Coalitions can be very potent if well organized.

Successful advocacy can benefit not only the general services system but also individuals' own feelings of being effective and having an impact on their environments. Successful advocacy efforts are based

upon the recognition of certain rights and it is your group's willingness to insist on societal acceptance of those rights which makes their pursuit possible.

VIII. THROUGH A MURKY CRYSTAL BALL

This decade will present new challenges for disabled people and their families. With the threat of shrinking governmental support for existing programs, it may well be that fewer new programs will be developed, with the exception of independent living programs which are already being planned in many parts of the country.

The emphasis will more likely be on strengthening existing programs, offering new voluntary services, monitoring existing services, and enforcing civil rights legislation. The scarcity and expense of energy resources will make it even more important to develop accessible mass transit systems and accessible public facilities (parks, restaurants, office buildings, schools) throughout the community.

Ethnic minority populations are increasing in most cities, and programs must be developed to meet their needs. The numbers of elderly people (over sixty-five) are growing steadily and are projected to increase at an average of half a million a year. Higher divorce rates are expected to continue, with family stress and the lack of family support services contributing greatly to these breakdowns.

More mothers will join the work force as increased income is needed to maintain an adequate standard of living. The need for good child care programs will continue to increase. Affordable housing will continue to be scarce as new construction cannot keep up with demand.

These projected social trends will greatly affect the families of disabled people. But by anticipating and planning for the future, we can more accurately pinpoint the issues which need to be addressed now, and help to prevent sudden events from being catastrophic. Family strength, individual maturity, good support systems, adequate information, and responsible citizen involvement will be needed more than ever if we are to achieve the goals which were the promise of the last decade. We can achieve these goals, *together.*

IX. FURTHER READING AND RESOURCES

Families can have their own reference libraries without much expense. Home libraries can be valuable resources to use in family problem solving and in providing the most recent information on disability aids, equipment, advocacy, programs, and services. We suggest you include the following basic materials in your libraries.

BOOKS

Davis, M.; Eshelman, E.; McKay, M.; eds. *The Relaxation and Stress Reduction Workbook*. Richmond: New Harbinger Publications, 1980. This book offers dozens of useful exercises and techniques, all aimed toward stress-management and relaxation. The assertiveness training information is particularly applicable for disabled people and their families.

Goldenson, Robert M. *Disability and Rehabilitation Handbook.* New York: McGraw-Hill Book Co., 1978.
This book provides a comprehensive and very readable goldmine of information on every major category of disability, as well as sections on the role of the family, various rehabilitative services and programs throughout the country, and case examples of how families have or have not coped with disability.

Hale, Glorya, ed. *A Source Book for the Disabled*. New York: Grosset and Dunlap, 1979.
This is a most useful and comprehensive guide to equipment, home and personal adaptations and aids, leisure and recreation, and independent living. It is a must for the family with a physically disabled member.

Power, P.W.; Dell Orto, A.E.; eds. *The Role of the Family in the Rehabilitation of the Physically Disabled.* Baltimore: University Park Press, 1980.
This is a paperback collection of readings about how families are involved in helping their disabled members.

Satir, Virginia. *Peoplemaking*. Palo Alto: Science and Behavior Books, Inc. 1972.
This book offers a down-to-earth, positive approach to child-rearing and family relationships. Concrete examples and suggestions are given to enhance self-worth and communications.

Wright, Beatrice S. *Physical Disability — A Psychological Approach.* New York: Harper and Row, 1960.
For those who are interested in personality theory, this is a classic offering. Such issues as "grievances" and "gratifications" in the everyday relationships of disabled people are covered.

MAGAZINES

Disabled USA - The President's Committee on Employment of the Handicapped, Washington, DC 20210.
"*Disabled USA* presents the case for disabled adults." This is an extraordinary magazine which features different timely themes in each issue. It is attractively printed and pertinent.

The Exceptional Parent - ($12.00 per year, bimonthly) Write to:
The Exceptional Parent
P.O. Box 4944
Manchester, NH 03108
This magazine provides a wealth of practical information to families of children with disabilities. It features articles on helping parents to advocate for their children, covers national organizations and their activities, and presents family issues and book reviews.

Rehabilitation Gazette: The International Journal of Independent Living for the Disabled - ($3.50 per copy for disabled individuals) Write to:
Rehabilitation Gazette
4502 Maryland Ave.
St. Louis, MO 63108
The *Gazette* is published once a year by a volunteer staff. Its aim is "to reach, to inform, and to dignify the disabled throughout the world." It offers excellent, interesting articles and nicely written reviews of books for disabled persons.

BOOKS ON SEX AND DISABILITY

Bass and Geloff, eds. *The Sexual Rights and Responsibilities of the Mentally Retarded.* Available from Medora Bass, 216 Glenn Road, Ardmore, PA 19003, 1975.

Chitouras, Sophia; Cornelius, Debra; Daniels, Susan; Makas, Elaine. *Who Cares? A Handbook on Sex Education and Counseling Services for Disabled People.* Compiled by the Sex and Disability Project, George Washington University, Washington, DC, 1979.

Gordon, Sol. *Living Fully: A Guide for Young People with a Handicap, Their Parents, Their Teachers, and Professionals.* Ed-U-Press, 760 Ostrom Avenue, Syracuse, NY 13210, 1975.

Gordon, Sol. *Sexual Rights for the People who Happen to be Handicapped.* Syracuse: Human Policy Press.

Heslinga, K; Schellen; and Verkuyl, A. *Not Made of Stone: The Sexual Problems of Handicapped People*. Available from Charles C. Thomas, Publisher, Springfield, IL and Woodhead-Faulkner Ltd., Cambridge, England.

McKee, Kempton, and Stiggall. *An Easy Guide to Loving Carefully.* Available from Planned Parenthood of Contra Costa, 1291 Oakland Blvd., Walnut Creek, CA 94596, 1980.

Mooney, Cole, and Chilgren. *Sexual Options for Paraplegics and Quadriplegics.* Boston: Little, Brown, and Co., 1976.

Multi Media Resource Center, 1525 Franklin Street, San Francisco, CA 94109. *The Sensuous Wheeler: Sexual Adjustment for the Spinal Cord Injured.*

Taggie and Manley, Scott. *A Handbook on Sexuality After Spinal Cord Injury*, 1978.

PAMPHLETS AND BOOKLETS

Public Affairs Pamphlets:

Dickman, Irving R. *Independent Living: New Goal for Disabled Persons* (No. 522).

Ogg, Elizabeth. *Recreation for Disabled Persons* (No. 571).

Koestler, Frances A. *Jobs for Handicapped Persons, A New Era of Civil Rights* (No. 557).

Ayrault, Evelyn West. *Helping the Handicapped Teenager Mature* (No. 504).

All of the above pamphlets are easy reading and highly informative. They are available through: Public Affairs Pamphlets, 381 Park Ave., New York, NY 10016. Single pamphlets are $.50 each.

How to Get Food and Money - The Peoples' Guide to Welfare and Other Services In Los Angeles County, published by the Hunger Organizing Team, 5539 W. Pico Blvd., Los Angeles, CA 90010. At $.25 per copy, this is a great guide to welfare programs and assertiveness for consumers of welfare services. It is tailored for Los Angeles County but is applicable to other parts of the nation. It is available in English and Spanish.

Consumer Survival Kit is published by the Maryland Center for Public Broadcasting. Write to: Maryland Center for Public Broadcasting, Owings Mills, MD 21117

Request Booklet #520 - *Handicapped: New Services, Products and Laws.* This is published by the Maryland Center for Public Broadcasting to accompany its *Consumer Survival Kit* television series. It covers such broad-based issues as disability rights,

affirmative action, clothing selection, new products for disabled people, and handling parent/student and school conflicts.

The following booklets published by the Institute for Information Studies are available through the National Rehabilitation Information Center (NARIC), 8th and Varnum Streets, NE, Catholic University of America, Washington, DC 20064, (202) 635-5826.

New Life Options: Independent Living and You. (Co-produced with the Institute for Rehabilitation and Research.) This booklet explores the new options now available to disabled individuals who seek an independent lifestyle of their own making. The booklet includes a section on sources of technical assistance and financial support for independent living programs.

Making Friends and Influencing the Media. This manual for consumer organizations and advocacy groups focuses on how to influence the portrayal of disabled people in the mass media. It takes a practical "how-to-do-it" approach and provides examples of press releases, tip sheets, and other tools of the trade.

Lobbying for the Rights of Disabled People: Views From the Hill and from the Grass Roots. This document provides disabled people with basic information on how to effectively influence legislators, government policy makers, program administrators, political parties, and similar organizations on issues relating to the well-being of the handicapped population.

Financial Resources for Disabled Individuals. This document will assist disabled individuals in obtaining the cash benefits and other monetary resources they need to meet their basic living needs and prepare themselves vocationally.

Learning to Live with Disability: A Guidebook for Families. This document, designed as a self-help manual for families with disabled members, serves to increase awareness regarding the roles and needs of families affected by disabilities.

Hiring and Supervising Personal Service Providers: A Guide. This publication aids in recruiting, selecting, supervising, and terminating personal employees; and helps disabled employers and their attendants, interpreters, readers, and drivers to establish wholesome, effective, and rewarding interpersonal relationships.

DEPARTMENT OF HHS PUBLICATIONS AND OTHER NEWSLETTERS

A wealth of free literature is available from the government through its special branches. The Office for Civil Rights, Washington, DC 20201, publishes free brochures on disability legislation.

Publications of the National Institute of Mental Health are available by writing to the Public Inquiries Section, 5600 Fishers Lane, Rockville,

MD 20857. Over 200 separate publications are available (limit of ten publications per requester). English and Spanish editions are available, and all booklets are free.

For answers to specific questions about alcohol use and drug abuse, write to:

The National Clearinghouse for Alcohol Information
P.O. Box 2345
Rockville, MD 20857
or
The National Clearinghouse for Drug Abuse Information
P.O. Box 416
Kensington, MD 20795.

Handicapped American News, published by the Rehabilitation Services Administration, may be obtained by writing to:

Handicapped American News
200 Independence Ave., SW
Washington, DC 20201.

Word from Washington, published jointly by United Cerebral Palsy Associations, Inc., Epilepsy Foundation of America, and the National Society for Autistic Children, follows and reports on all legislative and policy issues relevant to disabled people. This free monthly newsletter of interest to advocacy groups and programs is available from:

United Cerebral Palsy Associations, Inc.
Suite 141, Chester Arthur Bldg.
425 Eye St., NW
Washington, DC 20001

Closer Look, published by the Parents' Campaign for Handicapped Children and Youth, is an *outstanding* newsletter which keeps its readers up-to-date on programs and services, advocacy information, governmental activities, and funding sources. It can be obtained free by writing:

Closer Look
P.O. Box 1492
Washington, DC 20013.

X. NATIONAL RESOURCES

DISABILITY FOUNDATIONS

Arthritis Foundation
3400 Peachtree Rd., NE
Atlanta, GA 30326
(404) 266-0795

Voluntary organization that supports research with seventy-three chapters, some offering medical equipment on loan; distributes a free newsletter.

Muscular Dystrophy Association, Inc.
810 Seventh Ave.
New York, NY 10019
(212) 586-0808

Promotes research, provides diagnostic care and orthopedic devices through local chapters; publishes pamphlets concerning muscular dystrophies and neuromuscular disorders; distributes *TIPS,* a quarterly newsletter, and *MDA News,* a newsletter, at no charge.

National Amputation Foundation
1245 150th St.
Whitestone, NY 11357
(212) 767-0596

Provides services aimed at integrating amputees into the community; offers information on adaptation to artificial limbs; publishes a newsletter *The AMP* (ten monthly issues for $3.00).

The National Easter Seal Society for Crippled Children and Adults
2023 W. Ogden Ave.
Chicago, IL 60612
(312) 243-8400

Concerned about all physical handicaps and communication disorders; offers treatment, education, and research. Comprehensive range of publications including a magazine for students and professionals, *Rehabilitation Literature,* published ten times a year for $15.00.

The National Foundation/March of Dimes
Public Education Department
Box 2000
White Plains, NY 10602
(914) 428-7100

Provides information on birth defects and information on income maintenance and available financial services.

National Kidney Foundation
116 E. 27th St.
New York, NY 10016
(212) 889-2210

Because so many neuromuscular diseases and spinal cord injuries affect the excretory system, the National Kidney Foundation is included in this list. Founded by parents, this organization has fifty-four affiliates; services are primarily publications and referrals to financial aid and medical services; *KF Newsletter* is free.

National Multiple Sclerosis Society
205 E. 42nd St.
New York, NY 10010
(212) 532-3060

A voluntary association that funds research and education about multiple sclerosis; 173 local chapters provide direct services such as equipment loans to patients. Publishes a quarterly newsletter *M.S. Messenger* which is free to patients, $5.00 to others.

National Paraplegia Foundation
333 N. Michigan Ave.
Chicago, IL 60601
(312) 346-4779

A voluntary consumer organization with fifty-three local chapters; will refer to best sources of care; publishes literature on paraplegia; gives information on devices, equipment, personal care for paraplegics; the $5.00 cost of the magazine *Paraplegia Life* pays for membership.

Paralyzed Veterans of America
7315 Wisconsin Ave.
Suite 300W
Bethesda, MD 20014
(301) 652-2135

An advocacy organization for veterans; distributes information pamphlets on barrier-free design and housing; directly assists disabled veterans in gaining housing, hospital rights, vocational rehabilitation, employment; has thirty chapters. Publishes *Paraplegia News* monthly for $4.50 a year. Order from: 935 Coastline Dr., Seal Beach, CA 90740.

Scoliosis Research Society
Orange County Medical Center
101 S. Manchester
Orange, CA 92668
(714) 634-5739

A professional research society; will send *Scoliosis, A Handbook for Patients; Scoliosis . . . What's That*?; and a bibliography on request.

Spina Bifida Association of America
343 S. Dearborn St., Rm. 319
Chicago, IL 60604
(312) 663-1562

A parent network of 100 chapters; membership comes with a subscription to the magazine, *Pipeline,* for $6.00 a year.

United Cerebral Palsy Association, Inc.
66 E. 34th St.
New York, NY 10016
(212) 889-6655

A voluntary organization with 300 local affiliates; supports research and distributes information; local chapters provide a variety of services including preschools, speech therapy, personal counseling. A free legislative newsletter, *Word from Washington,* published by United Cerebral Palsy Governmental Activities Office, Chester Arthur Bldg., Suite 141, 425 Eye St., NW, Washington, DC 20001.

United Ostomy Association, Inc.
1111 Wilshire Blvd.
Los Angeles, CA 90017
(213) 481-2811 or (213) 481-0628

Organization for lay people; 400 local chapters; does not answer medical questions or advise about equipment; offers information regarding proper ostomy care and rehabilitation; has insurance plans for members; publishes a magazine *Ostomy Quarterly* for members of local chapters.

SOURCES OF SPECIAL INFORMATION AND SERVICES

Accent on Information (AOI)
Gillum Rd. & High Dr.
P.O. Box 700
Bloomington, IL 61701
(309) 378-4213

For a $6.00 service charge AOI will research any subject pertaining to physical handicaps, such as products, careers, legislation; publishes consumer quarterly periodical, *Accent on Living*, with information on aids, services, and day-to-day needs for $3.50 per year.

Children in Hospitals, Inc.
31 Wilshire Park
Needham, MA 02192

Provides information for parents and professionals about needs of children and parents when either is hospitalized; book list from Susan Leffler, 525 Lowell St., Lynnfield, MA 01940.

American Automobile Association
8111 Gatehouse Rd.
Falls Church, VA 22042
(703) AAA-6345

Publishes information on such subjects as driver training services, special equipment, and transportation facilities.

Human Resources Center (all physical handicaps)
I.U. Willets Rd.
Albertson, NY 11507
(516) 747-5400

Provides vocational training and rehabilitation for handicapped persons; information to employers; direct services and information internationally.

Institute on Attitudinal, Legal and Leisure Barriers
Regional Rehabilitation Research Institute
1828 L St., NW, Suite 704
The George Washington University
Washington, DC 20052
(202) 676-6377

Publishes free periodical, *Re: Search,* six times a year; major projects: attitudinal barrier removal, sex and disability, employment rights.

National Council For Homemaker-Health Aide Services
67 Irving Pl.
New York, NY 10003
(212) 674-4990

Refers to local chapters with services that make it possible for people with handicapping conditions to live in their homes; will research local aide services for developmentally disabled people.

Sister Kenny Institute
Abbot-Northwestern Hospital
Chicago at 27th St.
Minneapolis, MN 55407
(612) 874-4400

Rehabilitation center for persons with musculoskeletal or neurological disabilities and communication disorders; publishes books and pamphlets on care of handicapped people, including information on speech problems, bed care, stroke.

ORGANIZATIONS WITH DIRECT SERVICES OR PUBLICATIONS ABOUT CLOTHING

Amputee Shoe and Glove Exchange
1115 Langford
College Station, TX 77840
(713) 845-4016

A free service; provides for exchanges between consumers; maintains a registry with information on ages and sizes.

Clothing Research and Development Foundation, Inc.
1 Rockefeller Plaza, Suite 1912
New York, NY 10020
(212) 765-0750

Distributes a bibliography on clothing for disabled people.

Home Economics Extension Service
South Building
Department of Agriculture
Washington, DC 20250
(202) 447-3743

Local units teach food preparation, home management skills, and sewing to disabled people; distribute publications.

The Ruth Rubin Feldman National Odd Shoe Exchange
1415 Ocean Front
Santa Monica, CA 90401
(213) 394-8746

Annual membership of $5.00 required to register on the exchange; matches people of similar needs, taste, ages.

ADVOCACY/INFORMATION

American Coalition of Citizens with Disabilities
1346 Connecticut Ave., NW
Rm. 308
Washington, DC 20036
(202) 785-4265

Speaks out on a range of problems from housing and transportation to education and employment; composed mainly of disabled citizens;

members may be organizations ($100 a year) or individuals ($5); monthly paper, *ACCD Action*, is distributed to members; quarterly newsletter — *The Coalition* free on request to nonmembers.

American Association for the Advancement of
Science — Project on the Handicapped in Science
1776 Massachusetts Ave., NW
Washington, DC 20036
(202) 467-4497

Encourages elimination of education and career barriers to disabled science students and disabled scientists; offers career counseling to students; provides information on financial aid to disabled students.

Closer Look — A Project of the Parents' Campaign
for Handicapped Children and Youth
Box 1492
Washington, DC 20013
(202) 833-4160

Nonprofit service organization of parents dedicated to working for the right of handicapped individuals to full participation in the mainstream of society. Produces many publications. Can tell you about your child's right to education under federal and state law and about other rights to equal opportunity, from early childhood to adulthood.

Disabled American War Veterans
National Headquarters
P.O. Box 1403
Cincinnati, OH 45214

Promotes the welfare of service-connected veterans and publishes *DAV*, a monthly magazine.

Disabled Rights Center
1346 Connecticut Ave., NW
Suite 1124
Washington, DC 20036
(202) 223-3304

Promotes employment rights; publishes *Consumer Warranty Law* and *Your Rights and How to Enforce Them: A Guide for Users of Medical Devices,* $2.00.

Human Resources Center
Willets Rd.
Albertson, NY 11507

This private nonprofit organization provides vocational and educational training for severely disabled children and adults and conducts research, evaluation, and training programs. Send for publication list.

The Library of Congress
Division for the Blind and Physically Handicapped
Washington, DC 20542

Provides a variety of free library services, through 140 cooperating libraries, for blind and physically disabled people.

Mainstream, Inc.
1200 15th St., NW
Washington, DC 20005
(202) 833-1139

Counsels consumers, business, government, and school systems on barrier removal, affirmative action, and attitude change; publishes *In the Mainstream* bimonthly, at no charge.

National Association of the
Physically Handicapped
2810 Terrace Rd., SE
Washington, DC 20020

Membership is open to anyone with a physical disability who will join forces to fight to eliminate barriers and solve problems common to all disabled people.

National Congress of Organizations of the Physically Handicapped, Inc.
6106 N. 30th St.
Arlington, VA 22207

This strong lobbying group promotes employment, education, equal rights, and rehabilitation of people with physical disabilities, as well as legislation and social integration. Publishes the *COPH Bulletin.*

National Rehabilitation Association
1522 K St., NW
Washington, DC 20005

Facilitates communication between professionals working with disabled persons. Membership is open to everyone concerned with the problems common to all disabled people. Publishes bimonthly *NRA Newsletter,* a quarterly legislation newsletter, a magazine, *The Journal of Rehabilitation*, and many pamphlets.

Developmental Disabilities Office
Office of Human Development Services
Department of Health and Human Services
330 C St., SW
Washington, DC 20201

This agency coordinates programs provided for by the Developmentally Disabled Assistance and Bill of Rights Act, a law to help people with cerebral palsy, epilepsy, autism, and other disabilities defined as developmental, which require special services and provisions.

Office for Handicapped Individuals
Department of Education
400 Maryland Ave., SW
Rm. 3106, Switzer Building
Washington, DC 20202
(202) 245-0080

A coordinating and advocacy unit which runs a clearinghouse to disseminate information to individuals and organizations on all matters pertaining to the handicapped community. OHI will answer questions on the many federal programs for handicapped persons and direct individuals to the appropriate federal or private organization. The Office for Handicapped Individuals is represented in the ten regional Department of Education offices throughout the country.

President's Committee on Employment of the Handicapped
1111 20th St., NW
Washington, DC 20036

Established in the mid 1940s, this agency publishes many useful booklets and leaflets. Write for their publication list.

Rehabilitation International
The International Society for Rehabilitation of the Disabled
432 Park Ave., S.
New York, NY 10016

A nongovernmental federation of national organizations, agencies, and groups in more than sixty countries which are involved in problems of rehabilitation. Publishes *The International Rehabilitation Review.*

Rehabilitation International, U.S.A.
20 W. 40th St.
New York, NY 10018

Independent national organization affiliated with Rehabilitation International. Membership includes annual subscriptions to *Rehabilitation World* and the *International Rehabilitation Review.*

ORGANIZATIONS FOR PEOPLE WITH VISUAL IMPAIRMENTS

The American Council of the Blind
1211 Connecticut Ave.
Suite 506
Washington, DC 20036
(202) 833-1251

A membership organization devoted to improving educational, rehabilitation, and employment opportunities for blind people, as well as increasing public understanding of their problems and capabilities. Its members, most of whom are visually impaired, take an active part in legislation and court cases involving the rights and interest of persons with visual loss. The Council offers free information and publishes a free, bimonthly periodical, *The Braille Forum,* available in Braille, large type, disc, and tape editions. Subscription requests should be addressed to: 190 Lattimore Rd., Rochester, NY 14620.

American Foundation for the Blind
15 W. 16th St.
New York, NY 10011
(212) 924-0420

A nonprofit organization that supports research concerning visual loss; offers information and publications available in Braille, large type, and recordings; and provides other services to blind individuals. The Foundation has a legislative office at 1660 L St., NW, Washington, DC

20036 offering legal consultation and action on matters of national importance. The organization's quarterly newsletter and catalog of publications can be obtained by writing to their national office.

American Printing House for the Blind
1439 Frankfort Ave.
Louisville, KY 40206

Publishes and distributes talking books and books in Braille, large type, and embossed formats.

Guiding Eyes for the Blind
Yorktown Heights, NY 10599
and
The Seeing Eye, Inc.
Morristown, NJ 07960

Contact for information on guide dogs.

National Association for Visually Handicapped (partially seeing)
1201 Balboa St.
San Francisco, CA 94121

National Federation of the Blind
1101 St. Paul St., Suite 412
Baltimore, MD 21202
(301) 659-9314

Chapters throughout the country are working to change attitudes and ensure the implementation of laws guaranteeing the civil rights of blind individuals. The Federation offers scholarships to blind students and direct legal aid in cases of discrimination.

The Braille Monitor, a monthly publication in Braille or recordings, contains news and issues of importance to blind people. It is offered free on request from the National Federation of the Blind, 218 Randolph Hotel Bldg., Des Moines, IA 50308.

Where Do I Go From Here? is a talking book for newly blind people. It is available from *Dialogue Magazine*, 3100 Oak Park Ave., Berwyn, IL 60402.

ORGANIZATIONS FOR DEAF OR HEARING-IMPAIRED PERSONS

Alexander Graham Bell Association for the Deaf, Inc.
3417 Volta Pl., NW
Washington, DC 20007
TTY and oral: (202) 337-5220

Focuses on speech education for hearing-impaired and deaf people. In addition to offering information useful to parents and prospective teachers of the deaf, they provide information on equipment and aids. The Association offers college scholarships to deaf students who communicate with speech — for men and women who were born with profound hearing loss or who became deaf before learning to speak. Publications include a journal, *Volta Review,* a newsletter, annual monograph, and other books and pamphlets.

American Humane Association
P.O. Box 1266
Denver, CO 80201

Trains hearing dogs.

The Better Hearing Institute
1430 K St., NW, Suite 600
Washington, DC 20005

Nonprofit organization which gives information on the medical, surgical, and amplification help available for people with hearing problems. Toll-free hearing and help line — (800) 424-8576.

Council of Organizations Serving the Deaf
P.O. Box 894
Columbia, MD 21044

Offers visual aids; printed material; services for deaf persons, including legal counseling, adult education, driver safety, vocational training, and public information programs. Write for publications lists.

National Association of Hearing and Speech Agencies
919 18th St., NW
Washington, DC 20006

Makes referrals to one of its 169 member affiliates where a person with hearing or speech difficulties can receive appropriate help including diagnosis, evaluation, preschool hearing instruction, counseling, and rehabilitation.

The National Association of the Deaf (NAD)
814 Thayer Ave.
Silver Spring, MD 20910
TTY and oral: (301) 587-1788

Focuses on total communication, including speech, lip-reading, signing, and finger-spelling. A major concern of NAD is for the legal and employment rights of deaf people. Most states have NAD affiliate chapters. The Association publishes a periodical, *The Deaf American*, as well as a number of other books, pamphlets, and films.

OTHER NATIONAL ORGANIZATIONS

National Association for Retarded Citizens
2709 Avenue E East
P.O. Box 6109
Arlington, TX 76011
(817) 261-4961

Whether you are looking for diagnosis or a preschool program, special education or job training, housing or social and recreational activities for a retarded person, the National Association for Retarded Citizens and its state and local chapters will be helpful to you. Most of the members of the association are parents who have lived through many of the adjustments and challenges you are facing, and can draw on their own experiences to help you.

Epilepsy Foundation of America
1828 L St., NW
Washington, DC 20036
(202) 293-2930

In most states throughout the country, local chapters carry out work that can make a crucial difference in the lives of children and adults with epilepsy. A low-cost medication program and low-cost insurance program are available to Epilepsy Foundation of America members.

Whether you're a parent of a child with epilepsy, or an adult facing problems arising from epilepsy, you can find dedicated advocates in this organization ready to help. Regional offices and local contacts can help you find many of the resources you are looking for — including medical specialists, counseling, clinics, transportation, job training, camps for children, and special living arrangements for adults. Programs vary from area to area, so it is important to find out what your local group can offer.

The National Society for Autistic Children
169 Tampa Ave.
Albany, NY 12208
(518) 489-7375

Until recently, there was an almost total lack of services to help autistic children and their families. It still is a hard job, all too often, to find appropriate education and treatment. But through the determined efforts of parent organizations and dedicated professionals, there has been a dramatic increase both in the understanding of these children, and in school and other services that can help them. Members of the National Society for Autistic Children are convincing others that these children, like all children, have the right to be nurtured, educated, and accepted so that they, too, can lead lives that are as satisfying and useful as possible.

American Diabetes Association, Inc.
18 E. 48th St.
New York, NY 10017

Publishes bimonthly magazine, *ADA Forecast*.

Friedreich's Ataxia Group in America, Inc.
Box 1116
Oakland, CA 94611

Publishes a free newsletter.

National Hemophilia Foundation
25 W. 39th St.
New York, NY 10018

Publishes a newsletter, *Hemofax*.

Federal Information Centers in seventy-seven major cities will direct you to the correct federal, state, or local agency you need. Look in your telephone directory under U.S. Government, Federal Information Center, or write to the General Services Administration, Washington, DC 20405 for the leaflet *Federal Information Centers.*

The major source for the preceding information was: Closer Look, a Project of the U.S. Department of Education, Office of Special Education and Rehabilitative Services. Direct questions to: Closer Look, Box 1492, Washington, DC 20036, (202) 833-4160.

READER RESPONSE FORM

The Institute for Information Studies is committed to producing the most useful and current information on rehabilitation topics for disabled consumers and other members of the rehabilitation community. Therefore, we seek to identify your interests and needs, and to determine how we can improve our publications. The information you give us will be used to select relevant topics and channels for promotion and distribution for the coming year. We would greatly appreciate your completing the form below by checking the appropriate spaces corresponding to your situation.

1. I would like to be on your mailing list to hear about upcoming publications or services.
   ☐ YES ☐ NO
   Name _____ Title _____
   Organization _____
   Address _____
   Street (Box #) City State Zip
   Telephone # (____) _____
   area code

2. I am disabled. ☐ YES ☐ NO
   I have a disabled person in my family. ☐ YES ☐ NO
   I am visually impaired. ☐ YES ☐ NO

3. I work in:
   ☐ 01 State rehabilitation agency (general)
   ☐ 02 State rehabilitation agency (blind)
   ☐ 03 Private rehabilitation agency/workshop
   ☐ 04 Federal or regional government office
   ☐ 05 Rehabilitation professional organization
   ☐ 06 Disabled consumer organization
   ☐ 07 Insurance company
   ☐ 08 Legislative-branch office
   ☐ 09 Medical organization
   ☐ 10 Academic institution
   ☐ 99 Other organization (please describe) _____

4. I work as a:
   ☐ 01 Rehabilitation counselor
   ☐ 02 Job placement specialist
   ☐ 03 Educator/researcher
   ☐ 04 Staff development (training) specialist
   ☐ 05 Administrator
   ☐ 06 Public information provider
   ☐ 07 Medical practitioner (including practitioners of such allied medical professions as nursing, physical and occupational therapy)
   ☐ 99 Other profession (please describe) _____

5. I read _____
   Name of this Emerging Issues Publication

6. I found this publication (check all that apply):

Practical	☐ YES	☐ NO	Too long	☐ YES	☐ NO
Informative	☐ YES	☐ NO	Too short	☐ YES	☐ NO
Relevant to my needs	☐ YES	☐ NO	Too technical	☐ YES	☐ NO
			Too simplistic	☐ YES	☐ NO
Clear	☐ YES	☐ NO	Too vague	☐ YES	☐ NO
			Too detailed	☐ YES	☐ NO

Other comments _____

7. I found out about this publication from:

- ☐ Newsletter article or review. Which newsletter? _____
- ☐ Review copy
- ☐ Conference exhibit
- ☐ Journal article or advertisement. Which journal? _____
- ☐ Press release
- ☐ Friend or colleague. For which organization does this person work? _____
- ☐ Receiving an advance order form
- ☐ Don't remember/not sure
- ☐ Other (please describe) _____

8. What I liked most about this publication was: _____

9. For future, similar publications, here are some ways I think you could improve your product's content, format, and/or distribution: _____

10. I would be interested in seeing future publications on these subjects:

	Very Interested	Somewhat Interested	Uninterested
Job Opportunities for Disabled Persons in Science and Technology			
How to Use Sheltered Workshops			
Sexuality/Intimate Relationships			
Housing and Homemaking for Disabled Individuals			

11. I would be interested in attending a workshop, if held in my area, on:

	Very Interested	Somewhat Interested	Uninterested
Small Business Enterprises for Workers with Disabilities			
Social/Interpersonal Skills of Disabled Persons			
Job-seeking Skills			

12. I would be willing to travel (and have funds available) to attend such a workshop.
☐ YES ☐ NO

Thank you for your valuable cooperation!

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City _____ State _____
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INSTITUTE FOR INFORMATION STUDIES
200 Little Falls Street
Suite 104
Falls Church, VA 22046

INSTITUTE FOR INFORMATION STUDIES
EMERGING ISSUES AVAILABILITY FORM

The publications listed below are available while supplies last through the National Rehabilitation Information Center (NARIC). Please enclose $1 (check or money order, payable to National Rehabilitation Information Center) with requests for single copies. For two or more copies, please enclose $2 (postage and handling). When the original supply is depleted, copies will also be available through the clearinghouses listed below as well as NARIC. Each source has its own policy regarding borrowing or obtaining copies of documents from its collection, so contact the organization in question for further details. These publications are NOT available through the Institute for Information Studies.

National Rehabilitation
Information Center
4407 8th Street, N.E.
Washington, D.C. 20017
(202) 635-5826

U.S. Department of Commerce
National Technical Information
Service
5285 Port Royal Road
Springfield, VA 22161
(703) 487-4650

Project SHARE
P.O. Box 2309
Rockville, MD 20852
(301) 428-3100

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P.O. Box 190
Arlington, VA 22210
(703) 841-1212

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I would like to order the following publication(s). Write the quantity desired on the line preceeding each title. Enclosed you will find my check or money order for $_____.

_____ *Financial Resources for Disabled Individuals*
_____ *Hiring and Supervising Persoal Service Providers: A Guide*
_____ *Learning to Live With Disability: A Guidebook for Families*
_____ *Lobbying for the Rights of Disabled People: View from the Hill*

I would like to be on your mailing lists to hear about upcoming publications or services. ☐ YES ☐ NO

Name _____ Title _____
Organization _____
Address _____
City _____ State _____ (ZIP)

Telephone (_____) _____
Area Code

I am disabled. ☐ YES ☐ NO
There is a disabled person in my family. ☐ Yes ☐ NO

Name _____

Address _____

City _____ State _____

Zip _____

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