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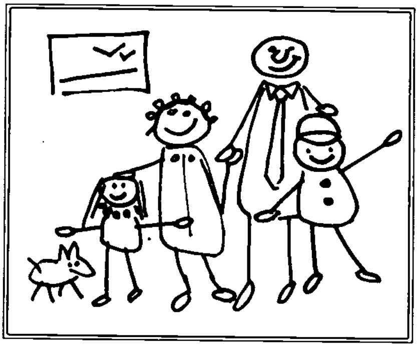
ABSTRACT

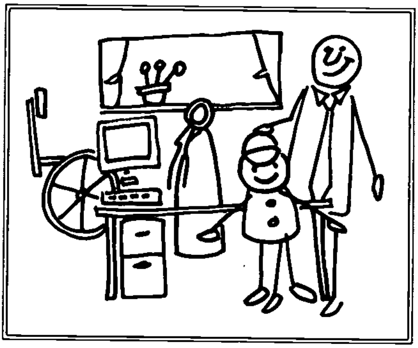
This guide is for parents of children with disabilities who require the help of a machine or device for some life-sustaining activity such as breathing or eating. Following an introduction, chapter 1 is on preparing for the child's return home including parent training, community-based services, and obtaining funding for home care. Chapter 2, on setting up the home, considers location of the child's bedroom, setting up the child's room, safety precautions, changing the physical structure of the home, and obtaining funding for home changes. Chapters 3 and 4 are on marital adjustment to home care and helping siblings, respectively. Stressed is the importance of communication and allowing siblings to express their feelings. Chapter 5 addresses concerns in working with nurses in the home and covers family rights, establishing roles and responsibilities, setting rules for the care of the child, and the relationship of nurses to siblings and parents. The concluding chapter is on meeting the challenges of parenting including development of identity, discipline, and expressing and listening to feelings. A directory of 31 organizations providing further information is attached. (DB)

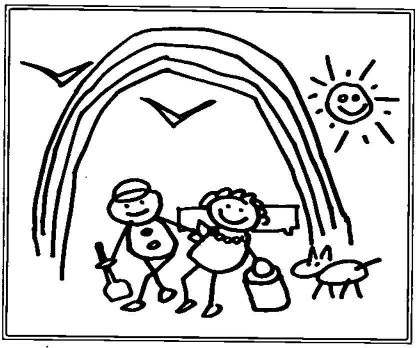
When Your Child is Technology Assisted

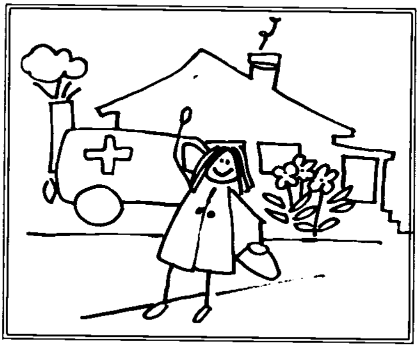
A home care guide for families

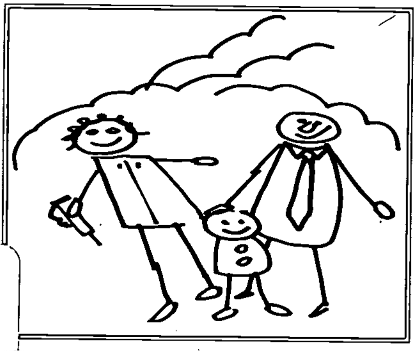
by Paul Kahn

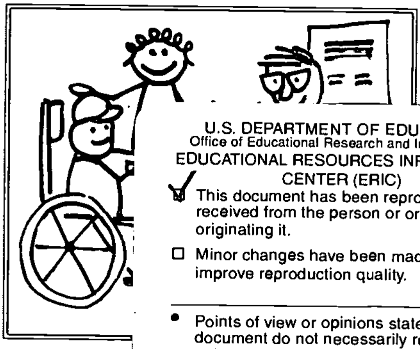












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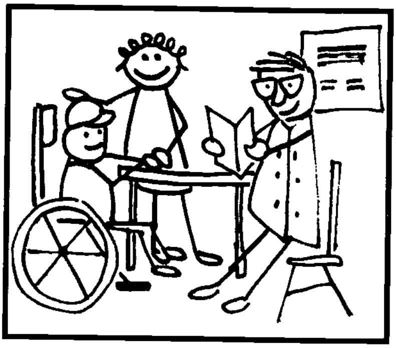
In Appreciation



I am grateful to many people for their help in creating this guide.

Thanks first to Kathleen Murphy for generously allowing me to adapt and incorporate her excellent materials. Thanks to Rolly and Ellen Edgerly, Linea Pearson, Stephanie Porter, and Nancy Terres for spending time to review the work in progress and make many valuable suggestions.

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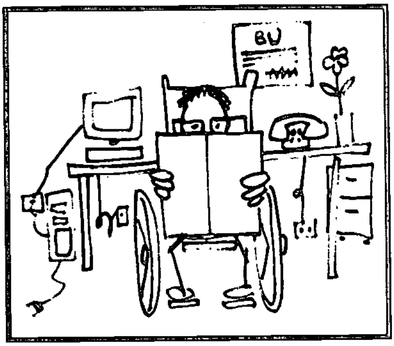
And finally, my deep gratitude to all the families, who by opening their hearts and sharing their knowledge, contributed so greatly to this guide.

Paul Kahn

Why This Guide was Written



"I wish we had been better prepared for what to expect when we brought Susan home from the hospital. Life got unbelievably complicated. We had to deal not only with all her medical needs, but also with nurses and therapists coming in and out of the house all the time and companies selling us the equipment and supplies she needed. We learned how to cope mostly by trial and error."

"With Joe home, my wife had to quit her job to take care of him. That put a lot of strain on me as the only breadwinner. We couldn't spend as much money or attention on the other kids. I worried that they would be resentful and that my wife would get burnt out being cooped up all the time. We love Joe, and we're glad he's with us. But, it's still a struggle trying to be fair to everyone in the family."

These are the voices of parents who are caring for their technology-assisted children at home. This guide was written to help the many parents faced with this difficult but rewarding challenge. Throughout, other parents will contribute their words of experience and encouragement.

"Technology-assisted" means using the help of a machine or device to perform some life-sustaining activity such as breathing or eating. Ventilators to support breathing, feeding tubes to supply nourishment, and dialysis machines to remove waste are examples of technological assistance.

Children need the assistance of technology for many reasons. Each affects the family differently. If the cause is a birth related condition, the new parents face the enormous stresses of complex medical care and an uncertain future for their child. If the cause is an injury, suddenly the parents and child face the loss of previous hopes and expectations as they adjust to living with a disability. For others the cause is the progression of a chronic illness or condition, such as muscular dystrophy. For the families of those children, technology can be especially troubling because it signals a decline in health and even perhaps the approach of death. So, the use of technology brings up many emotion-packed issues about saving a child's life, prolonging it, and maximizing its quality.

Only in recent years have children, whose lives are dependent on medical technology, been able to live at home with their families, instead of needing long-term institutional care. This change has been made possible by exciting advances in the sophistication, miniaturization and reliability of life support machines and the availability of community-based services.

Parents have found many benefits in bringing their technology-assisted children home, but also some difficulties. Among the benefits parents often cite is the increased physical and emotional well-being of their children. They feel a greater sense of mastery and control of their children's care. Family routines become more stable, and family unity is strengthened. Also, time and energy are saved that were formerly lost traveling to and from the hospital.

"You don't have a spare minute when you're taking care of a child like Sam. Anything he needs you have to do. And, when he's sick, you just can't call in anybody. You have to get a nurse."

On the other hand, families often find the constant responsibility of caring for a technology-assisted child to be stressful. This responsibility restricts their activities outside the home. And, this restriction, coupled with limited community services, can lead to social isolation. When parents are able to hire professional care-givers, they are relieved of some responsibility but face other problems. They have the job of coordinating and maintaining their child's professional care. With nurses and therapists coming into the home, the family loses privacy and has to deal with conflicts about authority and boundaries. Finally, the financial burden of home care can be very heavy because of limitations on what health insurance pays toward the costs of equipment, supplies, nurses, therapists and aides.

With thorough planning, the benefits of home care can be maximized and the hardships minimized. The primary purpose of this guide is to help families do this planning and develop realistic expectations, based on the practical advice of experienced families and professionals in home care.

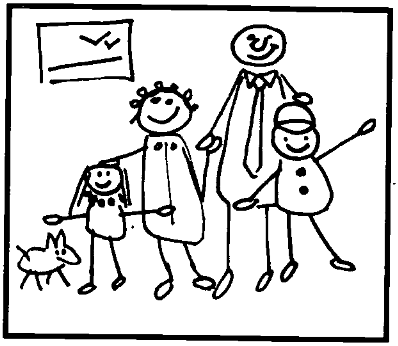
Some families will conclude that home care does not work for them. This may be because of financial burdens, the demands of jobs, the needs of other young children in the home, lack of local medical resources or housing problems. For instance, a third floor walk-up apartment would be difficult for the family of a child who uses a wheelchair. When circumstances make home care too difficult, families may feel guilty about "abandoning" their child to "institutionalization." But, a child cannot be either safe or happy living in a family that is overstressed or in a place that is hazardous.

In fact, the well-being of each family member depends upon other family members. Therefore, this guide focuses not only on the needs of the technology-assisted child, but also on the needs of parents, brothers and sisters and even the professionals who come into the home. This broader perspective can increase the chances of home care being successful over the years of a child's dependence.

The adults in the family, who are responsible for the care of the technology-assisted child, are usually referred to in this guide as "parents." But grandparents, step-parents, foster parents, guardians and other close relatives -- all whose courage, determination and love create a home for the child -- are also included under this term.

Chapter 1

Preparing for Your Child's Return Home



If you have a technology-assisted child in the hospital, you are probably eager to bring your child home but also anxious about how to make this transition safe for your child, to prepare yourself for what to expect, and to set up the services and supports that your child and family will need. Figuring out how to accomplish these goals is called developing a "discharge plan."

"We just wanted our daughter home so bad, we knew it was the right thing to do."

Effective discharge planning requires a team approach. Usually either a continuing care nurse or social worker from the hospital is responsible for coordinating the plan. Other members of the team include your child's physicians and specialists such as a respiratory therapist, physical therapist, occupational therapist, speech therapist and nutritionist. You are also a vital member of this team and, in some ways, the most important, because without your consent and commitment the discharge plan cannot be put into action. You always have the right to state your opinions, voice your concerns, ask for explanations and approve or reject recommended providers and services. The discharge plan has four main parts:

1. figuring out what you and your child will need (often called a needs assessment)
2. training you in your child's care
3. setting up services in the community
4. getting funding for those services

What You and Your Child Will Need

This part of the plan should answer several basic questions. First, what do you need to learn in order to take over the care of your child? You can help by being open about the gaps in your knowledge and skills and how you learn best. For instance, if your primary language is Spanish and you have difficulty understanding complicated concepts in spoken or written English, the discharge team needs to know, so they can arrange instruction for you in Spanish. Or, if you have difficulty remembering verbal instructions, you can ask that instructions be written down for you.

Second, how can you get over your anxieties? Many parents have doubts about their ability to learn procedures that only trained professionals perform in the hospital. They worry about the many responsibilities of home care and feel overwhelmed at times. Anxieties often get in the way of learning. By letting the team know how you are feeling, you can make sure that relieving your anxieties becomes part of the discharge plan.

Third, what equipment and supplies will your child need at home? The rehabilitation staff usually recommends devices to help your child move, sit, eat, dress and bathe, while the respiratory therapists recommend breathing equipment. Home care equipment may differ from what your child uses in the hospital. So, a good idea is to try it out before discharge.

Fourth, what community-based services will your child be using? These services may include delivery of equipment and supplies, home nursing and rehabilitation. You and the rest of the discharge team will work together to get these services, so tell the team how familiar you are with your local service providers and what assistance you will need.

And, fifth, how safe and convenient is your home for your technology-assisted child and what improvements should be made? As this is a complicated issue, it will be dealt with in greater detail in the next section of this guide.

Parent Training

Parents of most children with complicated medical conditions need training in giving medications, doing cardiopulmonary resuscitation and recognizing side effects and complications. Depending on your child's condition, you might learn how to do suctioning, chest therapy, tracheostomy care and gastrostomy care. If your child uses a ventilator, you will be taught how it functions. If your child has needs such as positioning, turning and range of motion exercises, you will also be instructed in these procedures. Finally, well child issues such as immunizations, child safety, growth and development, and behavior management may also be part of your training.

"The most difficult part of bringing Jim home was not having a medical team at my fingertips. If something went wrong, I had to solve the problem, instead of yelling for a nurse or doctor. I felt very overwhelmed and intimidated."

Training proceeds best when a clear plan with mutually agreed upon goals and schedules is written down and followed. The plan helps keep everyone "on track," and you will get a sense of satisfaction and renewed motivation as you see your goals gradually being met. Teaching methods can include demonstrations, readings, audiovisual aids and special dolls. Let the team know the methods that work best for you. Some people are naturally faster learners than others, but for everyone repetition is the key element. Although you might feel frustrated when you begin learning, eventually you will develop the knowledge and skills that you need.

Although this part of the discharge plan has been called "parent training," your child should also participate as much as possible. You can help your child build independence, self-control and self-confidence by assigning specific things to learn in order to prepare for coming home.

The amount of information and skills you need to learn will probably seem overwhelming at times. Other parents and professionals recommend reducing confusion by collecting all important written materials in a loose-leaf notebook. This notebook should contain the following:

- a medical summary
- nursing discharge orders
- an outline of your child's typical day
- medications, including action and use, dosage, frequency, way of taking, side effects and storage instructions
- special treatment instructions
- nutritional needs
- instruction on use and maintenance of equipment
- when to call the doctor
- phone numbers of physicians, utility companies (such as gas and electric), the fire department,paramedics, nursing agencies and equipment companies
- home equipment and supply list
- names and phone numbers of contact people at school
- learning needs

Another important tip is to assume responsibility gradually. First, practice your skills in the safety of the hospital. Next, try taking your child out for a few hours. Then bring your child home overnight if hospital and insurance policies allow. If all goes well, you are probably ready for the move.

Community-Based Services

The next part of discharge planning is organizing services in your community. This includes contacting agencies and people your child will use on a regular basis at home. It also involves giving emergency service providers a basic orientation to your child's medical needs, so they can respond effectively. Services your child might need regularly are leasing and maintenance of equipment, delivery of supplies, home nursing, follow-up medical care, and rehabilitation.

"We were scared we wouldn't be able to take care of our daughter the way she should be, because we were ignorant of what services were out there."

Often insurance companies limit the agencies and companies you can use. But, you do have some choices. To choose wisely, you must be able to communicate your child's needs clearly and know what you have a right to expect. Companies and agencies that provide the same services are usually in competition with each other and are eager for your business. So, you should approach them from a business frame of mind, as you would if you were interviewing job applicants.

When evaluating a home health agency, make sure that its nurses are licensed and that they have emergency medical training and experience with your child's medical condition. With equipment and supply companies, the important issues to consider are their ability to respond on a round-the-clock basis to any equipment problems and to make deliveries promptly and accurately.

In choosing any agency or company, getting recommendations from other families who have dealt with similar situations can be very helpful. The hospital or disability-related organizations such as the Easter Seal Society or the Muscular Dystrophy Association can often put you in touch with such families.

To assure proper emergency medical care, your child's physician should prepare a letter to go with your child on any emergency room visit. The letter should describe your child's special medical problems, baseline data, present treatment, including medications, and names and phone numbers of clinicians who know your child well. Copies of this letter can be kept in your loose-leaf notebook.

The physician or continuing care nurse should also alert utility and telephone companies to your child's special needs for heat, electricity and communication with service providers. These companies will then put you on a priority list for restoring services, if they are interrupted for any reason. Also, the fire department should be notified that you have someone in your house who might need emergency treatment or special help being evacuated. Experienced families recommend that you double-check to be sure all these contacts have been made, because they are so important to your child's safety.

Funding for Home Care

Lack of health insurance, inadequate insurance or limited financial resources can be severe barriers to bringing home a child with extensive and ongoing medical needs. Even families who thought they were well covered for catastrophes have found that their insurance companies can present limits and conditions when a child needs very expensive care.

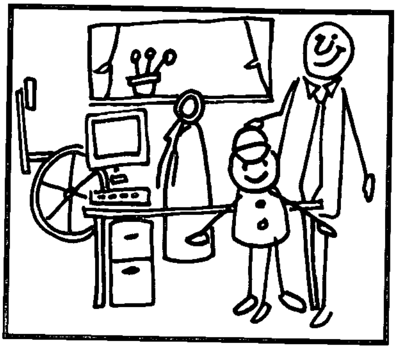
In many states, families can get help by applying to the Federal Medicaid Waiver Program, also known as the Katie Beckett Program. Under this program, an ill or disabled child's income and assets are counted separately from those of the family, allowing the child to qualify for Medicaid benefits. Contact the Department of Public Health or Public Welfare to find out if this program is available in your state.

Summary

The basic goal of discharge planning is for the care of your child to continue smoothly. When your child is in the hospital, its staff is responsible for providing care. When your child comes home, that responsibility shifts to you and a wide and changing group of people. Everyone who shares the responsibility must be well-informed, competent and sensitive to your child and family's needs. This applies to people your child might depend on outside the home, such as school personnel.

Understanding all parts of the discharge plan is important, so you can judge how well it is working and ask for any changes you feel are needed. Don't be shy about speaking up, because you are the final expert on your child. And, the well-being of your whole family is at stake.

Chapter 2



Setting up Your Home

Caring for your technology-assisted child will require changes in the physical layout of your home as well as in the relationships among family members. These changes are likely to cause tension and stress as those at home have to adapt. In fact, your child who has been hospitalized, may be the family member least likely to feel uncomfortable when home care begins. This stress can be felt even by parents of an only child who is technology-assisted. When there are brothers and sisters involved, how you arrange your home care can be even more complicated.

This chapter gives suggestions about safety and efficiency in home care. It also discusses how to balance the needs of your technology-assisted child with the needs of others in your family. It does not include specific electrical or building code requirements or directions on how to do modifications. Specific information about electricity and construction should be available from your hospital, case manager or other resources such as building contractors and public safety departments.

Certain basics that have to be in place before your child comes home. They are:

- smoke detector
- fire extinguisher
- electrical service and outlets adequate to handle equipment
- backup power source (generator or batteries)
- telephone
- heat

- running water
- space for equipment and supplies
- accessible entry and exit

After these basics have been covered, you can think about other physical, social and emotional aspects of home care.

Location of Your Child's Bedroom

Experienced parents recommend that, if possible, your child's bedroom be far enough away from your bedroom to give you privacy. You may not think this is important at first, but as home care goes on, you will find that you need a place to go and get away from everything and everyone. You need a place where you can be intimate with your spouse or partner as well as a place to talk without being overheard. You also want to just be able to go to the bathroom at night without having to "dress for the occasion."

"We made the dining room into Susan's room. But, it was in the center of the house, and to get anywhere else you had to walk through her bedroom. This wasn't good, because, as a teenager, she needed her privacy."

You may think that your child's bedroom needs to be close to your bedroom, if you have no outside help providing care at night. But, an intercom system could allow you to hear your child without you being heard. The key is to think about what might give you privacy without feeling as if you're neglecting your child.

Certainly sleeping arrangements are very personal choices. Different cultures have different customs. For some, privacy is not such an important issue. And, for many people, economic factors make sharing bedrooms a necessity. Base your choices on your family's values, needs and possibilities.

Changing the home for your technology-assisted child will affect your other children. To minimize their discomfort, try to keep the other children in the bedrooms they already have, rather than make them change rooms. Also, you can make sure that the flow of traffic caused by home care providers does not go through the bedrooms of your other children. You will also help them, if you can lessen the disturbance caused by the noise of machines and care at night.

A problem can arise when parents give the technology-assisted child the largest and best bedroom in the house. Siblings may resent this "unfairness" and see it as favoritism. Similarly, if your technology-assisted child has a separate room and siblings are forced to share a room, they may feel resentful.

One of the best ways to settle many of these "sibling rivalry" issues is to include all your children in the discussions and planning of home care. Obviously, the final decisions are up to you, but you can help your children to accept compromise, if you explain problems and choices to them. Children also tend to think more flexibly than adults, and they may come up with some creative solutions to space problems that you have not considered.

"When Billy first came home, our other kids were upset. They thought we gave him more attention."

In reality, you may not be able to satisfy everyone. At times, your other children may fling accusations at you for being unfair and loving your technology-assisted child best. All children use whatever they can to make their parents feel guilty in order to get what they want. This is normal behavior. If you have given the "bedroom" issue your best shot, then let it go. Your children will survive this experience, and there are better places to put your energy than with matters which you cannot control.

Setting up Your Child's Room

The best sources of information to help you set up your child's bedroom are families who already have technology-assisted children at home. If you do not know other families, ask someone from your hospital or home care company to help you contact some. "Veteran" parents are usually very happy to share what they have learned. They can teach you "tricks of the trade" to spare you many problems. When you visit another home, talk with as many family members as possible. The technology-assisted child, parents and siblings can each give you different ideas.

Supplies

Your technology-assisted child will need lots of supplies. Think about where you want to store the two basic kinds: the supplies used for daily care and excess supplies or inventory. In a house, there might be enough storage space, but the inventory is likely to be a problem if you live in an apartment. One solution is to order smaller quantities of supplies more frequently.

"We had a room downstairs for Jim's oxygen tanks, because that's where he spent a lot of time in order to be with the family."

It is best to keep the supplies needed for daily care where the care is most often given. This will likely be your child's bedroom. There are many ways to organize these supplies, including a closet with shelves, wall shelves, a dresser or a cabinet. Use labels, so that the storage area remains orderly and things can be found easily and quickly. Also think about a plan for who will restock the daily care supplies and when, so that the necessary items are always available.

Where you store the inventory is less critical, provided that you can find what you need and the items will not get damaged by extreme temperature or water.

Within a few months of starting home care, knowing what supplies you need and how often you have to place orders will fall into a pattern. A regular order schedule and list can be established with your home care company. When only small amounts of inventory can be kept on hand, you will have to be especially careful to make sure that the company delivers supplies in a timely fashion.

Space

You will probably find it most convenient if your child's bedroom has enough space to hold the needed equipment and supplies. However, a bedroom which looks like a hospital is not very appealing or psychologically healthy for your child. You can avoid this by placing the equipment and supplies out of the way and out of view as much as possible. For instance, they can be against the wall or under the bed to allow space for movement around the room and play.

Furnishings

When hired care providers will be spending a great deal of time with your child, you might want to provide a comfortable chair for them in or just outside the room. With young children, a rocking chair is useful to help comfort them, especially at night. You will also need tables or other surfaces for holding equipment. Having several small tables is best, because then you can easily rearrange things if you come up with a better layout or need to add more equipment.

"As Ken got older carrying him and his equipment up and down stairs became a problem. Putting in the elevator was a great help."

If your child will need a lot of lifting and moving, you might consider getting a hospital bed. While it is certainly less "normal" looking than a regular bed, it has many advantages for positioning and transferring. You might also consider having a mechanical lift to help get your child in and out of bed.

Safety Precautions

The bedroom and other locations in the house need to be equipped with fire extinguishers suitable for extinguishing electrical fires as well as regular fires. Your local fire department can help you decide what you will need and where to hang the extinguishers. Everyone in the house should be trained in how to use them.

Smoke alarms are also essential. Again, your local fire department can give you information on where to place them for the most benefit. Most smoke alarms are battery operated and will make a chirping sound when the batteries are low. Teach family members and others how to change them.

Where oxygen is used, special handling instructions and precautions about preventing fires should be written out and posted. While oxygen itself is not flammable, it does feed a fire and caution is needed when using and storing it. Alert your fire department to the fact that you have oxygen in your home.

Having a phone in your child's bedroom for use in an emergency is important. If you do not wish to have a permanent phone in the room, then a cordless phone is an ideal alternative.

Flashlights are handy during power outages. So, keep them in your child's bedroom, near any generator and at other key areas in the house. Let everyone who provides care for your child know where the flashlights are kept. Check flashlight batteries annually and change them when needed.

An Emergency Bag or "Go Bag" is useful for holding all the essentials needed by your child for travel outside of the home or for emergencies. A gym bag or knapsack is suitable and can be kept in a chosen place in your child's bedroom. In addition to medical supplies, a list of the names and phone numbers of hospitals, physicians, and other emergency contacts can be stored in the bag. Also include a notebook with a medical history that has the most important facts a physician would need to know, if your child had to be treated in an emergency department.

Changing the Physical Structure of Your Home

When preparing to bring your child home from the hospital, you might have to make some changes in the structure of your home, so your child can get around comfortably. You may even consider moving to a completely different home, in order to have more space for your child and all of the equipment. But, any changes in your home have the potential of causing stress for you and your other children.

"When you come into our house, you don't really notice anything different until you go into Pat's bedroom and bathroom. Most of the other changes were rearranging the furniture to make room for his wheelchair. We put the ramp by the kitchen door, because that's the door that we all use the most."

The goal is to provide a safe and accessible living space for your technology-assisted child, while balancing the needs of the rest of your family. In planning changes to your home, you can get advice and assistance from rehabilitation experts. Completing changes prior to your child's hospital discharge is best, because they will be more inconvenient to do later.

"We put on an addition and made a separate entrance. Now, nurses and deliveries don't have to go through the rest of the house."

Mobility

Some remodelling may be needed to allow a child who is technology-assisted to move around and get in and out more easily. For example, if your child uses a wheelchair, doorways may need to be widened and ramps built. Other possible changes are enlarging the bathroom and installing special safety bars in the tub. Changes can also make moving heavy equipment easier.

When changing your home, try to plan for the future. Ask yourself how your child's needs will change over time. For example, the child who uses a wheelchair will eventually need a larger one. So, if doorways in the home are widened, make them wide enough for an adult size wheelchair, rather than having to redo the job years later.

As you think about changes to your home, consider how they will affect the way your family lives. For instance, if your technology-assisted child's bedroom is upstairs and your family tends to gather downstairs to watch television, play games and talk together, you may want to have a stair lift installed. This will make it easier for your child to join in.

Emergency Exits

Planning how to get your technology-assisted child out of the home in an emergency is very important. There should be at least two exits which can be easily reached from the areas where your child spends the most time. Think about whether or not windows are wide enough to lift your child through in an emergency and how high they are from the ground. Once you have developed a plan of emergency exits, practice getting your family out. Calling a fire drill periodically can be an enjoyable family project and will teach everyone what their "jobs" are in an emergency. Drills should be done during the day and at night, with other care providers included, as they could also be involved in a real emergency.

Electricity

Your home must be wired to handle the amount of electrical power used by your child's equipment. In addition, you may want to have new outlets installed. You may even want a separate circuit just for your child's equipment, so a blown fuse elsewhere in the home will not interrupt service. The exact electrical requirements of the home will depend on the equipment.

When planning the electrical work, remember that your child will not be spending 24 hours a day in the bedroom. So, you might want to have new outlets installed in other rooms. As you think about where to put other outlets, give special attention to the dining room, living room and any other places in the house where family members tend to gather.

In communities where there are frequent power failures, a generator as a back up power source might be necessary. The generator will have to be stored where it is protected from the weather. It will also have to be tested regularly to make sure that it stays in good working order. Several people in the home should be trained on how to start the generator. Also, keep in mind that generators run on fuel, and a supply of the proper fuel will need to be stored somewhere safe. Some equipment, such as ventilators, are designed to run on 12-volt batteries. So, keep extra batteries charged and ready for emergency use, if a generator is not available.

Funding for Home Changes

For families with health insurance, payment for home changes has to be negotiated with the insurance company. If a physician has prescribed the changes for the safety of your technology-assisted child, you are more likely to get them covered.

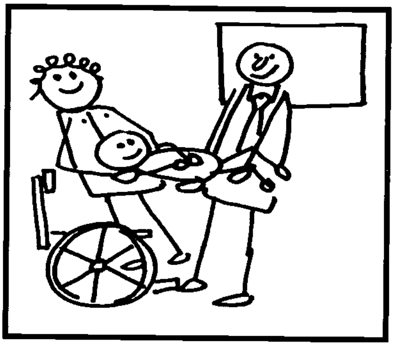
If there is a "cap" or limit on insurance for home changes, you might want to research other sources of funding. Sources within the community can include Lions Clubs, Kiwanis organizations, March of Dimes and Rotary Clubs. Other possible local resources may be friends or private contractors, who are willing to donate their time and supplies, banks or savings and loan companies, church groups and charitable organizations.

Summary

There are many things to think about during discharge planning and preparation for the home care of your technology-assisted child. One of the most concrete is how to set up your home. You will probably not be able to do everything you would like to, if you had unlimited resources. The "bottom line" is to do what you can afford, what makes sense to you as a parent and what you can live with in the long run.

Chapter 3

Marital Adjustment to Home Care



The family relationship most likely to be affected by the home care of a technology-assisted child is the one between spouses. This relationship will be referred to here as the "marital" relationship, with the understanding that not all couples who have a technology-assisted child are married or are of opposite sexes.

The marital relationship can suffer when there is a technology-assisted child in the family, because it is all too easy for adults to focus their energy and attention on being "mother" and "father" to the exclusion of being "husband" and "wife."

"You have to learn to communicate, because you can easily become very frustrated. My husband and I talk a lot. If we didn't talk and didn't laugh, the stress of home care would probably rip our marriage apart."

Three critical aspects of the marital relationship seem to be most often affected by the stresses of home care: communication and information sharing, defining roles and responsibilities, and intimacy.

Communication

Couples report that communication seems to improve at the beginning of home care. Generally one spouse becomes the primary caretaker of the child. That spouse becomes the communication link with the "outside" world, particularly between the health care system and the family. Most couples report major improvement in their communication as they share important information about their child on a consistent basis.

However, the skills learned to communicate health information do not necessarily extend to other parts of family life. Often, the day to day, more ordinary experiences of family members get lost in the home care shuffle. If partners do not function as more than just extensions of the health care system in relationship to each other, the marital relationship is at risk of disappearing altogether.

Tips on Communicating

Listen to Each Other

If you are the spouse at home who does most of the talking with the health care system, your partner needs to realize the importance of listening to you. Communication not only involves sharing what is going on, but also includes making decisions together. If you begin to feel alone in dealing with the responsibilities and details of home care, you will get burned out quickly and may resent always being the one to shoulder the burden.

"My wife is more responsible for the day-to-day handling of the situation. She relies on me more for long-range financial planning."

However, if you are the other spouse, you also need to be heard, as life goes on outside, away from your child and home care. The spouse who becomes consumed by home care might not appear as interested in outside matters, but that does not mean they are not important. Paying attention to each other's activities and cares will strengthen your relationship.

When listening, remember that there is often more to the message than just the words. Hearing feelings is an important part of listening. Often unstated feelings color the meaning of a message. If you communicate understanding and respect for your partner's feelings, you will build trust.

Of course, for listening to happen, partners must talk. But, if all that you talk about is your child, the marital relationship can easily fade away. So, try to set aside a specific time each week when you and your spouse agree not to talk about your child or the home care situation. You might be surprised by how difficult this is to do.

Communication Is Not Mind Reading

Do not fall into the trap of assuming you understand your spouse's feelings, thoughts or decisions, no matter how close you are. Nor should you assume that your spouse can read your mind, if you have not stated out loud what you need or want. Couples who think that one partner should have known something about the other run the risk of disappointment and resentment that could be avoided by better communication.

"With us, things build up, because one person doesn't realize that there's something going on in the other person's mind."

Art of Negotiation: Agree to Disagree or Compromise

Often, when one spouse has stated an opinion or decision, the expectation is that the other will understand, agree and go along. But, it is impossible for couples to agree on everything all of the time. When a difference of opinion doesn't matter, you can agree that it doesn't and then leave it alone. However, when it does matter, such as in the selection of treatment options, being able to compromise is essential. Each of you will have to give a little, until there is a mutually acceptable solution, even when neither feels the solution is ideal.

"At one point we pretty much stopped talking to each other, because we never agreed on anything. But the silence was as hard to live with as the fighting."

However, a major difficulty can occur when one spouse is constantly giving in to the other. When one partner must always win and the other lose, the game grows stale quickly. Try to approach compromise in a fairly concrete manner at first by writing out each person's position and then working toward a solution which is fair to both. This exercise might seem silly at first, but, until compromise is an everyday part of your relationship, it can smooth the way.

Defining Roles and Responsibilities

Home care often changes each partner's roles and responsibilities. In turn, these changes can create stress in the relationship. In many families, even when both partners work, one spouse becomes the primary link with the health care system. This spouse has to take on the brunt of the responsibility for absorbing information and for the day-to-day care of the technology-assisted child. If one spouse has to stop working in order to take care of the child, important roles as career person and economic provider are lost.

You and your spouse both need to feel valued for who you are and what you do. If you are the working individual, you have a dollar amount assigned to the value of your work, but at times a job may not seem as important as the daily care of your child. If you are the spouse at home, caring for your child does not have a dollar value assigned to it, but it helps keep your child alive.

"The biggest strain is that I can never get away for a vacation, because of the restriction in the number of nursing hours I can get a week."

The working spouse is physically removed from the direct and constant stress of day-to-day care routines. This has both positive and negative results. Having to concentrate on other matters allows the working spouse some relief. On the other hand, being removed from the home can also be a source of frustration. The working spouse may even feel somewhat guilty about being able to get away and focus on other matters.

"I wanted to jump in and learn everything I could about my son's disability, about his equipment and how to care for him. But, my husband felt a need to separate and not get close, because he was afraid of our son dying. He was trying to protect himself by not falling in love with his baby. We fought an awful lot, because all the burden of care was placed on me."

Home care may also push you to take on roles that you are not used to. For instance, you may have to become a strong advocate for your child in order to get important services, such as funding for an adequate number of home nursing hours. In this role, you may have to argue with insurance companies, which monitor costs and have limits on benefits. This can be uncomfortable if you tend to be hesitant and shy, but it can even be stressful if you are usually self-confident and assertive.

Tips for Negotiating Roles and Responsibilities

Balancing the value of day-to-day caregiving against income which feeds, clothes and houses the family is difficult. You and your partner can try to be supportive and appreciative of the work each of you does. When responsibilities shift at home, you might actually sit down and write out all the tasks connected with the maintenance of the family. These can then be divided, based as much as possible on you and your partner's particular strengths and interests.

Ask yourselves: is one of you better at dealing with the physician but not the nurses? The school system but not Medicaid? Similarly, is one of you more prone to see the negative side of everything, while the other is hopelessly optimistic? How can you balance each other?

Whatever is negotiated, both of you must "buy into" the plan or there is going to be frustration and discord later.

Intimacy

Companionship

An important and enduring aspect of the marital relationship is companionship. Time set aside to enjoy each other's company and talk about matters which are unrelated to child care is a vital part of being a "couple." Going out together can also be important, although many couples report difficulty leaving their child because of lack of respite care or because of their anxiety.

"We've made it a rule that we get out together Saturday nights to socialize or to shop."

Sexuality

A part of being intimate as a couple certainly includes having a sexual relationship. Commonly the sexual relationship between partners is virtually non-existent for the first few months of home care. This can happen for a number of reasons, and there is not necessarily anything wrong if partners find themselves sexually unresponsive or distant in the beginning.

Spouses who have a technology-assisted child at home are often on edge, feeling they must be ready in case their child cries out, needs comfort or care. Being on edge, they have difficulty shifting their focus of attention away from their child to themselves. Couples might feel guilty for "stealing time away" from their child to engage in sex. Also, the presence of nurses and other professional caregivers in the home can be extremely inhibiting.

Different people react differently to challenging situations. Loss or decrease of sexual desire may be experienced by one or both partners due to stress, anxiety or preoccupation. When there is an imbalance of desire between partners, frustration and anger can result and be compounded by accusations of being too sexual or unresponsive.

Guilt can be another cause for disruption in the sexual relationship, particularly if one or both partners becomes sexually aroused during times which either feels is "inappropriate," such as in the midst of a major crisis. However, individuals do sometimes become sexually aroused when life seems most fragile and the need for comfort and relief is intense.

Tips on Intimacy

Try to think consciously about intimacy and talk about it with each other. If you and your partner are feeling uncomfortable with the level of intimacy in your relationship, ask yourselves: what is the source of the discomfort? How can you recapture feeling closer? Both of you may now need to make a more a conscious effort to stay in touch with each other. But, while spontaneity might be lost, working at being intimate can help you achieve an even better relationship.

Timing is everything, and there is nothing wrong with making a "date" with each other. Even taking an uninterrupted nap together at a motel, a friend's or in-law's house has merit. You might find it difficult to get away. But by doing so, you're investing in yourselves and your relationship, and that effort will pay off.

You and your partner should not let anyone else determine for you what is an "appropriate" level of intimacy or sexuality. Whatever you agree on is right as long as both of you are honest about your needs. This may require some negotiation, but it is a private issue and not something to talk about with the neighbors, in -laws or nurses. Complaining to such people about your marital relationship will only alienate you from each other.

Also, remember that it is fine to seek outside, professional help, if you reach an impasse in your relationship. Many couples need assistance at various times, and you are better off to ask for help before matters get out of control and one of you withdraws altogether.

Summary

When there is a technology-assisted child in the home, the relationship between partners will be tested and challenged. However, what is good for the married couple will prove good for the rest of the family. Therefore, you and your partner should consciously nurture your relationship, even though doing so will necessarily involve time away from your children. But, the best gift that any parent can give a child is to love, honor and respect the other parent.

"Our experience has only strengthened us. We're better friends and much better parents."

Nonetheless, home care does not work for everyone. It can complicate difficulties that already exist in a couple's relationship. It can also force partners to re-evaluate their priorities and to examine what they want out of "family" and "marriage." Certainly, one option in that re-evaluation process is separation or divorce. However, if you and your partner wish to stay together, then both of you must give yourselves the best possible opportunity to succeed by investing time and thought in your relationship.

When they see their parents upset by their brother or sister's medical problems, siblings can become anxious and even depressed. If they are young, they may fear catching the illness or disability. And, as they get older, they may fear inheriting the total home care responsibility when their parents become infirm or die. Finally, siblings sometimes feel isolated. If they have been teased and embarrassed by peers because their brother or sister is "different," they might withdraw into themselves. This withdrawal can deepen, if the family treats the difference as a shameful secret, which cannot be talked about.

General Tips

Perhaps the most important thing you can do for your children is to let them know you love them. Don't assume that they can read your mind. Stop in the hectic whirl of daily responsibilities to verbalize your feelings. Emphasize how important they are as members of the family.

One way to show their importance is to involve them in the planning and decision-making that affects all of you. Expecting them to take on some household and home care chores also shows them that they are important. But, leave them time for fun. Of course, even though you try to be fair, they will sometimes rebel and complain. Children naturally test limits, so don't expect them to act like saints.

In general, try not to let your needs and fears get in the way of their right to be themselves. Because something "bad" happened to one of your children, you cannot keep the others in a protective glass case. Because you are hurting, you cannot expect them to "mother" you. Practicing self-awareness will help keep you from letting your needs take over.

Describing Your Child's Condition

Children are naturally curious, and they will want to know about their brother or sister's condition. So, give them honest, matter-of-fact explanations. By doing so, you will be showing that the condition is a routine, acceptable part of life.

In giving information, be guided by what your children ask. Very young children are especially interested in the "why" of things. As they try to make sense of the distressing and perplexing fact of their brother or sister's difference, they will often develop fantasies that reflect their fear, guilt and confusion. By helping them express these fantasies, you can correct their misconceptions and reassure them that they are not responsible.

"Sometimes his brother will say, 'I wish that Joe wasn't handicapped. I bet we'd wrestle together, if Joe could.'"

Children aged six to nine years old are more interested in the mechanics of things. They will, for instance, want to know what a ventilator does and how it works. Give them medical and technological information in language they can understand. Knowledge gives children of this age confidence and a sense of mastery. This helps them to be unafraid of their technology-assisted sibling.

Among ten to twelve year olds, concerns about the future begin to emerge. They will ask questions about their brother or sister's prognosis. Answer them honestly but without giving more information than they really want. And, remember that you do not have to know the answer to everything. Nobody does.

Older adolescents look ahead toward adulthood and often have concerns about whether their children will also be disabled and whether they will be expected to become caretakers for their brother or sister. Knowing if there is a hereditary factor in your child's condition will help them with their first concern. If there is, you might want to go as a family for genetic counseling, so that your children will have the most up-to-date scientific information.

Involving adolescents in planning for your technology-assisted child's future will help them with their concerns about responsibility. This planning might entail setting up trusts, choosing future guardians, investigating different living options and obtaining pre-vocational and vocational training. Your adolescents will be reassured by your ability to face up to your own mortality and make these preparations. In your discussions, emphasize that any promises of responsibility they make in their youthful idealism are voluntary and can be renegotiated later.

When you share information with your children, try to make your statements descriptive, rather than evaluative. For instance you might say "Your brother breathes differently than you by using a ventilator." But, avoid saying "Your brother doesn't breathe as well as you." The former statement gives a neutral fact, while the latter implies the inferiority of your technology-assisted child. Repeated over and over, judgmental words can create negative attitudes. Instead, use words carefully to foster an atmosphere in your family of acceptance and equality.

"I think my children are more responsible and more involved in their sister's care, because it's never been forced on them. It's always been a choice."

Even more powerful than words are actions. By confident loving and caregiving of your technology-assisted child, you will send a clear message to siblings that will help overcome any fear and reluctance to get involved. As you perform care chores, talk with your children about what you are doing and why. This gives them the confidence of knowledge and makes their brother or sister's special needs seem routine and acceptable.

However, even though you want your children to absorb your values and attitudes, they cannot be copies of you. A child who is expected to act just like another parent to a technology-assisted sibling is under enormous stress, and the result can be serious psychological harm.

Expressing Feelings

You can help your children maintain their emotional health by giving them opportunities to express their feelings about living with a technology-assisted brother or sister. Very young children cannot express themselves in words, so they are apt to communicate their distress or need for attention in actions such as crying, clinging or bedwetting. These can be aggravating, but they send an important message that the child is upset and needs help. Even when children become more verbal, they often do not describe their own feelings directly but instead tell stories about how someone else "cried" or was "bad." Letting your children know that you will not punish them for how they feel will give them security and confidence to share their doubts, fears and confusions.

"I don't want them to think that one is more special than the other. One just needs more care. I always tell them I have a lap for each of them and two shoulders for piggybacks."

You can also help your children express their feelings by encouraging their creativity. Activities such as keeping a diary, writing poetry and painting provide a safe, uncensored way for them to "get out" even their darkest emotions. And, by making something of beauty from these conflicted feelings, they learn to value themselves more.

At times, though, your children may need other sources of emotional support to draw them out. Under the pressure of responsibilities, you may not always have the time they need, or the ability to listen without advising or criticizing them. Sometimes, a friend or relative can become a more objective and compassionate confidante. And, sometimes professional help is needed, such as individual or family counseling or a professionally led sibling support group. Health care providers and disability-related organizations can usually help you find reliable sources for these services.

Benefits to Siblings

Although siblings of technology-assisted children face unusual stresses, many of them believe they have also benefited from their experiences. Their abilities to balance needs, interests and time have proved valuable in the larger world, which requires compromise by everyone. Their understanding and compassion for differences among individuals have made them more tolerant and broad-minded. And, the habits of caring and commitment they developed when young have made them valued workers, citizens and spouses in later life.

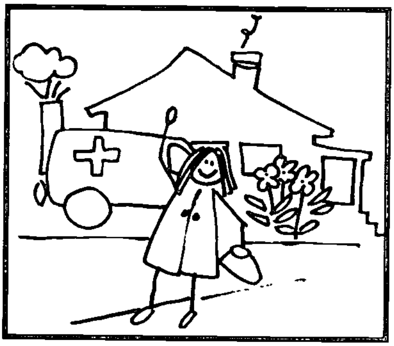
"I think that kids who have disabled siblings have to grow up faster and learn the realities of life and death. My son at the age of eight saw his brother resuscitated."

Summary

The experience of these siblings suggests that the meanings and consequences of caring for a technology-assisted child are not always the same. Instead, meanings and consequences are determined by the particular values and strengths of each family.

Chapter 5

Working with Nurses in the Home



The relationship between parents and nurses is complicated. Parents appreciate nurses who care for their child with skill and warmth, and often become close to them. On the other hand, the relationship can often be marked by tension. The boundaries between parenting and nursing can easily become blurred, resulting in conflicts about roles and responsibilities. Fears and frustrations about the child can get expressed through irritability and fault finding. Constant closeness can tend to enlarge small grievances. And, unclear needs and expectations can contribute to misunderstandings.

"I have a love/hate relationship with the nurses. I love having their help in the home, but they make me realize that my child is different. He has a reason for needing the nurses. And, that's hard."

The following information can help you establish a professional working relationship with nurses and avoid stress.

General Tips

Keep Expectations Reasonable

As a parent you have a right to approve or disapprove of an agency or a nurse. You also have a responsibility to be reasonable in your expectations. For example, you might feel that nurses who are married and have children work better in your home, but to expect that all the nurses you hire will be married and have children is unreasonable. Similarly, it is unfair to expect all the nurses to be female but not unreasonable to expect the majority to be.

Gender, age and race are difficult issues for some families, but, if you state your preferences up front, then consideration can be given to meeting them. Agencies can not be expected to comply with racial or ethnic biases. However, no one is interested in creating unnecessary problems by not trying to match the staff with the needs of the child and sensitivities of the family.

Keep Relationships on a Professional Basis

Parents can find it difficult to criticize nurses with whom they feel friendly. So, if you keep a professional distance from the nurses in your home and do not rely on them for your social support, you will be more likely to feel in control.

"A really good home care nurse knows where her professional and personal boundaries are. I've bonded with some nurses, and then the personal overlaps the professional. But, that can get really sticky."

Write Down Roles and Expectations

Discuss these with nurses before they begin working in your home, so they know what is expected of them. The more specific you are, the better.

Communicate Openly and Regularly

Agency nurses are required to keep a written log. You may also want to maintain a "communication notebook" in which any changes in schedules, special appointments or general information can be recorded and read by you and the nurses. The notebook does not replace direct communication but rather insures that everyone is aware of any changes.

Separate Parent and Nursing Responsibilities

Although you and the nurses will share your child's care, be clear about what is a parent's responsibility and what is a nurse's responsibility in your household. Often, the lines are not firm. For instance, if your child cannot eat independently, then feeding could be a parent task but also could be considered a nursing task. There are many circumstances where some thought will be needed to work out who is responsible for what. Be guided by both your preferences and the nurses' sense of their professional roles.

Family Rights

Home nursing is one of the primary services you are likely to need for your technology-assisted child. Your approach to it can serve as a model for thinking about your rights with other professionals. Remembering that you are a consumer of services, you should expect the nursing agency and its nurses to do the following:

- Provide competent nursing care for your child.
- Cover all agreed upon shifts.
- Replace a nurse who is not providing appropriate care.
- Provide regular supervision to nurses.
- Have a process for resolving any conflicts or problems between your family and nurses.
- Respect your authority and judgment in all areas of family life.
- Respect the privacy and lifestyle of all family members, unless some aspect of behavior puts your child at risk.
- Discuss with you when to call the doctor or involve anyone else in the care of your child, except in an emergency when you are not available.
- Keep up-to-date on new techniques and skills that could promote the well-being of your child and the independent functioning of your family.

"The ideal home care nurse is someone who will involve herself in Sam's life, who will give him choices about what he wants to do and who will give him the kind of care that I myself would be giving him.

Establishing Roles, Rules and Responsibilities

Shifts

Once you and the agency work out the nursing schedule, expect the nurses to follow it. If a nurse is tardy, inform the agency. You should generally expect an individual nurse to work the hours that have been scheduled. Unplanned changes can be difficult for your child and you. However, there must be some flexibility. If, for instance, a nurse had an infectious disease, you would not want your child to be exposed. Despite the inconvenience, rescheduling would be preferable.

Leaving Home

You must inform the nurses when you leave home, your expected time of return and where you can be reached. This is important for the safety of your child.

Emergency Plan

Write out an emergency plan and display it prominently in your child's bedroom, the kitchen or wherever makes the most sense. Update the plan as needed and include emergency phone numbers, the hospital where your child is to be taken, method of transport, physicians and others to notify.

Choose one or more alternative persons to assume responsibility for your child if you can not be reached, and write their names, addresses and phone numbers on the emergency plan. You might want to consider making a relative or other person a legal guardian for your child. While a hospital can provide your child with life saving treatment in an emergency, any additional treatment requires permission of a parent or guardian.

Care of Siblings

Legally, nurses are only responsible for the children they are hired to care for. They cannot be expected to serve as babysitters for siblings or other children in the home. You must plan for the care of your other children and inform the nurse of those plans.

Personal Relationships with Nurses

You are naturally going to like some nurses more than others. However, you need to be very careful of making negative comments to one nurse about another. This can create a lot of tension for all involved in the care of your child.

Problems with a nurse about caregiving need to be addressed directly to the nurse. If they are not satisfactorily resolved, then contact the supervisor or charge nurse. If dissatisfaction with a nurse is related more to personality than nursing care, think very carefully about how you wish to address it. Try to find a graceful way for you and the nurse to work things out or to part company without bitterness.

"When I have a problem with a nurse, I try to approach her in a positive way. I tell her, 'We really like what you're doing, but there's just this one thing you should be aware that we'd like done differently.' "

Also be very careful about not unloading dissatisfaction with your spouse on the nurses. To complain about your spouse to a nurse sets up a situation in which it is very difficult for the nurse to avoid taking sides. This can easily lead to your spouse becoming isolated. So, guard against bringing nurses into the middle of family disputes.

Sometimes a family member might develop romantic or sexual feelings toward a nurse. While feelings are spontaneous and should not be judged, actions can. Nurses are barred by professional ethics from engaging in intimate relationships with any family member, and they should never be pressured into doing so. A nurse who falls in love with a family member needs to leave and work out the relationship without the complications of a professional role.

Generally, the long-term presence of nurses in your home can intensify both positive and negative feelings. Such feelings are a reaction to the stress of caring for a technology-assisted child. As you try to cope with your anxiety, frustrations and longing for comfort and escape, nurses can be convenient targets for your emotions. Knowing this can help you put these feelings in perspective and manage them.

Money

Borrowing money from or lending money to nurses should be avoided. This can create discomfort in the home. Also, avoid buying or selling things to each other.

Gift Giving

Generally, family members are wise not to accept gifts from nurses or to give gifts. This can be awkward, but gift giving can become extremely expensive for both you and the nurses. If nurses purchase gifts for your technology-assisted child but not your other children, that can foster jealousy.

Dress

Home is where people normally relax and dress more casually, but family members need to observe some modesty, in order not to discomfort and embarrass the nurses.

"As a man, I feel like I'm under the scrutiny of women in my own home. I can't fall asleep on the couch in my underwear, if I want. I can't swear, if I get pissed off about something."

Nurses themselves should dress in a professional manner, but, in working with children, "professional" can be stretched to allow for clothing that is comfortable and practical. You also have the right to expect nurses to wear identification badges at all times, so that at meetings and outings people know who is the nurse and who is the parent.

Household Policies

You will have to make decisions and establish rules for nurses about many other matters. These include:

- where to park their cars
- where to store their personal belongings
- where to have their meals
- what household appliances and utensils they can use
- whether they can watch television, listen to the radio or make personal telephone calls

Generally, be guided by the understanding that nurses are paid professionals who are in your home to perform specific duties. While you want to create a comfortable working environment for them, you do not need to cater to them. Nor do you want to exploit them by asking them to do things unrelated to their professional responsibilities, such as run errands for you or answer the telephone when you or other family members are at home.

Setting Rules for the Care of Your Child

Routines

As a parent you set the schedules for your child's naptime, playtime, bedtime and mealtime. You also decide such things as how much television your child can watch, when friends can visit and what is okay to eat. By communicating these preferences clearly to the nurses, you can avoid much misunderstanding.

Discipline

Parents are always the final authority over their child. So, explain your family's philosophy of discipline to the nurses. Be specific about who is to discipline your child, with what methods, and under what conditions. You and the nurses will need to work together to be consistent.

"A nurse should have the ability to parent, rather than just take care of a child technically."

Sometimes you may use a method of discipline that the nurse is not willing to follow, such as spanking. In that case, try to work out an alternative method for the nurse to use. Also, keep in mind that children will realize very quickly if the nurses have no authority to discipline them and will take advantage of this fact.

Friends

Your technology-assisted child will benefit from spending time with friends. So, allow as much "space" as possible with friends without incurring too much risk. The older your child, the less likely friends are to want an adult hanging around. Some friends may want to learn some of your child's care. Think about whether you would be willing to let them, who would be best to teach them and if you should ask their parents' permission.

Giving your child "space" and allowing friends to provide care always present some level of risk. You and the nurses might disagree about how much risk is reasonable. However, try to work out some mutually acceptable standards. Giving your child conflicting messages will create confusion and self-doubts about what risks are okay to take.

Sexuality

Technology-assisted children, like all others, will at a certain age become concerned about their sexual ability and identity. This is an issue which adolescents often feel less inhibited about discussing with a trusted outsider, rather than with a parent. So, establish some guidelines regarding how much information you wish nurses to give your adolescent. However, talking and doing are two very different matters. Under no circumstances is it appropriate for a nurse to engage in any sexual activity with a dependent minor.

Nurses and Siblings

Sibling Relationships

It is extremely important for brothers and sisters to do things together. Decide with the nurses what their responsibility is in supervising these interactions. Keep in mind that your technology-assisted child will be getting a lot of attention from the nurses, and this is bound to be the cause of some jealousy and sibling rivalry. Some nurses will be better at "smoothing feathers" than others, but none are obligated to be responsible for your other children, except when they interact with your technology-assisted child. Try to figure out how to strengthen the relationships among brothers and sisters without interfering with the nurses' work.

Discipline

Families usually recommend that nurses do not discipline siblings, but you can decide if you wish the nurse to intervene in arguments or to call you. Siblings ought not to feel they can order the nurse around or that the nurse has no authority over them. Nor is it good for the nurse to be a constant "tattletale."

Participation in Care

Even before any of the children indicate an interest, you may want to think about the possibility of siblings helping care for your technology-assisted child. This can help siblings adjust to home care, and it can also be a big source of support for the family. However, as with friends helping, this needs to be discussed with nurses so they know your preferences. If the nurse feels uncomfortable, you might compromise by deciding that the other children can help only when you are present.

Nurses and Parents

Communication

During the early stages of home care, try to set aside a specific time during each shift to meet with the nurse to review your child's situation. This can be fatiguing, but establishing a relationship right from the beginning is important. And, the extra effort will pay off in the long run. Communication can also be enhanced by setting up a "communication buddy system," pairing new nurses with nurses who have been working in your home for a while. The new nurse will then have a designated person to contact for help.

Begin to think about what information you want from the nurses immediately and what information can wait. Early in home care, parents want to be told everything but learn over time that this is unnecessary. To be interrupted all day long for every detail is tiring. It helps to hold off on matters which do not require immediate attention and to let others be responsible when you are not needed.

Privacy

Privacy can be a major issue for parents who have nurses working in their home. So, let the nurses know clearly when you want to be left alone, except in an emergency. For example, some people like time in the morning to just sit quietly before starting the day, while others might need time after dinner to unwind.

What you do in your home is not the business of the nurses, unless it interferes with their ability to carry out their jobs or jeopardizes your child's safety. If you find a nurse's attitudes or judgments having a negative impact on your family, discuss the matter with the nurse and the nursing supervisor.

"Somebody is in our home all the time, and we don't have the normal family privacy. We had a nurse once who walked in on us in our bedroom, without even bothering to knock."

However, if the nurses feel too uncomfortable in your home because of some behavior of yours, they have the option to leave. So, try to balance the right of the family to act as naturally as possible with the fact that there are others in the home.

Summary

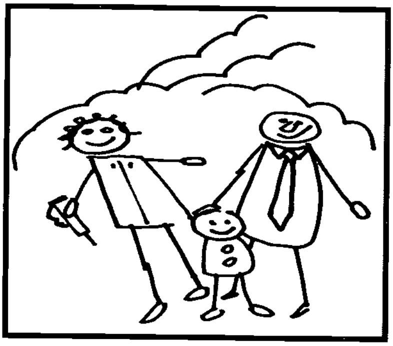
Having nurses in your home to help with the care of your technology-assisted child requires some attention to detail. You can make a difference by careful planning. The bottom line is that adjustment takes time. While planning ahead helps, there is just no way that everything can be sorted out in advance.

It will take time for you to understand the need to maintain a professional relationship with the very people who spend as much time in your home as some family members. It will take time for people to get used to one another, to trust each other's judgment, and to become a "team." You need to be patient with this process and to keep in mind that you are in this for the "long haul" and the greater good of your whole family.

"Because of having nurses I can take a job and make a commitment. And, I can go out and spend time with my other son."

Chapter 6

Meeting the Challenges of Parenting



Being a parent is never an easy job, but parenting a technology-assisted child can be especially challenging. Many of the yardsticks by which parents usually judge how their children progress do not apply. As a result, parents do not know what expectations to have. Parents' normal feelings of guilt, anger, fear and sadness about having a child with a disability can lead either to greater emotional involvement or distance. When parents are confused and fear that they are doing the wrong thing, they may suffer self doubts and become even less effective. The following suggestions can help you cope with these problems.

Development of Identity

The basic task of parenting is to help your child develop a positive sense of identity. This means having self-esteem and self-confidence. An identity is formed over time, and each succeeding stage of childhood poses its own challenges. For a technology-assisted child, these challenges can loom larger than for other children. You can help by being aware of the difficulties your child faces and finding ways of dealing with them.

The first challenge your child faces is the recognition of being a separate individual. This is normally the primary challenge for the first year of life, but for physically dependent children it can be an ongoing issue. If you are overprotective, your child might never "cut the cord." On the other hand, if you are too distant, your child might fear becoming a separate person and rely on fantasies of always being with you. You can best help your child become an individual by being available when needed, but not hovering. Let your child experience enough frustration and time alone to be challenged but not overwhelmed.

During the second and third year of life a child begins to have a sense of initiative and independence. As mobility increases, the child develops will power and self control and expresses clear preferences for how and when to do things. Technology-assisted children can have difficulty developing initiative because of their dependence on machines and care-givers, tight and constant supervision, and intrusive medical procedures. Instead of feeling more independent, they are constantly reminded of their dependence on doctors, nurses, therapists and parents.

"Because Mary is so dependent, she's a people-pleaser. That bothers me sometimes, but I have to step back and let her fight her own battles. I tell her she'd better get some grit and speak up for herself."

As a parent, there are a number of ways for you to help your child develop a sense of control. You can allow your child to gradually assume more responsibility for managing care and for controlling behavior. You can encourage the expression of choices and preferences. And, you can listen to your child's feelings and views. This stage of a child's growth inevitably causes some anxiety for parents. To do the best for your child at this stage, you must be willing to really begin the "letting go" process.

As a child progresses through the fourth and fifth years, the identity challenge shifts to being able to look at the future with hope and imagine a world of positive possibilities for work, relationships and independence. Technology-assisted children often have difficulty believing in these possibilities and might instead be overwhelmed by their difficulties and the obstacles to "normal" social and personal development. Rather than hope, they may feel doubt and despair.

You can awaken hope by exposing your child to positive adult role-models, who have similar conditions and needs. You can teach your child that there are many different kinds of people in the world and many equally valid ways of doing ordinary human things, such as speaking, and getting from place to place. You can also emphasize that all kinds of people, including people with disabilities, deserve respect and that their right to an equal opportunity to make a future for themselves is guaranteed by law. Sometimes children with differences are exposed to hurtful comments from others, based on fear, ignorance and prejudice. You can help by providing reassurances that these kinds of comments have nothing to do with your child's real worth.

"When we go out, people stare at Ken. And I want to say to them, 'What are you staring at? Take a picture.' I talk with him and my other children about the fact that everyone in the world is different. Some differences can be seen and some can't."

As at other stages, your feelings can get in the way of helping your child. Ask yourself: Do you have fears for the future? Are you passing them on to your child? Or, are you so invested in your role as care-provider that you are unconsciously blocking your child's development? Children are greatly influenced by their parents' opinions and beliefs whether they are directly expressed or implied. So, think about what messages you are sending.

"I used to feel really cheated. I wondered: why did this have to happen to one of my kids? What did I do to deserve this? And, what did he do?"

Building on the previous stages, the child, from about age five, moves on to the stage of identity formation that will be central throughout adolescence. The challenge of this stage is to develop a sense of competence. This can be difficult for a technology-assisted child, who does not achieve the usual milestones on the expected timetable, such as graduating from a tricycle to a two-wheeler, being unsupervised with friends, getting a first job, going on a first date, learning to drive. Missing these kinds of accomplishments, a child can start to feel inferior and that there is no point to getting older.

As a parent you can help by searching out what your child is good at and encouraging those abilities. If your child is excited by learning and reading, visit the library together. If your child is artistic, buy paints and set up an easel. If your child shows an interest in cooking, share making dinner. There is always something that your child will want to do and derive satisfaction from, if you recognize, encourage and applaud it. The investment in time and energy you make in this effort will pay off in your child's greater self-esteem.

"This is not an easy time for Kathy. She's 17, and the other kids her age are driving and going off to the malls."

In general, it is more likely that your child will develop a healthy sense of identity if you are able to appreciate your child as a separate, unique and valuable human being.

Discipline

Providing a child with consistent guidelines for behavior and with clear consequences for both good behavior and misbehavior is the goal of constructive discipline. All children need discipline. As they get older, they "internalize" the rules they have learned, and, instead of needing guidance from others, they become able to exert self-control, make good decisions and act independently.

Many parents feel torn between knowing they have to discipline their technology-assisted child and at the same time wanting to make special allowances or excuses, because their child has been through so much. They don't want to hurt their child, yet they know they should not spoil their child either. In fact, discipline is very important for giving a child the strength of character needed to meet the inevitable challenges of being technology-assisted.

"A lot of people treat Bill like a baby. But, I don't want him to be 15 years old and crying every time he can't get his way."

Rules of behavior need to be based on reasonable expectations. You can consult with physicians and therapists about what is reasonable to expect of your child, given his or her physical and cognitive capacities. However, there are some rules that almost all children can follow. At home, your child can be responsible for going to bed and getting up on time, performing as much self-care as possible, telling the truth, staying away from dangerous objects and respecting other people's possessions. In school, your child can be expected to pay attention in class, respect teachers, finish homework and work hard. Socially, your child can learn to cooperate with others, play by the rules, be sensitive to other people's feeling and communicate wishes and needs.

Many children learn valuable lessons about discipline and responsibility by performing household chores. Your child might be physically unable to wash the dishes or take out the garbage, but with imagination and patience you can probably find some reasonable tasks. For instance, you can give your child the responsibility of reminding you when to feed the family pet, making up grocery lists or helping younger siblings with their homework.

Almost all educators and psychologists agree that discipline is much more effectively established through rewards than through punishments. Your child's most important reward is your loving praise, but you can also use privileges, treats and even money as incentives. When you have to resort to punishment, your technology-assisted child should receive the same kind of penalties as you would give your other children, whether it is time-outs, being grounded or being required to apologize for the misbehavior.

Expressing and Listening to Feelings

You cannot prevent your child from feeling emotional pain. At various times, your child is going to feel sad, fearful and angry about difficulties and losses. You hate to see the child you love upset. You may feel guilty for causing this pain by bringing your child into the world or by failing to prevent an injury. You may feel helpless for not being able to provide a cure. But, you can accept your child's pain more easily, if you see it as a sign of strength and health. Instead of taking life "lying down," your child is protesting its injustice. This passion will help your child greatly in meeting the many challenges of a difficult life.

"We support him when he's sad, when he's upset that he can't run and keep up."

Allow your child to express feelings and respond with attention and empathy. Listening may be painful at times, but avoiding your child's feelings does not make them go away. It only makes the situation temporarily more comfortable for you.

Sometimes, with all good intentions, parents tend to silence their children. When a child complains about having to do some painful therapy or take some bad-tasting medicine, they might say, "Don't be a baby; it's for your own good." When a child expresses sadness about not being able to walk, they might respond with, "Lots of people are worse off than you." Or, if a child worries about the future, they might actually lie and promise an impossible cure, "if you pray hard enough."

Any attempts to shame or fool a child out of feelings can be extremely harmful. A child whose feelings are not respected can feel invisible and rejected. Such a child may quickly learn to wear a smiling, "good patient" mask to please the people needed for survival, but inside can be filled with fear and self-dislike. By contrast, if you listen to your child, recognizing the importance of feelings, you will be conveying your love and encouraging a sense of security and worth.

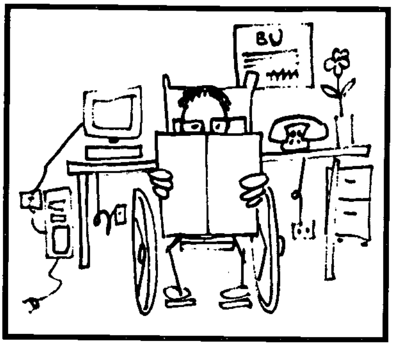
However, parents can do harm, if they "unload" their own distress on their children. Children tend to feel unreasonably responsible and guilty for anything that bothers their parents. And, they often confuse feelings and actions. So, if a parent were to say, "I am sick and tired of taking you to the bathroom!" the child might assume that some act of neglect, abandonment or retaliation will follow.

As a parent, your feelings are important, too, and you deserve an outlet for them. You can unburden yourself to your spouse, your friends, a support group, a therapist or even your journal. But not to your child. This does not mean that you can never disclose your feelings to your child or that you have to lie about them. For instance, if your child asks if you ever feel sad, you can briefly admit that you do. Then, wait for any further questions.

The key is to listen for what your child is ready to hear and respond to that. As children mature they want and need to know more about other people's feelings. By doing so, they develop empathy and the ability to form sustaining relationships. It will be a great tribute to your parenting when your grown child wants to really know you as a person and a friend.

Summary

Despite the difficulties, parents of children who are technology-assisted enjoy the same rewards as other parents -- the give and take of love, the satisfaction of passing on experience and beliefs, the pride in watching a child grow and develop. However, children who are technology-assisted may remain dependent on their parents or other caregivers longer than other children. Therefore, finding ways to avoid burnout and planning for the future are important issues for parents to consider.



Conclusion

This guide has focused primarily on the health care needs of technology-assisted children. But, over their lifetimes, such children are also likely to need other kinds of services, such as special education, adapted recreation, vocational rehabilitation and income assistance. A challenge to the family is to obtain and coordinate the needed services, which are provided by many different organizations, agencies and specialists.

"People in situations like ours should never sit back and be quiet. We have to get out and fight and be heard. We have to let others know that our kids deserve the same chances as anybody else."

Amid the changing providers, family is the one constant in a child's life. Knowing your child over time, you have a special perspective. And, the stability you give has great importance for your child's emotional and physical well-being.

For your child's services to work well, you and the providers must act as partners, communicating openly, clearly and with mutual respect. The providers contribute their expertise, information and access to resources. And, you contribute your long-term knowledge of your child, sensitive day-to-day observations and deep commitment.

As time passes, the needs and abilities of your child and family will change. And, these changes may lead you to reevaluate home care. For instance, as your child gets older and heavier, you may have more difficulty giving the physical care. Or, your child may need specialized independent living skills and vocational training that are not available in your community. Then too, as you get older and see your friends' children leaving home, you may desire more freedom from responsibilities. You will always be the parent, but at these stages in life you need to think through whether being your child's primary caregiver is the best option for everyone. Would having your child live in a residential facility, a group home or a staffed apartment be better? Parents often feel guilty if they give up home care, but sometimes the stresses can just be too great.

"Connecting with other families who have children with special needs has made the difference between coping and falling apart."

Certainly the rewards are also be great. Children usually do better at home both physically and emotionally. And, families that are together feel more sense of intimacy and common purpose. As a home care parent, you can enjoy the satisfaction of doing what you believe is best for your child and the rest of your family. And, you can gain new self-esteem by finding within yourself courage and abilities you might not have been aware of before. As one mother said,

"My son is probably my greatest teacher. He taught me that I have inner strength that I never knew I had. He helped me believe that I can make changes."

In fact, none of the parents interviewed for this guide ever expressed regret about the decision they had made to care for their children at home. The children, no matter how limited, gave them pleasure. Their survival was seen as a gift, worth every sacrifice. One parent summed this feeling up in these words:

"This is the best job I've ever had. The pay stinks, but the benefits are fantastic. This is my purpose in life, what I'm here to do. And, I try to do it with a happy heart."

Sources of Information

INJURY

American Trauma Society (ATS)
1400 Mercantile Lane S-188
Landover MD 20785 800-556-7890
E-mail: atstrauma@aol.com
Internet: http://www.amtrauma.org

ATS is a non-profit organization dedicated to the prevention of trauma and the improvement of trauma care. ATS coordinates a number of programs designed to prevent injury and to increase public awareness of trauma as the number one disease problem in society.

Brain Injury Association (BIA)
1776 Massachusetts Avenue S-100
Washington DC 20036
202-296-6443 FAX: 202-296-8850
Internet: http://www.biausa.org

BIA provides information and resources for persons with brain injury and families. It is a non-profit organization currently composed of 44 state chapters, a network of over 800 support groups and over 15,000 members nationwide.

Lash & Associates
22 Keewaydin Road
Wolfeboro, NH 03894
603-569-3826 voice and fax
E-mail: mlashnh@worldpath.net

Lash & Associates provides training programs, written information, helpful pamphlets and consultation for professionals, families, schools, and agencies on children and adults with brain injuries and disabilities.

National Center on Child Abuse & Neglect (NCCAN)
PO Box 1182, Washington DC 20013
703-385-7565 FAX: 703-385-3206, 800-394-3366
E-mail: nccanch@calib.com
Internet: http//www.calib.com\nccanch

NCCAN was established in 1974 as the primary Federal agency charged with helping states and communities address the problems of child maltreatment. Its library distributes materials dealing with child abuse and neglect.

National Spinal Cord Injury Association (NSCIA)
8300 Colesville Road Suite 551
Silver Springs MD 20910
301-588-6959 FAX: 301-588-9414, 800-962-9629
E-mail: nscia2@aol.com
Internet: http://www.spinalcord.org

In Touch With Kids is a program of the National Spinal Cord Injury Association, developed in 1988. It is a support network of children with spinal cord injury or illness and their families. It provides an opportunity for sharing ideas, feelings, resources, and innovative problem-solving techniques and solutions with other families.

PREVENTION

Children's Safety Network
Education Development Center
55 Chapel Street, Newton MA 02158
617-969-7100
E-mail: csn@edc.org Internet: http://www.edc.org

CSN is a publicly supported non-profit organization that engages in a wide variety of projects that promote health and education throughout the world.

Injury Prevention Center
Dartmouth Medical School
7455 Butler Bldg Rm 8, Hanover NH 03755-3851
603-650-1780, FAX: 603-650-1614
E-mail: susan.martin@dartmouth.edu

The Injury Prevention Center's mission is to reduce the incidence of injury, death and disability through prevention and intervention efforts. It accomplishes this through the education of both professionals and the general public about the causes and consequences of injuries; the implementation and evaluation of prevention and intervention strategies in joint efforts with health care providers, state agencies, and other organizations; and its resource center which offers technical assistance and a variety of educational and other materials relating to injuries.

Safe Kids
1301 Pennsylvania Avenue, Washington DC 20004
202-662-0600, 202-393-2072
E-mail: info@safekids.org,
Internet: http://www.safekids.org

Safe Kids was the first nationwide childhood injury prevention organization to raise awareness among parents and caregivers that injuries are the leading health threat facing children today.

PARENT GROUPS

Association for Retarded Citizens (ARC) of Georgia
Parent Empowerment Project
2860 East Point St S-200, East Point GA 30344
404-761-3150 FAX: 404-767-2258
E-mail: peparc@aol.com

This non-profit association is for parents and individuals or groups concerned with the quality of life of persons who have mental retardation, developmental or other disabilities.

Federation for Children with Special Needs
95 Berkeley St. S-104, Boston MA 02116
800-331-0688 (Massachusetts only)
617-482-2915 FAX: 617-695-2939
E-mail: fcsninfo@fcsn.org
Internet: http://www.fcsn.org

The Federation is a child advocacy and information center consisting of staff members who are parents of children with special needs. Information is available on special education laws, health issues, resources, coordinating care and obtaining services.

National Parent Network on Disabilities (NPND)
1727 King Street S-305, Alexandria VA 22314
703-684-6763 FAX: 703-836-1232
E-mail: npnd@aol.com

The Network provides a forum and national voice for parents of children, youth, and adults with special needs. NPND shares information and resources in order to promote and support the power of parents to influence and affect policy issues concerning the needs of people with disabilities and their families.

PACER Center
4826 Chicago Avenue South, Minneapolis MN 55417-1098
612-827-2966 FAX: 612-827-3065
E-mail: mnpacer@9teens.com
Internet: http:/freenet.msp.mn.us/ip/family/pacer

PACER is a statewide non-profit organization that serves families of children and adults with disabilities. PACER programs help parents become informed and effective representatives for their children in early childhood, school-age and vocational settings. Through knowledge about laws, resources and parents' rights and responsibilities, families become better equipped to work with agencies to obtain appropriate services for their sons and daughters.

Sick Kids (Need) Involved People of NY Inc (SKIP)
545 Madison Avenue 13th Floor, New York NY 10022
212-421-9160 FAX: 212-759-5736

SKIP specializes in case management for people at home with complex medical needs and developmental disabilities. It makes families equal partners in their children's case management and service decisions.

Washington Parents Are Vital in Education (PAVE)
12208 Pacific Hwy SW, Tacoma WA 98499
206-588-1741 FAX: 206-984-7520
E-mail: wapave9@mail.idt.net
Internet: http://www.shell.idt.net/~wapave9

The majority of Washington PAVE staff are parents who have children with special needs. PAVE, a non-profit organization, exists to share information and resources with people whose lives are linked to children and adults with disabilities.

EDUCATIONAL/VOCATIONAL

National Center for Youth with Disabilities (NCYD)
UMN UMHC Box 721 420 Delaware SE
Minneapolis MN 55455-0329
612-626-2825 TTY: 612-624-3939, FAX: 612-626-2134
E-mail: ncyd@gold.tc.umn.edu

NCYD provides easy access to current research findings and information on resources and advocacy efforts, and disseminates policy and program development information to agencies, health and human service professionals, educators, policymakers, parents and youth.

Project School Care/Children's Hospital
300 Longwood Ave Judge Baker 2, Boston MA 02115
617-355-6714 FAX: 617-355-7940

Project School Care was established to document and foster access to educational services by children who depend on tracheostomies, gastrostomies, intravenous shunts, peritoneal dialysis, ileo/colostomies, ureterostomies, and other technology-assistance.

LEGAL

Disability Rights Education and
Defense Fund, Inc. (DREDF)
2212 6th Street, Berkeley CA 94710
510-644-2555 FAX: 510-841-8645, TTY: 510-644-2626
E-mail: dredf.org

DREDF is a national law and policy center dedicated to furthering the civil rights of people with disabilities, and promoting their full integration into mainstream society.

National Association of Protection
and Advocacy Systems (NAPAS)
900 2nd St NE S-211, Washington DC 20002
202-408-9514 FAX: 202-408-9520, TDD: 202-408-9521,
E-mail: hn4537@handsnet.org

NAPAS is a federally mandated system in each state and territory which provides protection of the rights of persons with disabilities through legally based advocacy.

US Department of Justice/Civil Rights Division
PO Box 66738, Washington DC 20035-6738
800-514-0301, TDD: 800-514-0383, FAX: 202-307-1198
Internet: http://www.usdoj.jov/crt/ada/adahom

The Department of Justice enforces The Americans with Disabilities Act (ADA), a comprehensive civil rights law for people with disabilities. It enforces the ADA's requirements in Title I, employment practices by state and local government, Title II, programs, services, and activities of state and local government, and Title III, public accommodations and commercial facilities.

GENERAL

Association for Care of Children's Health (ACCH)
7910 Woodmont Ave S-300, Bethesda MD 20814
301-654-6549 FAX: 301-986-4553
E-mail: acch@clark.net
Internet: http://www.wsd.com/acch.org

ACCH is a leader in defining, promoting, implementing, and supporting standards for the best practice and policy in the care of children and families. With a multidisciplinary network of close to 4,000 members, ACCH advocates for change, has excellent reading materials for children and families on hospital care and hosts annual conferences.

Family Resource Coalition
200 South Michigan Ave 16th Floor
Chicago IL 60604-2404
312-341-0900 FAX: 312-341-9361
E-mail: hn4860@handsnet.org

The goal of the Family Resource Coalition is to bolster parents' ability to help themselves, promote healthy childhood development, and prevent problems of child abuse and neglect, teen pregnancy, and juvenile delinquency.

Mothers Against Drunk Driving (MADD)
511 E John Carpenter Freeway S-700, Irving TX 75062-8187
214-744-MADD FAX: 214-869-2206/2207
E-mail: info@madd.org
Internet: http://www.madd.org

MADD is a non-profit organization with more than 500 chapters and community action teams nationwide. Its focus is to look for effective solutions to drunk driving and underage drinking, while supporting those who have already experienced the pain of these crimes.

National Association of Developmental Disabilities Council (NADDC)
1234 Massachusetts Ave. NW S-103, Washington DC 20005
202-347-1234 FAX: 202-347-4023
E-mail: naddc@igc.apc.org
Internet: http://www.igc.apc.org/naddci9capc.org/naddc

NADDC is a national organization representing Developmental Disabilities Councils that plan, advocate and work for change on behalf of people with developmental disabilities and their families. They help councils solve problems internally and externally, in management and in systems advocacy, to meet challenges at the state level.

National Easter Seal Society
230 West Monroe Street S-1800, Chicago IL 60606-4802
800-221-6827 FAX: 312-726-1494, TDD: 312-726-4258
E-mail: nessinfo@seals.com
Internet: http://www.seals.com

Organized to help people with disabilities achieve independence, Easter Seals provides quality rehabilitation services, technological assistance, and disability prevention, advocacy, and public education programs. States have local chapters.

National Information System & Clearinghouse
Center for Developmental Disabilities Education Center
USC School of Medicine, Columbia SC 29208
800-922-9234 FAX: 803-935-5250

The Clearinghouse provides information and referral to providers of services for families of infants and young children with disabilities. Specialists assist families in accessing services such as parent support and training, advocacy, health care, financial resources, assistive technology, early intervention, child protection and other information resources.

National Information Center for Children and Youth with Disabilities
PO Box 1492
Washington DC 20013-1492
800-695-0285 FAX: 202-884-8441
E-mail: nichcy@aed.org
Internet: http://www.aed.org/nichcy

The Center provides information on disabilities and disability-related topics. A special focus is children and youth with disabilities, birth to age 22. It produces publications on disability and education issues, including many in Spanish. They are also available on the Internet (gopher aed.org)

National Rehabilitation Information Center (NARIC)
8455 Colesville Rd S-935, Silver Springs MD 20910-3319
301-588-9284 FAX: 301-587-1967
E-mail: naric@capaccess.org
Internet: http://www.naric.com/naric

NARIC is a national disability and rehabilitation library and information center that collects and disseminates the results of federally funded research projects and also includes commercially published books, journal articles and audiovisuals.

South Carolina Services Information System
Center for Developmental Disabilities
USC School of Medicine, Columbia SC 29208
800-922-1107

The System provides information and referral to providers of services for families of children with disabilities. Specialists assist families in accessing parent support and training, advocacy, health care, financial resources, assistive technology, early intervention, child protection and other information resources.

Written Information

Choosing Home or Residential Care

by Marilyn Lash, M.S.W. and Paul Kahn, M.Ed.

This book describes the benefits and drawbacks of home and residential care for children with severe physical disabilities and the impact on other family members.

Contact:

Crotched Mountain Foundation
Book Order
1 Verney Drive, Greenfield NH 03047
603-547-3311, FAX: 603-547-6212
Internet: info@cmf.org http://www.cmf.org

Exceptional Parent Magazine

A monthly publication for parents of children and young adults with disabilities and special health care needs, it also includes a publications catalog and resource listings.

Contact:

5551 Kinderkamack Road, Oradell NJ 07649
201-634-6550, FAX: 201-634-6599,
800-534-1910 (Book Orders),
E-mail: epmag12@aol.com
Internet: http://www.familyeducation.com

Working Toward a Balance in Our Lives

by JS Palfrey et.al

A resource book for families with practical advice and suggestions on hospital and home care, and community services.

Contact:

Project School Care
Children's Hospital
300 Longwood Avenue
Boston, MA 02115
617-735-6714

About the author

Paul Kahn, M.Ed., is a psychotherapist and writer, whose personal experience of living with a progressive physical disability has heightened his awareness of the challenges that individuals and families face. He is the Consumer Coordinator at the Research and Training Center in Rehabilitation and Childhood Trauma at New England Medical Center and is on the staff of the Department of Psychiatry at Beth Israel-Deaconess Medical Center in Boston.

He believes that persons with disabilities and their families can enjoy a high quality of life, if they are provided with adequate physical, psychological and educational support, and if architectural and attitudinal barriers to their participation in society are removed.

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