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ABSTRACT

The guide offers information to parents of developmentally disabled children, with special focus on services available in the State of Florida, Section 1, "A Beginning," introduces the guide and states its purposes, and serves to reassure the parents and family members. The next three sections address the needs, rights, and roles of child, parent, and family. They are: (1) "Accepting Your Child" (including a discussion of types of developmental disabilities); (2) "What You Can Do as a Parent"; and (3) "The Family." Section 5, entitled "Getting Started with Professional Help," discusses decision-making; diagnosis, evaluation, and referral; and the team approach. Section 6, "Florida Services," outlines support services in the areas of medicine, health, education, family support, community assistance, and legal aid. "Facing Your Futures Together," section 7, touches on issues involving adolescence and sexual adult relationships, employment and financial independence, and how parents can get on with their own lives. A final section consists of five appendices which include information on Florida statutes relating to rights of persons with disabilities, relevant federal statutes, and a list of resource organizations at the national level. (JW)

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FLORIDA
DEVELOPMENTAL
DISABILITIES
PLANNING COUNCIL

FOREWORD

The painful reality of having a child who will be permanently disabled is not an easy thing to accept. The feelings of fear, grief, guilt, anxiety, anger and pain which accompany this realization are *appropriate*, and few people are able to, at once and without question, accept such a child. After all, no one has prepared you for this shock, for your dreams of a perfect child to be permanently shattered.

You may wonder if you will be able to meet the demands you see stretching for years before you. You may worry about the increased financial burden on your family. You may even doubt whether you will ever be able to sleep through the night again. You may ask, "Why did this happen to me?"

Yet your child is like any other child you love. And the sooner you are able to pick up the pieces of your life and get on with the care and nurturing of your child, the more both of you will accomplish.

Your job in the years ahead will not be easy. Coping with a disability is not fun, or simple. Yet it can be tremendously rewarding and filled with joy, as many parents of children with disabilities so willingly share.

This guide is designed to help you face the reality of a child with a disability. Hopefully, it will give you some very real ways to begin to sort through your pain and confusion so that you can start to help your child, yourself, and your family.

As you read through this guide, don't think of what could have been. Instead, put your attention on how you will respond and what you intend to do now that "this" has happened. Think of what you have, and what can be done today, tomorrow, and next year. Your reward will be your child's enriched life.

Please use this guide often. It will keep you from wasting valuable time during your child's growing years. It will tell you who, where, and how to find help when you need it.

A long and often hard road lies in front of you. We hope that this guide will get you started, will help you to take those first critical steps. We also hope that after reading this guide, you will know that you will not have to walk alone.

K. Joseph Krieger, Executive Director
Florida Developmental Disabilities
Planning Council
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We would also like to thank the staff of the Public Information Office of the Department of Health and Rehabilitative Services for their able assistance in developing, illustrating and producing this guide. The creativity and professionalism of all persons involved is deeply and sincerely appreciated.

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"There is no such thing as a
problem without a gift for
you in its hands."
Richard Bach in *Illusions*

SECTION 1: A BEGINNING

This publication is about your child, your family and developmental disabilities. It was written to give you information about your child's special needs, rights and possibilities. It will raise questions and, it is hoped, answer some questions that you now have. Other answers may take longer to find. This guide is intended to help you make a beginning, to take those first needed steps.

There are eight sections in this guide. Each is included for a particular reason and to provide you with specific information relating to your child and his or her disability. Overall, the purpose of this guide is to:

- Assure you that help is available for your child and your family. Services that may be useful to you are identified throughout.
- Remind you that a child with a disability is more *like* other children than different from them. And first of all, he or she has all the same needs and rights as any child.
- Define disabilities, tell you something about what you can expect, and help you find other sources of information.
- Explain some of you and your child's legal rights and tell how you can get legal advice at reduced or no cost.
- Show how parents can and must take the lead in finding and obtaining needed services for their child.

We ask that you save the guide and keep it with other papers important to your child's well-being. Perhaps you may not be able to use this information at this time. If you feel that way, put the guide aside for a while and come back to it later. Remember that there is no need to rush things right now. Take your time to think, get information, and settle down with your child and his or her needs.

It is perfectly "normal" to grieve for the child who could have been. In a sense, the child you had hoped for, planned on, and anticipated with much love, is gone forever. Now, faced with this unexpected loss, it is natural for you and your family to experience feelings of denial, anger, hurt and, eventually, acceptance. Once you have reached the stage of being able to accept your child, great reward and satisfaction await you, for your child is special in many ways besides his or her disability.

If nothing else, it is hoped that this guide may offer a glimpse of light on the challenge which lies ahead of you and your family. No matter how dark your situation or your child's condition may seem, there is truly a way that will enable you to do what will be needed.

This guide will show you the many hands that are willing to help you manage. The only thing required of you is that you take the first step.

> "Be proud of your child; accept him as he is and do not heed the words and stories of those who do not know better. The child has a meaning for you and for all children. You will find a joy you cannot now suspect in fulfilling his life for and with him. Lift up your head and go your appointed way."
>
> Pearl S. Buck, in *The Child That Never Grew*

SECTION 2. ACCEPTING YOUR CHILD

Many parents have written about the anguish they felt when they first learned that their child had a developmental disability. They talk of the unsteady path that their feelings followed for days, weeks, even months after they knew their much-loved child would live his or her life with a handicapping condition.

In the beginning many parents are shocked. They can hardly believe that such a thing could happen to them and their child. Many parents refuse at first even to believe that the information could be true. Gradually, as they accept the information and go beyond their shock and dismay, parents frequently become depressed and angry. But these feelings pass, and parents usually are able to accept their child — with his or her special limitations. They recognize that each of us is handicapped or limited in some way. In fact, no one is really perfect.

Somewhere, somehow, most parents manage to get over the questions that focus on the past and the pain — "Why did this happen to me?" — and turn instead to the question that will open the door to the future: "Now that this has happened, what will I do about it?" (Kushner, 1983). Once this important transition is made, the parents of a child with a developmental disability can tackle the important business of life, planning for a future that may well be as bright as that of any child's.

Your Child's Needs

In fact, once you can accept your special child and his or her limitations, you will quickly realize that your child's needs are more *like* other children's needs than *not like* them. Your child will go through the same social experiences, the same developmental processes, the same psychological learning as other children. The disability may cause problems which may interfere with your child's growth or experiences, causing some delay in developing certain skills. But, if your child is allowed to be a child — experience, learn, feel and think as a child — and if he or she is treated with all the love and attention all children deserve, he or she will continue on to more mature growth and development.

Perhaps this can be better understood if you can see that your child is first of all a child, and only secondly a child with a disability. It really is up to you to determine how much of his or her potential your child can reach, given the particular disabling condition.

Your child's needs include the need for:

- physical and emotional care
- stimulation of body and senses
- education
- recreation, sports and play
- medical care
- social opportunities
- legal resources and protection
- independence and self-sufficiency
- and especially, love, affection and acceptance as a real person.

Your Child's Rights

Once you understand that your child has the same needs as any child (in addition to whatever special needs he or she may have because of the particular disability) you may also be interested to discover that your child's rights are the same as the rights of all people.

Your child has the right to live his or her life in the most comfortable, creative and fulfilling manner possible, in freedom, with joy and with the opportunity for continuing growth. Your child has the right to a job matched to his or her abilities and limitations. He or she needs equal treatment and equal opportunity and the certainty of living with dignity.

Your child, like all children, has many other rights as well. Some of these include:

- The right to be part of a family.
- The right to religious freedom and practice.
- The right to speak openly without fear of punishment.
- The right to protection against abuse or demeaning treatment.
- The right to privacy.
- The right to suitable social and recreational activity.
- The right to appropriate and humane medical care.
- The right to education and training services.
- The right to live in the least restrictive environment possible.
- The right to a responsible, impartial guardian or advocate to protect and ensure the exercise of these rights.

In Florida, these rights are protected by Florida Statute, Chapter 393.

Your Child's Disability

If you have just learned of your child's disability, you are probably at a loss about what you need to do first. You may be near panic, or close to despair, or very angry. Many parents report these as well as other intense feelings. All are hard to deal with, but they can and do change. Parents need to remind themselves that their child's disability is not their fault. And, once these painful and negative feelings are recognized, you can take deliberate steps to handle your feelings. Only then will you be able to deal with your child in a truly positive way.

Discover

In the meantime, while you are still struggling to come to terms with your child's disability, there is much you can do:

1. *If you have just learned of your child's disabling condition, no matter what your child's age and level of handicap, now is not the time to make a decision to send your child to an institution or other situation where others would provide the care.* Later on, that may be a choice you will make, but it requires clear thinking and careful consideration of all your options. You need to know

much more about your child, his or her special disability, potential and limitations. You even may be counseled now — by doctors, grandparents or well-meaning friends — that sending your child "away" will be best for your entire family. Resist these pressures, at least for now, until you can get the information you need.

Right now, all your child really needs is to be loved and treated like every other child. You will want to explore all possibilities at this stage; not settle on a quick solution. Your child's life deserves this careful thought.

2. *Begin talking with other parents.* One of the best ways to get information about your child's disability is to ask the parents of a child with the same condition. Talking with someone who has "been there" will give you a great deal of information on what you can expect as your child grows. Other parents also can offer the understanding, support and encouragement that comes from actual experience. In this difficult time, other parents can do much to help and often are delighted to do so.

If you do not know how to find these other parents, you can start by contacting the organizations working with the major disabilities listed in Section 6 of this guide. Remember that it is important for both you and your child to ask for help and information.

3. *Find out where your child is today, and start there.* Nothing you read or hear about your child is final or exact. Each child is different, and the degree or severity of the disability may differ in many ways. Also, if your child is very young, detailed testing may be impossible. Some developmental disabilities, like autism, are very difficult to diagnose. Others, like Down Syndrome, although easy to identify, can vary greatly from child to child. Finally, with constant changes in research, service and legislation, there is much more that can be done today, regardless of the disability. These changes may help your child's future.

4. *Take that first step.* It is important to get started, to take the first step, no matter how much you, your doctor or other professionals know about the disability. Even if your child is only a tiny baby, he or she can begin immediately in an infant stimulation program. If your child is older, it is even more important to start immediately on a program that will help the child and reduce the negative effects of his or her disabling condition.

Many parents also have found that to begin a program of positive action brings relief to them as well as to the child. It gives a sense of moving forward, of helping their child and themselves. Even if an exact diagnosis is not complete, children who are delayed in their development need not wait to get help. Starting treatment early has the added benefit of reducing later problems.

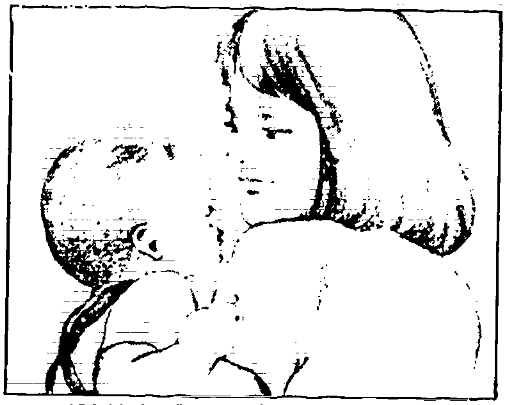
5. *Get as much information as you can about your child's disability.* The more you know about your child's problem, the better. This guide includes brief descriptions of some disabilities, but there is much more to know. Much of the information you will find may not agree. Neither will the opinions offered by people you and your child meet. You will more than likely read and hear different points of view and will need to make up your own mind.

When you are gathering information, be aware that much has changed in the past ten years in the field of helping children with disabilities. Try to get recent information. Even then, it may be that no one knows exactly what your child's problem is. Luckily, you can still get information on how to treat your child, no matter what the diagnosis.

Early Intervention

The reasons for seeking immediate help for a child with a developmental disability are many. Perhaps most important, by providing training and care for your child at an early age, you actually may reduce the limitations your child may face in later life. An effective educational program can give your child every opportunity to develop to the fullest the capacities and potential he or she may have.

The chart which follows shows some steps in a child's normal development. It shows at *about* what age children *do* certain things. Some children do these things earlier or later, but most follow the steps in order.



What is a *developmental disability?* A developmental disability is a mental, physical or emotional condition which affects the normal development of an individual. A person with a developmental disability is someone who is limited physically and/or mentally in his or her ability to perform the activities of daily living (taking care of personal needs, graduating from high school, getting a job, raising children, etc.). A person who has a developmental disability has a need for a combination of special care and treatment. He or she may require extended or lifelong services that are individually planned to meet special needs.

Federal legislation* defining developmental disabilities states that the person's ability to carry out certain major life activities must be affected. These life activities are defined as:

- self care
- learning
- mobility

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*Public Law 95-602, the "Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978" which was passed November 6, 1978.

- self-direction
- economic sufficiency
- use of receptive and expressive language
- capacity for independent living

In order to be considered developmentally disabled under the federal definition, a person must be affected in three of the areas listed.

Florida legislation defines "developmental disability" as a disorder or syndrome which may be the result of retardation, cerebral palsy, autism, or epilepsy and which constitutes a substantial handicap that can reasonably be expected to continue indefinitely.

In the "Retardation Prevention and Community Services Act" passed by the Florida legislature in 1977, state treatment programs for the developmentally disabled were directed to emphasize those programs that have the potential to prevent or reduce the severity of retardation and other developmental disabilities.

The legislature also insisted that first priority be given to developing and using those services and programs which will allow persons with developmental disabilities to "achieve their greatest potential for independence and productive living, which will enable them to live in their own homes or in facilities located in their own communities . . ."

Types of Developmental Disabilities

There are many problems which are considered to be developmental disabilities. These problems can be physical, mental or emotional. Sometimes a child has more than one handicapping condition. For example, he or she may have a physical disability in addition to a mental disability. Children with mental retardation may develop some emotional problems as they begin to socialize with other children and adults. A child with cerebral palsy may need special help in learning to communicate. A child who is blind or deaf may be frustrated by his or her limitations. A child with Down Syndrome may have heart or respiratory problems. And so on.

Often both the child and the family need some sort of counseling to learn ways of handling their special problems.

It is also important to keep in mind that no two children with a disabling condition are alike. In the same ways that non-handicapped children are different from each other, so each handicapped child is special or unique. Each child deserves and needs an assessment and treatment program which will help him or her to develop to the limits of his or her own abilities.

So you can see how very important it is to know something about the many possible disabilities. The following descriptions will tell you briefly about the kinds of disabilities your child might have. Remember that these are very general descriptions and are offered here as a start to an indepth look at information which will be important to you. There are many excellent sources of information. Some are listed in Section 6 of this guide.

Physical Impairments

This type of developmental disability includes many physical problems which may put severe limitations on a child's participation in school, family and social life. It can be the result of an injury at birth, or something caused by a disease or accident, like poliomyelitis. It may be inherited, as, for example, with osteogenesis imperfecta, or brittle bone disease. Other physical impairments might include cleft palate, club foot, lack of upper or lower extremities and other conditions usually apparent at birth.

Blindness and deafness are considered physical disabilities as are such chronic health conditions as hemophilia, leukemia, asthma and heart conditions which limit a child's strength and alertness, and, as a result, affect ability to perform at school, at home or in the family setting.

Other diseases such as juvenile arthritis, muscular dystrophy and multiple sclerosis may fall into this category. Handicaps caused by physical impairments vary considerably. They also require different methods of treatment, depending on the severity of the physical impairment.

Cerebral Palsy

Cerebral palsy refers to a group of neuromotor disorders caused by damage to the brain, usually at the time of birth. These disorders involve the brain (cerebral) and muscle control (palsy). Typically, some damage has occurred to the part of the brain which controls the muscles and, as a result, they do not work properly.

Children and adults with cerebral palsy may move and speak awkwardly. They may have uncontrollable jerking movements, a poor sense of balance, speech and hearing problems, and sometimes, mental retardation.

There are about 750,000 known cases of persons with cerebral palsy, and some 25,000 babies are born with this disability each year. In one state survey, as many as 6 out of 1,000 babies born had cerebral palsy.

Doctors do not always know what causes cerebral palsy. There are, however, a number of factors that can interfere with the development of the brain:

- infections during pregnancy
- Rh factor incompatibility
- complications during delivery
- lack of oxygen at birth
- injury or infection

Three common types of cerebral palsy include:

Spastic - characterized by tense, stiff, contracted muscles
Athetoid - characterized by involuntary, uncontrolled motion
Atatic - characterized by a disturbed sense of balance and depth perception

(continued on page 8)

Growing Signs

Age	Language
3 months	A. Does he laugh or make happy noises? B. Does he turn his head to sounds?
6 months	A. Does he "babble", repeat sounds together (i.e., mum-mum-mum)? B. Is he frightened by angry noise?
9 months	A. Does he understand "no-no", "bye-bye"? B. Will he imitate any sounds or words if you make them first?
12 months	A. Does he have at least one meaningful word other than "mama", "dada"? B. Does he shake his head for "no"?
18 months	A. Does he have at least 6 real words besides his "jargon"? B. Does he point at what he wants?
2 years	A. Does he talk in short (2-3 word) sentences? B. Does he use pronouns ("me", "you", "mine")?
2½ years	A. Does he use plurals or past tense? B. Does he use the word "I" correctly most of the time?
3 years	A. Does he tell little stories about his experiences B. Does he know his sex?
4 years	A. Does he say a song or a poem from memory? B. Does he know all his colors?
5 years	A. Can he print his first name? B. Does he ever ask what a word means?

This chart was adapted from the Developmental Attainment Form for Children 0-5 Years, The John F. Kennedy Institute for Handicapped Children, and prepared in this form by David M. O'Hara, D.A.S.S. and Barbara Mosher, M.S.W., from an earlier version by Arnold J. Capute, M.D., M.P.H., and Robert F. Biehl, M.D., M.P.H.

Social Skills	Movement	Body Use
A Does he smile at you? B Does he reach for familiar people or objects?	A. Does he support himself on forearms when lying? B Does he hold his head up steadily while on his stomach?	A. Are his hands usually open at rest? B Does he pull at his clothing?
A Does he stretch his arms out to be picked up? B Does he show his likes and dislikes?	A. Does he lift his head when lying on his back? B Does he roll from back to front?	A Does he transfer a toy from one hand to the other? B. Does he pick up small objects?
A Does he hold his own bottle? B Does he play any nursery games ("peek-a-boo", "bye bye")?	A. Does he sit for long periods without support? B Does he pull up on furniture?	A. Does he pick up objects with his thumb and one finger? B Does he finger-feed any foods?
A Does he cooperate in dressing? B Does he come when you call him?	A Is he walking (alone or with hand held?) B Does he pivot when sitting?	A Does he throw toys (objects)? B Does he give you toys (let go) easily?
A Does he copy you in routine tasks (sweeping, dusting, etc.)? B Does he play in the company of other children	A Does he walk upstairs with help? B. Can he throw a toy while standing without falling?	A. Does he turn book pages (2 or 3 at a time)? B Does he fill spoon and feed self?
A Does he ask to be taken to the toilet? B Does he play in company of other children?	A Does he run well without falling? B. Does he walk up and down stairs alone?	A Does he turn book pages one at a time? B. Does he remove his own shoes, pants?
A Does he tell his first and last name if asked? B Does he get himself a drink without help?	A. Does he jump; getting both feet off the floor? B Does he throw a ball overhand?	A Does he unbutton any buttons? B. Does he hold a pencil or crayon adult fashion?
A Does he share his toys? B Does he play well with another child? Take turns?	A. Does he pedal a tricycle? B Does he alternate feet (one stair per step) going upstairs?	A Does he dry his hands (if reminded)? B Does he dress and undress fully including front buttons?
A Does he tell "tall tales" or "show off"? B Does he play cooperatively with a small group of children?	A Does he attempt to hop or skip? B Does he alternate feet going downstairs?	A Does he button clothes fully? B Does he catch a ball?
A Is he a "mother's helper", likes to do things for you? B Does he play competitive games and abide by the rules?	A. Does he skip, alternating feet? B Does he jump rope or jump over low obstacles?	A Does he tie his own shoes? B. Does he spread with a knife?

Surgery can correct some of the problems caused by cerebral palsy. One recent development in medical research is a delicate but often effective operation on the brain which has been performed with success in a limited number of cases. Many new medicines are now available. Speech, occupational and physical therapy, among other specialized services, can help to improve muscle control and enable children with cerebral palsy to develop to their full potential.

Epilepsy

Epilepsy is a disorder of the central nervous system. Brain cells create abnormal electrical discharges that cause seizures. There are many types of epilepsy and a variety of symptoms: muscle spasms, mental confusion, loss of consciousness.

There are about two million persons with epilepsy in the United States, or 1 percent of the population. This means that about one in every 100 persons in this country has epilepsy.

Not all people who have epilepsy have seizures. The seizures themselves vary considerably but are grouped into three main types:

1. Grand Mal - characterized by falling, loss of consciousness, stiffening and shaking of entire body, irregular breathing. This type of seizure may last for several minutes and occur frequently or hardly ever.
2. Petit Mal - characterized by "blank spells," losing awareness, slight twitching, staring, blinking. This type of seizure is most common in children 6-14 years of age. A seizure may last only a few seconds and may occur dozens or even hundreds of times a day.
3. Psycho Motor - characterized by a period of mental confusion followed by pointless or repetitive movements, pain or dizziness. This type of seizure can occur at any age and may last up to 20 minutes.

In many instances, doctors never really discover what causes epilepsy. It can be related to:

- brain injury before, during or after birth
- head injuries
- poisons (including lead, alcohol)
- diseases (such as measles, encephalitis)
- disorders of the circulatory system
- traumas
- nutritional disorders

Anyone could have an injury or illness that could lead to epilepsy, although most epilepsy appears early in life. Thirty percent of all epilepsy shows up before a child is 5 years old; 34 percent of cases become evident in early adolescence; and 23 percent of epilepsy appears in adults. More males than females are likely to have epilepsy.

Encouragingly, epilepsy need not be a handicap. Some 80 percent of people with epilepsy can be totally or almost totally free of symptoms through continuing treatment. Epilepsy can be controlled partially or completely through anticonvulsant drugs, or in some cases, by special diets or surgery.

Autism

Autism is a neurological condition characterized by severe problems in communication and behavior. Children with autism are unable to relate to people in a normal manner.

Although autism typically appears during the first three years of life, it can be suspected as early as a few weeks or months after birth. It can occur by itself or in association with other disorders which affect brain function. About half of all autistic children also develop epilepsy.

About 4 in every 10,000 children have autism, which is four times more likely to occur in males than in females.

No one knows exactly what part of the nervous system is affected in autism. Some research points to damage in the part of the brain which controls language and information gathered from the outside world. Other research points to a chemical imbalance as at least part of the cause of autism. No known factors in the psychological environment of the child have been proved to cause autism. (This also means that parents cannot, under any circumstances, cause autism.)

Some of the characteristics of autism are:

- disturbances in the development of physical, social and language skills
- abnormal responses to sensations
- speech and language difficulties
- abnormal ways of relating to people, objects and events:
  - may be withdrawn, apathetic, unresponsive
  - may be resistant to change in the environment
  - may be disinterested in people and surroundings
  - may show unusual interest in inanimate objects
  - may exhibit behavioral problems which may include self-injury, repetitive or aggressive behaviors.

There is no known cure for autism, but there are different treatment programs which can help the child with autism. Special education programs using new techniques can teach the child to speak, to take care of personal needs and to act in ways which are socially acceptable. There is also a growing body of research in biochemical, sensory stimulation and behavioral intervention that will help to make the future even brighter for a child with this developmental disability.

Mental Retardation

Mental retardation is not a disease or an illness; it is a disabling condition, in much the same way as blindness or deafness is a disabling condition. It is true that mental retardation may be caused by an illness or infection, but it is the result and not the process. It cannot be "cured" and is likely to be a life-long condition. It is not the same thing as mental illness.

The child who is mentally retarded will develop more slowly than other children. He or she may have unusual difficulty in learning, social adjustment and in working. A child with mental retardation may have poor judgment, be unable to reason successfully, have difficulty deciding how to act in new situations, and sometimes be unable to learn completely from past experiences.

Just as every child is an individual, so every child with mental retardation is an individual. There are many differences in personality, behavior and in the ability to learn.

There are more than six million persons in the United States who have some form of mental retardation. One in every 10 Americans (or 10%) has a mentally retarded person in his or her family. There are over 100,000 people with mental retardation identified each year. In Florida, an estimated 3 percent of the population have some degree of mental retardation.

Mental retardation can be caused by any condition which impairs development of the brain before, during or after birth. More than 350 causes have been identified, although in over three quarters (or 75%) of all persons with some form of mental retardation, the specific cause is not known.

Sometimes the child is injured at birth. Sometimes the mother becomes ill during pregnancy, for example, with the German measles. Sometimes something happens to the genes or the material in the cell which directs the growth of a child. Often no simple cause can be found.

Children with mental retardation are found among every race, religion and nationality. The condition occurs in every educational, social and economic background. Any person could become functionally retarded due to brain damage from an illness or injury.

Down Syndrome is one kind of mental retardation that is caused by a change in body cells before birth. It used to be called "Mongolism" because of the slight oriental shape of the eyes and the usually dark, straight hair of persons who have this form of mental retardation. Often there will be other medical problems as well.

Children with Down Syndrome are often described as warm, happy and willing to learn. But they learn very slowly and are likely to reach their limits early. If your child has Down Syndrome you will want to take advantage of special programs as early as possible. This will help your child to reach the highest level of his or her ability.

All children with mental retardation can be helped by education and training, and most will be able to live productive and meaningful lives. In fact, almost 90 percent of people with mental retardation are only mildly retarded, while about 6 percent are moderately retarded, 3.5 percent severely retarded and only 1.5 percent profoundly retarded.

All children and adults with mental retardation need the same basic services as everyone else — education, health, vocational, recreation, religious and social services. It is important to keep in mind that with early identification, diagnosis and educational programs, these children can lead useful adult lives.

Spina Bifida

Spina bifida is often called open spine. (The scientific name is myelomeningocele.) It is a problem of the central nervous system that can be identified easily at birth. The bones in the spine do not close or are only partially closed. In the opening that is left, some of the membranes, nerves, or even part of the spinal cord come out and form a type of sac, usually near the lower back. This can cause fluid to collect in the brain, causing great pressure that may result in brain damage and mental retardation. It also can cause other deformities of the feet, legs or hips. Your child may lack sensation in the lower body. There may be limited or no bladder or bowel control.

Doctors do not know why spina bifida occurs. Surgery is needed to close the open area in the spine, and is done as early as possible, usually within the first day of life. This surgery provides protection from infection. It is also a first step in the process of repairing defects.

Children with spina bifida may be severely physically impaired. Many learn to walk with braces. The degree of disability will vary from child to child, as with all developmental disabilities. Years ago, 80 percent of babies born with spina bifida died in infancy. Today, 95 percent will live, have normal intelligence, and most will be able to walk to the school bus and between classrooms.

Learning Disabilities

A learning disability is a problem with understanding and using written or spoken language. It is often difficult to diagnose and is sometimes called the invisible handicap. It is sometimes confusing because a child with a learning disability most often has average or above average intelligence. Many children with these hard-to-define problems develop behavioral problems as well, becoming disruptive at home or school.

While a learning disability is hard to diagnose, there are many signs which warn a parent to look for help. Perhaps your child has one of these signs.

- Your child is failing in reading, spelling, writing or arithmetic while teachers insist the child could do better if he or she tried.
- Your child is poorly coordinated, clumsy, awkward, has difficulty in writing, tying shoes or catching balls.
- Your child is confused in language, speech, or following directions.
- Your child is usually forgetful or inattentive.
- Your child is easily distracted, impulsive, over-active or overly quiet.

There is no one known cause for a learning disability, just as there may be more than one effective way to deal with the disability once you are aware of it. But it is important to discover the disability as early as possible to allow the child to learn ways of getting around any problems it may cause. A correct diagnosis, followed by special educational, medical, psychological and social services will help most children with a learning disability lead normal, productive lives.

Emotional Disturbances

A child who is emotionally disturbed experiences emotional problems to the extent that his or her ability to get along at school and at home is seriously affected. The child may be extremely depressed or be terrified of school. Some children become overly aggressive or even abusive. Or a child may become withdrawn and unable to relate or be with family or peers.

The exact causes of emotional disturbances are not completely known. However, treatment can be successful. Psychiatric therapy, counseling, and in some cases, medicines can make positive improvements in a child's behavior. The child may or may not be developmentally disabled, depending on whether his or her learning, self direction, self-care or capacity for independent living also is affected.

Developmentally Delayed

"Developmentally delayed" is a term often used to describe a child who does not seem to be growing and changing according to expected steps. A child can be delayed in one or several, often overlapping, areas. These areas are body movements, speech and hearing, self-care, response to other people, ability to behave, and ability to follow directions. Often both the cause and the extent of delay are difficult to diagnose.

There are many stages in a child's growth. (These were described earlier in this section on the "Growing Signs" chart.) These stages are predictable and happen at about the same age in most children. When these actions and skills do not seem to happen at the expected age, parents will want to start asking questions.

There may be nothing wrong or there may be a reason to be concerned and to get help in infancy or early childhood.

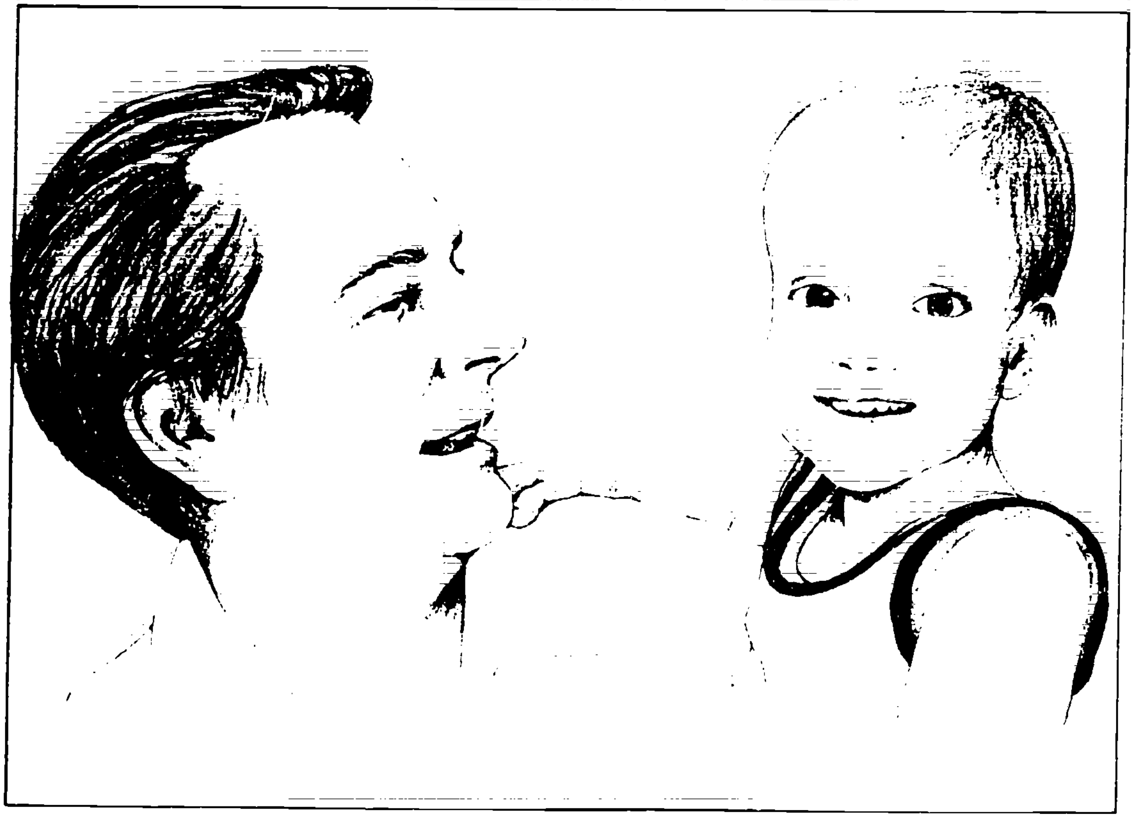
Programs which stimulate a child to develop new skills and abilities are offered by the Florida public school system. These programs rely on people in schools, health centers, and at home to encourage and support a child's growth and progress.

The term "developmental delay" most often simply alerts parents to watch closely as a child grows. Since parents usually know their child best, they are often the first to recognize a potential problem and get help. Fortunately, in today's world, the child with a developmental delay need not be handicapped or held back in any way.

In fact, a child with a physical or mental disability is not, at birth, handicapped, but instead is simply disabled. Doctors, parents, teachers, therapists, relatives and friends will be the ones who may convince a child with a developmental disability that he or she is handicapped.

For all who work with these children it may be hard to avoid doing this, for our own fears, misunderstandings and prejudices will come out in many different ways. Often, a person may not even be aware that this is happening.

It is especially important that you, as a parent who cares for a child with a developmental disability, treat your child as if he or she will succeed. There may be unusually difficult obstacles in the way, but your child can still reach some level of success if he or she is supported, encouraged, loved and allowed to succeed as well as fail.



"You can rebel, resent, resist the situation, constantly question why it happened, play the martyr, mope, and be defeated. Or you can accept the challenge, take up the gauntlet and find the blessing and victory in it, building on and appreciating the positive points, looking for and appreciating the opportunities to grow in depth and sensitivity as a person, finding deep joy in all evidence of overcoming limitation, no matter how small."
Judith L. Jogis, mother of a disabled child in "To Be Spoken Sadly,"
The Disabled and Their Parents:
[illegible]

SECTION 3: WHAT YOU CAN DO AS A PARENT

You may have just been told your child has a developmental disability. Or you may have known for some time that your child is "different" and needs special care. Whatever the situation, you are probably learning how to handle your own fears and disappointments, anger or hurt, shock and dismay.

Sometimes, parents of children with disabilities get so involved with this new and often frightening situation that they forget that they are people too. In your trips to medical doctors, hospitals, therapists, psychologists, social services, eye doctors, etc., it becomes very easy to put yourself far down the list of things requiring special attention. But parents are people too. In fact, one of the best things you can do for your child is to take care of yourself. Then you will be able to do the many things he or she will need you will be able to do these things without resentment, and perhaps most important of all, you will be able to love your child more freely.

Parent Needs

One of the first things you may discover as the parent of a child with a disability is that you never seem to have enough energy. But stop for a moment and think about it. Your sleep may be interrupted by a child who is in pain or who just can't sleep. You may be carrying your child and his or her special equipment for hours at a time. You may be worried about what you can do or what must be done next. You may be working at a full-time job or doing all those things needed to keep your home and family "normal." You may be doing everything alone or with only occasional help. When you stop and think about it, there are many new demands on you and your energy. No wonder you may be tired or lack the energy to do your usual daily activities!

Many parents of children with disabilities don't ask for or accept help for themselves. Please don't make this mistake. You deserve an occasional break from your child, like every other parent. You need uninterrupted sleep, just like most people. And while it may not always be possible to do either, it will certainly help both you and your child if you take good care of yourself physically.

Whether you have come to accept your child and his or her disability may depend on the support, acceptance and encouragement of friends, family and other people. Unfortunately, many of those closest to you will not know how to do this. They, too, may be afraid. Or they may worry about saying or doing the wrong thing. Often family and friends must handle their own feelings before they are capable of offering their help and support to you.

Other parents of disabled children have faced these same problems and frustrations. Many have joined to share their experiences and offer support to one another by forming parents' organizations. These parents can understand what you may be going through, the doubt and uncertainty you face, the courage and endurance that will be needed.

Many of these parents are willing to help you and your child. They are eager to share their personal stories and to help you as you begin your own journey. Even if your child's diagnosis is not yet known, some of these parents may be able to help you find information and services for your child.

In Florida a statewide Parent-to-Parent organization is now being formed. There already may be a group in your immediate area. To find out, call or write the Florida Developmental Disabilities Planning Council, 1317 Winewood Boulevard, Building 1, Suite 309, Tallahassee, Florida 32301, (904) 488-4180, or contact the disability group listed in your local telephone book.

Finally, the health care of a child with a developmental disability can place a serious financial burden on the entire family. There may be special medical treatment, braces, hearing aids, glasses, tutors, wheelchairs, learning materials, communication devices, special classes, homemaking help. There may also be necessary hospitalization, transportation costs and lost income from work. Not many families can pay for these things from their own incomes. Luckily, there are many ways for families of children with disabilities to get help in meeting their expenses.

Finding out where to get financial help and actually getting it will take time. It may be a difficult and time consuming job. But if your family meets the requirements for financial help you should claim it. Most important of all, no child or adult with a developmental disability should go without needed help.

Social Security

Social Security is the largest government support program. It is not welfare. Most people who work for any length of time have had Social Security deducted from their paycheck. A part of the money collected in this way is set aside for families with a disabled member.

Monthly Social Security benefits are available to:

- workers who were severely disabled before the age of 65;

- retired workers over 62 years of age and their dependents; and
- children of retired, disabled or deceased workers, provided that the children are either under 18 years of age, or were severely disabled before the age of 22 and continue to be disabled.

Supplemental Security Income (SSI) for Aged, Blind, and Disabled is another Social Security program. If a person is 65 years of age or older, or if the person is any age, including children, and also blind or disabled, he or she may receive monthly payments from the Social Security Administration.

To find out if the disabled child or adult in your family is eligible for these payments, a parent, guardian or other responsible adult can apply to the Social Security Office.

For information and application forms for Social Security programs, call your local Social Security Office. Local telephone numbers are listed in the telephone book under Social Security Administration.

Veteran's Administration

The Veteran's Administration is another government agency which may be able to help. CHAMPVA, the Civilian Health and Medical Program of the Veteran's Administration, is a health and medical care plan. Financial aid for medical care is provided to a spouse or child of a veteran (living or deceased) who has a permanent, total disability. This disability must be the result of an injury that happened while the person was in military service. Benefits usually end when the dependent child turns 18 years of age, unless that child is not able to support him/herself because of a mental or physical disability that was obvious before the age of 18. In this case, the child can continue to receive benefits.

For more information about this program, call toll free or write:

Veteran's Administration Regional
Office
Benefits Information and Assistance
Post Office Box 1437
St. Petersburg, Florida 33731
1-800-282-8821

Veteran's Benefits for Families

Another program from the Veteran's Administration provides for the education of wives, widows, or children of veterans who are 100 percent permanently disabled. The disability must have come from an injury during the time the person was in military service. The selection of training programs for children with disabilities is given special attention.

For more information contact:

Education Assistance Department
Veteran's Administration Regional
Office
Post Office Box 1437
St. Petersburg, Florida 33731
1-800-282-8821

Medicare

Medicare is another federal program that is financed through Social Security taxes paid by employers and employees. Medicare covers all people over 65 who are eligible for Social Security as well as younger people who are disabled. Disabled adult children who receive Social Security benefits from their parents' employment can receive Medicare benefits. Any child under age 18, disabled or not, may receive Children's Benefits if the parent is retired, disabled, or deceased.

There are [illegible] rts to Medicare. Part A is hospit[illegible] nce and does not cover doctor [illegible] r custodial nursing home care. T[illegible] s free. Part B helps to pay doctor [illegible] tpatient hospital services and the [illegible] medical services and supplies. Part B [illegible] osts people who use it a small monthly fee. Some items, like eyeglasses and hearing aids, are not covered by Medicare. Both Parts A and B have deductibles or an amount that must be paid by the user before additional expenses are covered.

For more information call toll free or write:

Medicare
Post Office Box 2360
Jacksonville, Florida 32231
1-800-342-7586

Medicaid

Medicaid or Medical Assistance is administered by the Department of Health and Rehabilitative Services and is financed by federal, state and county funds. It provides services for persons in financial need who are unable to pay for needed medical and health care services.

Anyone who receives public assistance, or welfare, or Supplemental Security Income (SSI) may receive a Medicaid card. A family may be eligible for Medicaid if it earns a minimum monthly income, or none at all, and owns little or no property. Or, a family may have a higher income, receive no public assistance or SSI benefits, yet have very high medical bills because of a child with disabilities. This family might also be eligible for a Medicaid card if they meet some other financial requirements.

Once a person has a Medicaid card, he or she may choose to use the services of a private doctor who accepts Medicaid or to go to public clinics. The program also allows your child to receive hospital care, nursing home care, laboratory services, dental care, and many other related services.

To find out more about Medicaid programs; contact the local district Medicaid Office nearest you. (See Section 6.)

Hill-Burton

Persons who do not qualify for Medicaid or other public plans and do not have adequate health insurance coverage, but need medical care, may be able to receive free care or below-cost hospital or other medical facility services under the Hill-Burton Act. Hospitals or medical facilities that receive federal funds for construction and modernization under the Public Health Services Act (Titles VI and XVI) are required to make available a reasonable volume of free services for people who are unable to pay for these services.

For information and assistance contact your hospital admitting department or social services department to see if funds are available. Since not all hospitals offer this program, you may also want to write or call for a list of Florida facilities in your area which have funds available.

Office of Community Medical
Facilities
1323 Winewood Boulevard
Building 1, Room 256
Tallahassee, Florida 32301
(904) 488-8672

Insurance Benefits

Many families with a child who has a developmental disability may have a personal medical insurance policy. If you have medical insurance, one of your first steps might be finding out exactly what benefits or services are covered. To do this, you will need to start first with your child's physician and find out what care your child needs, why, and if other options are available. Once you have this information, your next step is to contact the benefits department of your health insurer or your own employer. When you reach the benefits department, find out which services are covered or not covered. Be sure to record all information you receive, including the name of the person who is giving the information to you. It is usually helpful to follow up on your telephone conversation with a letter to this person stating what you understand the insurance benefits to be. Keep a copy for your files.

When you file a claim, fill out all forms carefully and completely. Provide as much information as possible, for example, photographs, detailed explanations, daily routines, background medical data. Keep copies of all information sent. Always talk to the person handling your claim rather than talking with a different person each time.

This will help to keep information together and will shorten the time it takes to process a claim.

Other Programs

There are a number of other income support programs. Most have income level requirements and sometimes other requirements as well. These programs include:

- Aid to Families with Dependent Children (AFDC)
- Food Stamps
- Vocational Rehabilitation Services
- Emergency Assistance Grants
- Private Voluntary Agencies
- Local fraternal organizations, service groups and foundations
- The local organization that provides services to people with disabilities like your child's (for example, United Cerebral Palsy, the Association for Retarded Citizens, etc.)

To find out more about these and other resources, call your Department of Health and Rehabilitative Services District Office or your local human resources department or department of social services listed in the telephone book under your county government. Ask the person who answers to explain who qualifies for each program.

Tax Deductions and Tax Credits

There are a sizeable number of income tax deductions and credits available to parents of children with developmental disabilities. Every parent can benefit by using these deductions and credits.

Every year the Internal Revenue Service publishes up-to-date tax information. This information is available from your nearest tax office or by mail from your closest IRS regional office. Check your telephone book under Internal Revenue Services for the telephone number.

Medical Assistance Options

Besides the programs already listed, you may want to:

1. Talk with your doctor. He or she may be a participating member of programs which provide free care to unemployed persons and their families.
2. Contact your county medical association and ask if they can refer you to any special programs or care givers.
3. Check with any area HMO (Health Maintenance Organization). Some of these groups are providing free medical care at after-hours clinics.
4. Contact your union or the AFL-CIO and see if they are participating in any free health care programs.
5. Call your local dental association to see if assistance for dental care is available.

Parent Rights

Many parents of children with disabilities find that society as a whole is quite unprepared to accept their child. They, as well as the child, frequently are avoided by strangers, treated poorly by doctors, teachers and other professionals, and patronized or pitied by friends and relatives. Some of these parents simply accept the reactions of others and believe that, as parents of a child with a disability, they no longer have the same position in life as a "normal" family. This is simply not true.

As parents, you have some very basic rights, rights you should know and insist on. These include*; as a start, the following:

- The right to sound medical information, explained in terms and ways that can be understood clearly.
- The right to regular re-evaluation of your child and his or her progress.
- The right to information that will help you meet your child's special needs.
- The right to information about your child's future.
- The right to know about available community resources including rehabilitative services.
- The right to hope, encouragement and consideration.
- The right to meet and talk with other parents who have children with disabilities.
- The right to a personal life apart from your child, including the right for recreation, for time alone, for time with each other, for time to read, paint, write poetry, visit with friends, exercise, or whatever.
- The right to complain, to cry, to feel sorry for yourself, to be angry; in short, the right to be as human as you were before your child was born.

Along with these basic rights, parents will want to be aware of the legal rights of any child with a disability. These rights are identified by both the Florida Legislature and the United States Congress.

The most current federal law is the Developmental Disabilities Act and it was passed in 1984. It is known as Public Law (P.L.) 98-527, and it updates earlier laws to include a wider range of disabilities and to provide more services to people who have them.

In this law support is given to moving people now in large institutions and to keeping others from entering them. Special effort is encouraged to keep people with disabilities in their own homes and communities; to learn, work and live as normally as possible. Most of these people will require special services. Others may need total care. The law makes clear that such services must be given.

Before this law there were several others. You will want to become familiar with them. They affect all parts of the lives of people with disabilities.

- Public Law 91-517 — The Developmental Disabilities Services and Facilities Construction Act of 1970.
- Public Law 93-112, Title 5, Section 504 — The Rehabilitation Act of 1973, usually known as the DD Act or just Section 504.

The DD Act and its amendments define developmental disabilities and the services required for them. One requirement of the DD act is that every state have a protection and advocacy system. (See page 28.)

This system must deal with many problems: employment discrimination, rights to education, transportation and building accessibility, guardianship, adult protective services, relocation of people from institutions, and rights of people in institutions. The DD act also gives support and technical aid to individuals and groups that work with handicapped people and their needs.

This aid can include discussion of issues, legal action to enforce laws, public hearings, and coordination of services. It can mean helping people learn to be their own advocates or spokespeople or serve as advocates for someone else. These services are given free of charge.

Under Section 504 any public or private building or service which uses public tax dollars must be accessible to people with disabilities. Services must be available and physical barriers (for example, no wheelchair ramps or too-narrow doorways) must be eliminated. All public transportation must be usable by people with disabilities.

- Public Law 94-142 — Education for All Handicapped. This guarantees a public education for children with handicaps from age 0-21 (effective October 1, 1980). This law
  - requires states to provide special education and related services to children with special needs.
  - provides financial assistance to states and local school districts to provide needed programs and services.
  - establishes and protects due process or the right to legal action for parents and other advocates.
- Chapter 393, Florida Statutes — Retardation Prevention or Community Services Act. This law
  - redirects Florida treatment programs for the retarded and other developmentally delayed individuals to emphasize programs to prevent or reduce the severity of the disability.
  - gives priority to developing and using community based placements, services and treatment programs.
  - provides for the operation of services by private businesses, not-for-profit corporations, units of local government, and other organizations instead of exclusively by state agencies.
  - creates the Florida Developmental Disabilities Planning Council as an advisory body for

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*This list was adapted from *The Disabled and Their Parents: A Counseling Challenge* by Leo Buscaglia an excellent and moving book that will be most helpful to anyone who cares about a child with a disability or his or her family.

programs and services affecting persons with developmental disabilities.

There are numerous other Florida and federal statutes which concern people with disabilities and handicaps. These laws affect the everyday lives of each of us. A brief overview of these laws can be found in Section 8, page 35.

Parent Role: Taking Action

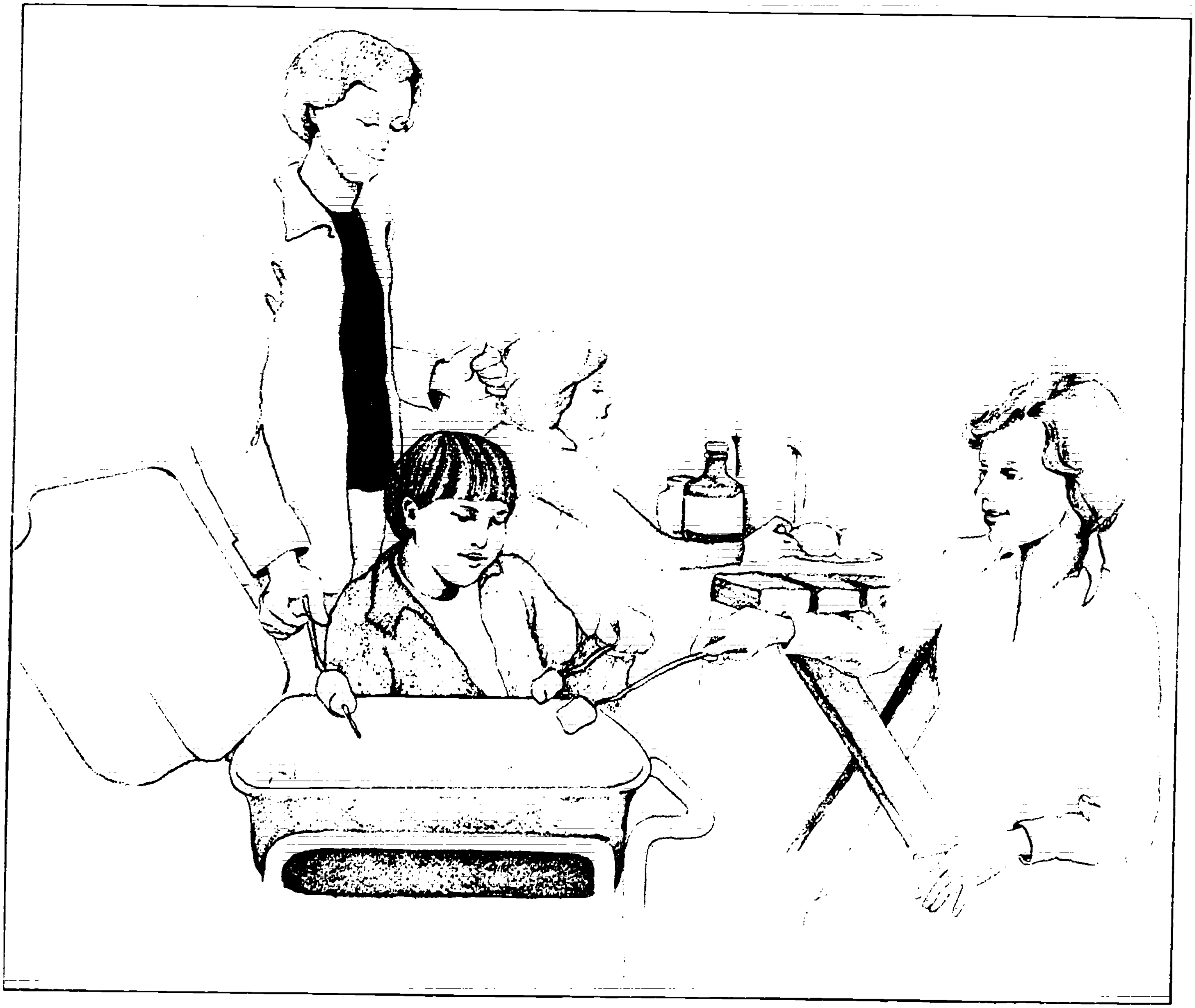
If your child is to be helped, you, as a parent, must be willing to move past accepting your child's disability, past understanding of his or her special needs, and into the new role of taking action to develop a total life plan for your child. Action is any planned activity that leads to change. Now and as your child grows, you may see much that needs to be changed. As the person who cares the most about your child, you are also the one who can see what needs to be done. Or what must be done.

You are your child's most important advocate. You will need courage and stamina to take on this task, but the benefits for your child will be worth it. The sooner you are able to begin, the more you will be able to do. The following steps will get you started.

1. *Get information.* You and your child need to know as much as possible about his or her specific disability. Ask your doctor for possible sources of information. Use your public library. Make sure you understand any scientific or technical terms. If you do not, ask your doctor or another professional to explain in terms you can understand. Write to the organizations listed in this guide in Section 8. Check any other possible sources for information. Read. Ask. Discuss.
2. *Learn.* Become an expert on your child's disability, treatment program and probable progress. If your child needs or can benefit from some activity or exercise, find out how you can help. Observe carefully any procedures that your child's doctor, therapist or other professional performs on your child. Notice how your child responds to certain people, the environment, and other objects, toys, animals. Be a detective: the more you learn the more you may be able to help.
3. *Record.* Keep copies of the information you find about your child's disability. Make and keep a written log of his or her appointments, evaluations and referrals. Note the treatment given. Keep copies of all letters about your child. Ask for and obtain in writing the diagnosis and comments of professionals involved in your child's program of care. Take notes on your telephone conversations about your child. Include the date, reason for calling, what was said, any outcome expected. Save any scrap of information that may be useful later. Keep this guide with your other information in a file, notebook or other safe place.
4. *Believe.* Both you and your child are lucky to be alive now instead of even 10 years ago. Today, people with disabilities are encouraged and helped to lead their lives in the fullest way possible. Know that your child can benefit from the best possible care. Have faith in yourself as you struggle to cope with your own feelings while you go on to help and care for your child.
5. *Act.* Although many people will be involved in the care of your child, only one person may be aware of everyone else: you. Some of the other people will be helpful, and others will not. Often the quantity and quality of help and support your child gets will depend on how well you and these people get along. But it is the *parent* who must guide the child through the services needed. To be an effective guide, the parent must do more than get information and make appointments. In all cases the parent must actively work to get what is deserved and needed for the child.

As your child's case manager you will be doing a difficult job. You will be putting — or pulling — the pieces of care together. As your child's advocate, you will speak for your child's legal and human rights and work to get changes that may be needed to protect them.

Finally, as your child's mother, father or legal guardian, you will need to make plans for your child and his or her care in the event that you die or are yourself disabled.



"Joy can be real only if people look upon their life as a service and have a definite object in life outside of themselves and their personal happiness."
Leo N. Tolstoy

SECTION 4: THE FAMILY

The challenge of raising a child with a disability is great. It may not be all sad or dreary, but it can be a difficult and time-consuming job. All family members will be affected. Each family member will in some way also affect the child with a disability.

Family Needs

As a family member, you may want to meet other families who have children with disabilities. You may discover that the problems you thought were yours alone are shared by many. You may find that the needs of your child can quickly overshadow the needs of other family members. This will be harmful to all, including the child with a disability, if feelings of resentment build up. It is a hard job for any family to learn to balance everyone's skills and needs. It is also a job that will require shared information, careful thought and planning together.

Coping with other relatives may seem impossible, particularly if you have just learned of your child's disability. You may need to "bend over backwards" to help grandparents, aunts, and uncles at a time when you are yourself troubled. Some relatives may never accept your child. On the other hand, given a chance to adjust, your relatives can be a valuable support system.

Family Rights

A family also needs to know what its individual members' rights are. Each person must understand that living with a child with disabilities doesn't take away the basic rights of other family members. Each person has the right to go on living his or her own life, to work and play, to laugh, love and be loved — apart from the child with disabilities.

It is especially important that the care of the child with a disability be shared among all family members, not just one. Your child will learn much from the variety of interactions that come from being cared for by different people. Other family members will benefit, too. The direct, personal contact with the child's care will help each family member to better understand the problems caused by the disability and to accept the child with his or her limitations.

Together, a family can create the kind of home that will allow the child with a disability to learn and grow in comfort and security. In such a home, each family member will share in the joy of daily successes and triumphs as well as the pain of failure and unmet hopes.

Family Role: Support for the Developmentally Disabled Child

For the most part, your child will learn about the world outside from each person in the family. If they are afraid, your child will learn fear. If they are embarrassed, your child will learn that he or she is an embarrassment. If they are patronizing, your child will learn that he or she is to be pitied.

On the other hand, if they are cheerful, he or she will learn to be cheerful too. If they encourage, your child will learn hope. If they love, so will your child.

This may seem overly simple but, we do *learn* to be human, and our family members are our first teachers. (Buscaglia, 1975) And, as the child learns what it is to be human, the rest of the family learns what it is to be more humane.

Basically, the family is a training ground for your child. Your safe home, where your child's basic needs are met, is also the place where he or she will experiment with behavior and feelings. What your child learns at home from all family members will be the foundation for how he or she will behave and feel in the outside world.

Because of this, the family plays a vital role in your child's development and growth. The family, as a unit, will be the first to teach your child to be human, to build his or her unique personality, to develop a positive self-image, to love, and to face the ever changing outside world. It is from the family that your child will learn and experience that, even with severe disabilities, it is okay to be exactly like he or she is.

"Hope is the beginning of
plans. . . ."
Norman Cousins

SECTION 5: GETTING STARTED WITH PROFESSIONAL HELP

As you read this guide, your child will probably be in one of these stages along the way to getting help:

1. Newborn — Physical problems are already present: open spine, arm or leg malformation; cleft palate, Down Syndrome, or other problems.
2. One - three years — You may notice signs that your child is developing more slowly than other children the same age. (See Growing Chart, p. 6.)
3. At or near school age — Many small or large signs may signal a problem to parents or teachers: difficulty in getting along with other children; inability to follow directions or pay attention; inability to tell the difference between certain shapes and sounds.

It's not easy to accept that your child may be different from other children at any age. Getting started may be easier, however, if your child is at the first or second stage.

A physical problem may need immediate attention. Decisions about what to do may need to be made quickly, sometimes without much information. Sometimes, doctors or other professionals may even suggest that you not allow treatment for your child.

Making Decisions

Some hard questions which might help parents who must make decisions about whether to treat a child with a serious disability might be:

- What are the chances my child will die without treatment? Who will be responsible?
- Can treatment be given with equal benefit at some other time?
- Will my child suffer? How will I feel about that?
- What will cause the least harm and the most benefit to my child? To myself? To our family?

Fortunately, in nearly every case now there is hope for the child's life. New parents may want to ask the hospital staff to put them in touch with other parents of children with birth defects. Those parents can help you think through the earliest questions.

If your child is slightly older, you may not know what the extent of the disability may be. You may even be afraid to find out. Remember that a child's handicap actually may be reduced if the child gets the right treatment or training.

Stage three is usually the hardest point to enter a service system of places and people that may include schools, teachers, tests, psychologists, counselors, therapists and medical services. Often these people and their services will disagree on their assessments of what your child's needs are. They may suggest different programs for his or her care. This can be very confusing.

There are some basic steps to expect and to plan. These steps may be different for every family. They will usually include medical care, education and training programs, and support for the family. Some of these basic steps are listed below.

If your child is very young:

- Get any medical care needed for your child.
- Learn all you can about your child's disability.
- Make appointments with a clinic or doctor to find out more about your child. Ask your doctor to help.
- Begin asking questions; find parents of children with the same disabilities.
- Set your own limits to safeguard your health.

If your child is older:

- Get an evaluation or screening. Health departments may refer you to the special education department of your school system.
- Keep in touch and follow up on any program that is planned for your child.
- Seek out an advocate or contact person on whom you can rely.
- Recognize your importance to your child's progress. You are parent, care coordinator, and spokesperson. Your continued involvement is vital.

In Section 3 of the guide there are more suggestions on how to get started. These first steps can be difficult and even painful. Yet they can lead to a richer and more satisfying life than you ever dreamed was possible.

As a parent, you face what may seem like a maze of services and people. This is one reason why it is so necessary that you take seriously your role in securing, coordinating and monitoring your child's care.

On pages 22 and 23 is a chart, developed by the Maryland State Planning Council on Developmental Disabilities, which shows some of the many services and where they may fit into the life of your child and your family. Many of these services will be repeated at different times and places; many will be used continuously.

The chart is intended to give you a broad overview of what you can expect. Some definitions and more detail will follow in Section 6 of this guide.

Diagnosis, Evaluation and Referral

Getting help starts when you find out what the problem is. This is called a diagnosis. Specialists from different fields will want to test and examine your child. When they have done this, they will make their diagnosis and talk with you about what can be done.

There are several ways you can get an evaluation and diagnosis of your child and his or her disability. You may want to start by seeing your own doctor or asking for a referral to another specialist. You also can contact the local developmental services office of the Department of Health and Rehabilitative Services (HRS) for referral to their Diagnostic and Evaluation Unit.

You also can find out about the services in your area by calling the local office of your:

- County School Board
- Association for Retarded Citizens / Florida
- Florida Epilepsy Foundation
- United Cerebral Palsy
- Florida Society for Autistic Citizens
- County Head Start Program
- Spina Bifida Coalition of Florida
- Easter Seal Society

Once you and the professionals know what your child's disability is, a plan for care and treatment can be developed. This plan will include the physical, social and emotional health of your child. Since you are the one who will choose the plan that best meets your child's needs, be sure that you understand exactly what is planned. If you are not comfortable or do not understand some of the technical words used, be sure to ask questions.

Below are some of the words which you may hear when discussing services for your child.

A Word of Caution . . .

No matter how many so-called experts see your child, none will ever be as familiar with him or her as you are. You will be able to recall and relate your child's growth and development pattern. You will know his or her present performance better than anyone. You will know how your child eats, sleeps, plays and works. Many children with disabilities have been able to learn and live full lives only because a parent refused to accept a wrong diagnosis for the child and continued to seek help.

If something about a diagnosis or treatment program strikes you as not right for your child, discuss it with your doctor or other professional. Tell why you believe there is a problem. (Doctors are people too, and anyone can make a mistake!) If you still have doubts, ask for a second opinion — or a third. Trust yourself and what you know to be true about your child. A life may be at risk.

A most compelling example of a parent's unwillingness to give up her child is the story of Christy Brown, a severely disabled man with cerebral palsy. Because he could not communicate in any way as a child, doctor after doctor insisted he was mentally retarded as well as physically disabled. His mother refused to accept this diagnosis and continued to look for ways to help her son. Today, writing with his left foot, he is the successful author of several books, including one titled *My Left Foot*.

The Team Approach

When you first begin to look for help for your child, the team that provides services or treatment may be just you, your child and your medical doctor. Eventually, depending on the specific needs of your child, the team may grow to include a medical social worker, an occupational and physical therapist, a psychologist, teachers, a speech and language pathologist and a number of medical specialists. Each of these professionals will be more or less helpful to

Audiology — Special training for hearing problems

General Practice — Traditionally, the services of a family doctor" refers to the private offices of a doctor trained in general medicine, or sometimes internal medicine. Sometimes this doctor will help the patient or family manage health problems. This doctor will call in specialists as necessary.

Habilitation — A combination of treatment and therapy required to help a child or young person acquire skills necessary to grow up to be as independent as possible

Internal Medicine — Special training which covers most medical problems except surgery

Neurology — Special training which studies problems and diseases of the nervous system.

Nutrition — Science dealing with diet and proper foods to eat for health and for special medical conditions.

Obstetrics — Special training in pregnancy and childbirth.

Occupational Therapy — Special therapy to help people with a disability develop skills necessary to their work and every day life

Ophthalmology — Special training for problems with eyes. This doctor may operate on the eye

Optometry — Special training for testing eyes and writing orders for glasses or contact lenses

Orthopedics — Special training which focuses on the skeletal system

Otolaryngology — Special training for problems of ear, nose and throat

Pediatrics — Special training in the medical problems of children from birth to teenage years

Pedodontics — Special training in children's dentistry.

Physical Medicine and Rehabilitation — Special training for doctors in the treatment of physical disabilities

Physical Therapy — Special training to use heat, massage and exercise to improve muscles in the body and improve coordination.

Podiatry — Special training for problems of the feet

Psychiatry — Special training to treat mental and emotional problems. Doctor can prescribe drugs and medical treatment

Psychology — Special training for mental and emotional problems. Does not include prescribing drugs or medical treatment

Rehabilitation — A combination of all kinds of treatment and therapy required to assist the person with disabilities to get or regain skills necessary to be as independent as possible

Speech Therapy — Special therapy for speech problems or learning problems.

Urology — Special training in problems of the urinary system

Vocational Rehabilitation — Special therapy to help the person with disabilities select an occupation or career and learn the tasks necessary to perform in a job. Includes counseling on how to find a job.

your child, depending on the services he or she needs. For example, for a child who is missing a leg, emphasis would be placed on medical, psychological and rehabilitative educational programs.

The best way to provide these services is through a team approach, coordinating efforts and working together. Unfortunately, this doesn't always happen. The medical doctor may not know what the speech therapist is doing. The speech therapist may not know what the classroom teacher is doing. And so on. No wonder close cooperation is frequently hard to come by!

This situation may be made worse by the doctor or specialist who believes that what he or she is doing is the most important part of your child's treatment program. One of your many tasks will be to make sure that your child is viewed as a person and not as a limb, a reading level, or a task.

As soon as possible, the treatment team should also include your child. He or she deserves to be a part of the decision-making process. It may be necessary to translate or explain what is going on in terms your child can easily understand, but it will be well worth the effort to allow your child some control over his or her life. As he or she matures, and if he or she is capable of doing so, your child may well take over the coordination and management of treatment and care. For right now though, you will be the one who makes decisions as you seek and then follow a prescribed treatment program.

A System of Services and Support*

This chart gives an overview of services and support needed through several stages of a child's life. Most of them are services provided by agencies and organizations. You will find more information about these on the following pages.

Some of this support is more personal. It has been discussed earlier in this guide. Both kinds of service and support are important to your child. They often work together and are necessary at the same time. As you will see, most extend over a lifetime.

Type of Services	**Infant (0-3)**
EDUCATION	■ Infant stimulation ■ Early intervention Programs from local education agency, voluntary associations, or health centers
HEALTH CARE	■ Your doctor ■ Your health department Well baby clinic Early medical treatment First diagnosis / evaluation ■ Genetic counseling
FAMILY SUPPORT	■ Extended family and friends ■ Parents of other children with disabilities ■ Respite care Baby sitters Day care
OTHER COMMUNITY SERVICES	■ Parent organizations ■ Financial aid

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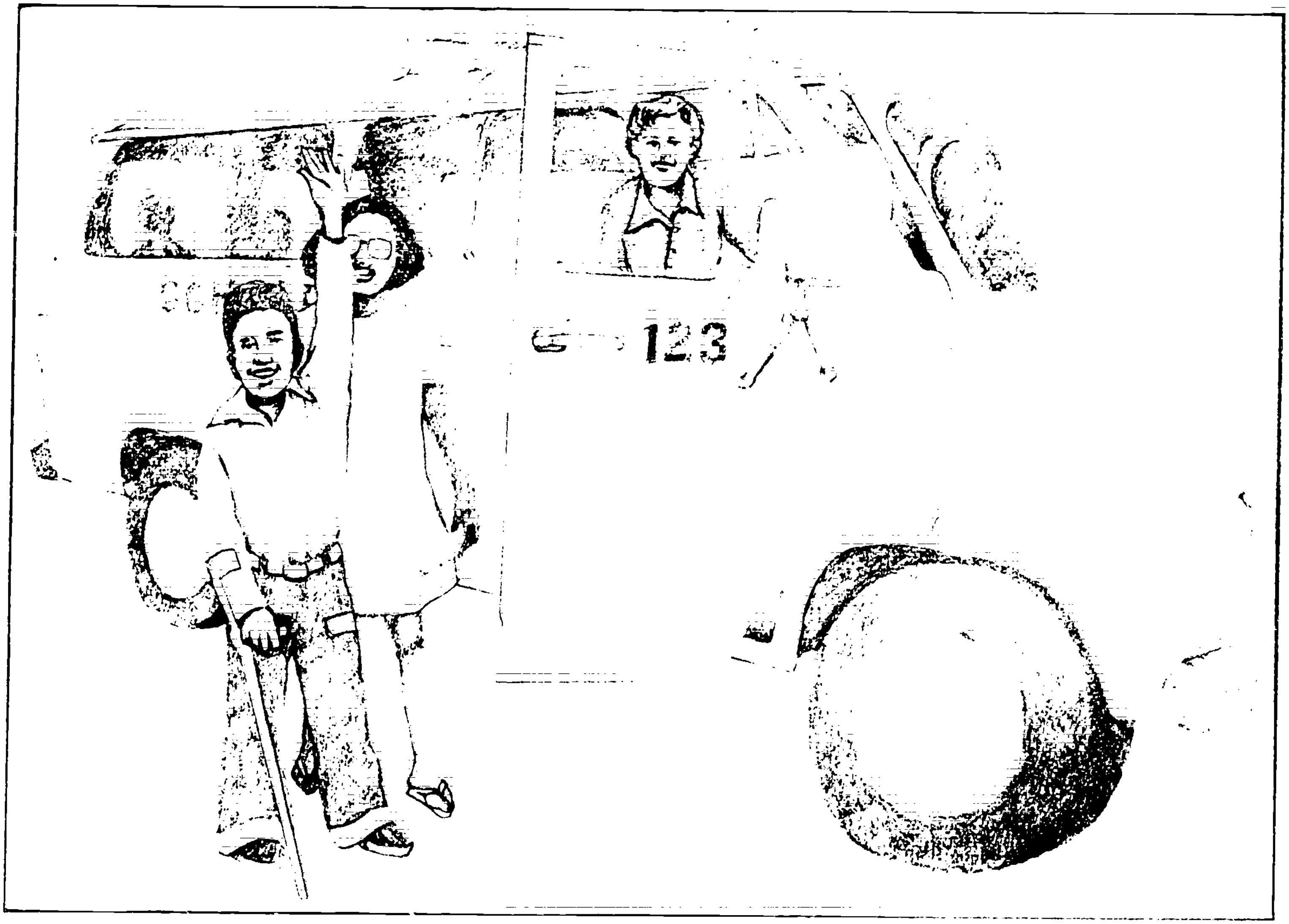
*Developed by the Maryland State Planning Council on Developmental Disabilities.

Early Childhood (3-5)	**Childhood (5-12)**	**Teen / Adult (13 and up)**
■ Pre-School Public Private centers with comprehensive early training programs ■ Day care ■ Early screening for school placement	■ Placement in regular programs ■ Placement in special programs ■ Development of Individualized Education Program — IEP ■ Special education division of local education department ■ Private schools — day or residential	■ Continued screening and evaltion — local education agency ■ Placement in regular or special public school programs ■ Vocational training Activity centers Training centers Workshops for job skills life skills
■ Comprehensive diagnosis / evaluation Clinic or private doctors ■ Continued treatment	■ Follow-up evaluation ■ Continued health care including mental health service	■ Continued health care, evaluation and treatment
■ Continued family / friend support ■ Respite care ■ Family counseling	■ Continued family / friend support ■ Respite care ■ Counseling ■ Residential facilities Private Public Community-based, away from home	■ Continued family support services ■ Future placement arrangements Independent Living Group homes Community residential alternatives Residential facilities
■ Continued parent organization support ■ Continued financial aid ■ Day care ■ Foster care ■ Adoption services	■ Continued parent organizations ■ Continued financial aid ■ Recreation ■ Church ■ Clubs ■ Transportation ■ Advocacy system Legal rights	■ Parent / voluntary groups ■ Financial aid ■ Continued community services ■ Advocacy system Legal aid Planning wills / trusts



"Courage is not the absence of fear; it is the making of action in spite of fear."
M. Scott Peck, in
The Road Less Traveled

SECTION 6: FLORIDA SERVICES

In Florida, the Department of Health and Rehabilitative Services (HRS) is the state agency primarily responsible for the evaluation and treatment of persons with developmental disabilities. HRS meets this responsibility by providing services locally through its regional offices. Because of the size of our state and the number of services needed, HRS divides the state into 11 districts. Each district may serve one or more counties. A directory of these districts and the counties included in each can be found on page 29 of this section.

HRS provides services grouped into specific program areas. These areas are:

- Aging and Adult Services
- Alcohol, Drug Abuse and Mental Health
- Children's Medical Services
- Children, Youth and Family Services
- Developmental Services
- Economic Services
- Health
- Health Planning and Development
- Medicaid
- Vocational Rehabilitation

A complete list of specific services offered within each program is included for your information in Section 8, page 34, of this guide. It is not necessary for you to contact a specific program office or to know exactly what services your child may need. Simply call or write the District Administrator of the district office nearest you and you will be referred to the appropriate program office. Or, you may call the Developmental Disabilities Planning Council at (904) 488-4180 to ask for assistance.

Other services and treatment programs are provided by not-for-profit agencies, county public health units, voluntary agencies, associations, local school districts, and other state agencies. The names and addresses of some of these are included in the next few pages.

Medical / Health Related Services

The associations and corporations listed below offer a wide variety of programs and services, from advocacy assistance to treatment programs. Some are related to a specific disability, others are more general. Most offer information and referral services as part of their programs and can direct you to other agencies in your immediate location.

American Diabetes Association
Florida Affiliate, Inc.
3101 Maguire Boulevard, Suite 288
Post Office Box 19745
(305) 894-6664

American Heart Association, Inc.
Florida Affiliate Office
810 63rd Avenue North
Post Office Box 42150
St. Petersburg, Florida 33742
(813) 522-9477

American Red Cross
National Headquarters
17th and D Street, N.W.
Washington, D.C. 20006
(202) 737-8300
(Also, you may want to check your local phone directory under American Red Cross.)

Arthritis Foundation
Florida Chapter
3205 Manatee Avenue West
Bradenton, Florida 33505
(800) 282-9487

Association for Retarded Citizens / Florida
106 North Bronough, Suite M1-7
Tallahassee, Florida 32301
(904) 681-1931

Florida Association of Rehabilitation Facilities
124 West Jefferson Street
Tallahassee, Florida 32301
(904) 224-3660

Florida Easter Seal Society
1010 Executive Center Drive, Suite 101
Orlando, Florida 32803
(305) 896-7881

Florida Epilepsy Foundation
Post Office Box 6059C
Orlando, Florida 32853
(305) 422-1439

Florida Society for Autistic Citizens
1523 Julie Tonia Drive
West Palm Beach, Florida 33406
(305) 965-0409

Leukemia Society of America, Inc.
National Headquarters
800 2nd Avenue
New York, New York 10017
(212) 573-8484

March of Dimes Birth Defects Foundation
Regional Office
12550 Biscayne Boulevard
North Miami, Florida 33181
(305) 895-2856

Mental Health Association of Florida
Post Office Box 11068
Tallahassee, Florida 32302-3068
(904) 877-4707

Muscular Dystrophy Association
1301 Seminole Boulevard, Suite 105
Largo, Florida 33540
(813) 585-5446

National Kidney Foundation of Florida, Inc.

1 Davis Boulevard, Suite 304
Tampa, Florida 33606
(813) 251-3627

National Multiple Sclerosis Society
Area Office
1522 Roswell Road, Suite C
Marietta, Georgia 30062
(404) 977-1002

Spina Bifida Coalition of Florida
996 Florida Town Road
Pace, Florida 32570
(904) 994-4001

United Cerebral Palsy of Florida, Inc.
Post Office Box 6476
Tallahassee, Florida 32301
(904) 878-2141

Upjohn Healthcare Services
Florida Region Administration
Post Office Box 2607
Winter Park, Florida 32790
(305) 629-0636

Education and Related Services

Many children with disabilities will spend their educational lives in special programs or classes. These programs fall into five basic types.

1. **State schools for the disabled** for those children who are blind, deaf, have cerebral palsy or other severe disabilities.
2. **Segregated schools** in which children with all types of physical and mental disabilities within a given area in a community are bused to and educated in a single segregated facility.
3. **Segregated classrooms** are located within a regular elementary or secondary school and made up of children who have the same or similar defects. For example, all children with mental retardation will be taught together in a regular school but in a "special" class with a specialist teacher for the full school day.
4. **Integrated classrooms** usually offer a special class for a particular problem in a regular school. The children are in this class for only part of the school day, joining other students for some school subjects. For example, a child who has mental retardation may have an academic class in a special classroom but join students without disabilities for art, physical education, shop subjects or music.
5. **Itinerant programs** will serve a child who has acquired special skills which allow him or her to handle a regular school program. For example, a child who is blind will need to read, write and type in Braille before being placed in a regular class at the appropriate grade level. An itinerant teacher, trained in Braille, will visit the child regularly to locate books in Braille, to transcribe special materials, or to help with any problems between the child and the regular teacher. Otherwise, the child functions in the same way as other students. Children with specific learning disabilities and who have no other obvious physical impairments are often placed in programs of this type.

All of these programs are offered at different levels, depending on the ability of the individual student. Placement and follow-up services (which "follow" a child to be sure a placement is right for that child) are offered through the public school system in Florida. For information on education and related services you may wish to contact:

The Bureau of Education for Exceptional Students
Florida Department of Education
Knott Building
Tallahassee, Florida 32301
(904) 488-1570

Florida Instructional Materials Center for the Visually Handicapped (FIMC)
5002 North Lois Avenue
Tampa, Florida 33614
(800) 282-9193

Captioned Videotape Project for the Hearing Impaired
Florida School for the Deaf and Blind
Post Office Box 1209
St. Augustine, Florida 32084
(904) 824-1654

FSDB Outreach Project
Child Study Center
Florida School for the Deaf and Blind
Post Office Box 1209
St. Augustine, Florida 32084
(904) 824-1654

Division of Blind Services
Florida Department of Education
Knott Building
Tallahassee, Florida 32301
(800) 342-1828

Division of Blind Services Library for the Blind and Physically Handicapped
Post Office Box 2299
Daytona Beach, Florida 32015
(800) 342-5627

Manderfield Industrial Training Laboratory
401 Platt Street
Daytona Beach, Florida 32014
(904) 252-4722

Many of the agencies already listed in the guide offer support services to families with children who have disabilities. You also can find out about other programs and services by contacting the agencies and organizations below.

Florida Council of Handicapped Organizations
Post Office Box 2027
Satellite Beach, Florida 32937
(305) 777-2964

Head Start
Humanics Associates
Florida Office
255 Whooping Loop, Suite 255
Altamonte Springs, Florida 32701
(305) 834-6538

Parents Anonymous of North Florida
Mt. Vernon Square, Suite M
1106 Thomasville Road
Tallahassee, Florida 32303
(904) 224-8481
or

Parents Anonymous of Gulf Coast
Post Office Box 10087
Bradenton, Florida 34282
(813) 746-1904
National Hotline - (800) 421-0353

Also, check the list of HRS services in Section 8 to see if a specific HRS program area may be helpful

Economic Services

Earlier in this guide you found a number of possible sources of financial assistance to help with meeting your child's medical treatment expenses. Often the financial burden of a child with disabilities creates a drain on other areas of your budget as well. If you need help in meeting your everyday expenses, the Department of Health and Rehabilitative Services (HRS) may be able to help.

Some of the economic services administered by the HRS District Office which serves your county include:

- Aid to Families with Dependent Children
- Food Stamps
- Refugee Assistance Program
- Low-Income Energy Assistance Program and
- Work Incentive Program

If you need assistance, contact your HRS District Office (see page 29).

Community Assistance

For several years now both state and federal efforts at serving persons with disabilities and their families have been directed at helping the disabled to remain in the community. To do this, both the federal and state governments have developed and continue to support a number of community-oriented services. These services help to make it possible for a person with disabilities to live, work and play in a community setting.

Transportation

Getting places is a problem often brought up by parents and individuals with disabilities. Sometimes, even when services are available in a particular area, they are of no use to a person with disabilities because he or she is unable to get to them.

In many communities, both public and private organizations provide transportation to schools, workshops, recreation and medical facilities. Sometimes agencies arrange for buses or car pools using specially designed vans. If public transportation can be used, some agencies may provide the fare. There may even be a business in your area that will provide transportation for your child for a fee.

All public school systems must provide free transportation, to and from school, to children with disabilities which limit free physical movement. Some Florida counties have special transportation services. For information call your local school system transportation department or your county social services unit.

Recreation

Recreation includes many different activities that will greatly benefit your child: physical exercise, socializing, playing, and generally having fun. Your child is entitled to recreation programs and the use of public recreational facilities just as other children are. Remember that these programs and facilities are paid for by your taxes or organizations that are bound by nondiscrimination laws and practices. You may have to insist that your child be included, but to do so is certainly your right and is in the best interest of your child.

Many groups already have special programs to meet the needs of children with disabilities. Others have programs which group children with similar disabilities together. For example, your local YMCA may sponsor a summer day camp for children who are deaf. Or your area may have a Scout troop for those children who are confined to wheelchairs. Check with your local groups or clubs to see what is being done. If no programs are under way, ask the group to start one.

You may also want to contact your county recreation department for information about any special programs they may sponsor. Phone numbers may be found in the telephone book under your local government listing.

Some programs are just for those children who have disabilities. The Florida Special Olympics is one of these programs. Held throughout the year, the Special Olympics gives children who are mentally retarded a chance to compete for awards in physical events such as swimming, basketball, volleyball, track and field events in county, district and state games.

For information, contact the physical education teachers in local special education schools or write to:

State Special Olympics Headquarters
2639 N. Monroe Street, Suite 151-A
Tallahassee, FL 32303
(904) 385-8178

Summer camp programs, both day and overnight, are designed for children with disabilities and give children a chance to explore a new environment — and to get along without a parent. They also allow the parent(s) a chance to have a vacation.

Persons with disabilities may form their own group or club for the purpose of socializing, eating out, dancing, going on trips, etc. Some private companies specialize in arranging trips for people with disabilities.

All of these possibilities may require some extra effort on your part. But playing and being with friends is an important part of being a child. Other parents may be a good place to start your search to find recreational activities suitable for your child. Some of the sources already listed may be helpful, too.

Religious Training

Both children and adults with disabilities will benefit from religious education and participation in religious services. People with disabilities have the same feelings, values and spiritual needs as anyone else. Growing spiritually is a vital part of every person's development and is no different in a person with a disability.

Hopefully, your minister, priest or rabbi is already familiar with meeting the spiritual needs of people with disabilities. If not, perhaps he or she will be willing to learn more about disabling conditions to be better able to serve your child.

Some Associations for Retarded Citizens have sponsored special programs to involve both clergy and congregation with people with disabilities. Your local association may be able to provide information, guidelines and materials for training members of your church to provide religious education and services to your child.

Employment Options

Today, more than ever before, your child can look forward to several options for both finding and keeping a job. Depending on your child's specific disability, these options range from sheltered workshops to modified or adapted work stations in a regular employment situation. In fact, your child may well be able to assume financial responsibility for part or all of his or her care. Your child will have the opportunity to lead a productive, full and satisfying life — including having a paying job — if special care and training begin at an early age and are continued as long as necessary.

Job specific training is available through your public school system and through vocational rehabilitation programs offered by the state or private agencies.

Goodwill Industries of America is an example of an agency that may both train and employ people with disabilities. For information on the agency nearest you call or write:

Goodwill Industries of America
9200 Wisconsin Avenue
Washington, D.C. 20014
(301) 530-6500

For assistance in exploring employment options for your child contact your local school system or the HRS District Office serving your area.

Alternative Living Arrangements

Keeping your child at home or in a home-like environment while he or she is very young is thought by many parents and professionals to be best for the child. During this period when your child is growing and learning so much, you and your family can provide for most of your child's needs. Many agencies also provide services in the community to help in your effort to keep your child at home. These community services include day care, respite care, infant stimulation and school programs.

Yet even with these services, some parents cannot manage at home. You may need some other alternative. You might consider placing your child in foster care or in an adoptive home.

Or you may consider placing your child in a community-based residential program or group home for children or adults who are physically or mentally handicapped. Here young people can be with friends their own age, maintain a normal daily routine, and still get the supervision and care they need.

Voluntary agencies may be able to provide assistance in finding a group home. So will your HRS District Office.

Finally, an institutional residential program may be necessary. You may want to consider both private and public facilities. In general, very young children are accepted into public facilities only if they have very serious medical or behavioral problems. Private facilities may be able to accept your child, but they are usually very expensive. The current trend in Florida and other states is away from large institutions. In fact, two of Florida's six institutions already have been closed and residents moved to smaller community facilities.

For information on state residential facilities contact the HRS District Office serving your area.

Legal Aid

Sometimes, even with the number of state and federal laws, people with disabilities and their families need to defend their rights to receive needed services.

If you feel that your child is not being treated equally, there are many steps you can take. These steps may include complaints to appropriate boards, appeals and grievance procedures. If you still are not satisfied with your child's treatment program, you may require legal assistance.

In Florida if you need legal help, you can contact the Statewide Human Rights Advocacy Committee (address and phone number below) for help, or you can call or write one of the statewide legal services listed below.

Statewide Legal Assistance or Referral Services

Statewide Human Rights Advocacy Committee
1317 Winewood Boulevard
Building 1, Room 310
Tallahassee, Florida 32301
(904) 488-4180

Florida Bar Lawyer Referral Service

The Florida Bar
Tallahassee, Florida 32301-8226
(800) 342-8012

Florida Commission on Human Relations
325 John Knox Road, Suite F-240
Tallahassee, Florida 32303
(800) 342-8170

Florida Justice Institute, Inc.
1401 Amerifirst
One S E 3rd Avenue
Miami, Florida 33131
(305) 358-2081

Florida Legal Services, Inc.
226 West Pensacola, Room 216-218
Tallahassee, Florida 32301
(904) 222-2151

Governor's Commission on Advocacy for Persons with Developmental Disabilities
Office of the Governor
The Capitol
Tallahassee, Florida 32301
(800) 342-0823

Southern Legal Counsel, Inc.
115 N E 7th Avenue
Gainesville, Florida 32601
(904) 377-8288

You may also want to get a copy of *The Pro Bono Directory* from The Florida Bar. The directory is a complete listing of low-cost and free legal assistance. Send your request to:

Legal Assistance Project
Department of Public Interest Programs
The Pro Bono Directory
The Florida Bar
Tallahassee, Florida 32301
(904) 222-5286

HRS District Offices

HRS District One (includes Escambia, Okaloosa, Santa Rosa, Walton)
P O Box 12836
160 Governmental Center
Pensacola, Florida 32576
(904) 436-8200

HRS District Two (includes Bay, Calhoun, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Leon, Liberty, Madison, Taylor, Wakulla, Washington)
2639 N Monroe, Suite 200 A
Tallahassee, Florida 32303
(904) 488-0567

HRS District Three (includes Alachua, Bradford, Citrus, Columbia, Dixie, Gilchrist, Hamilton, Hernando, Lafayette, Lake, Levy, Marion, Putnam, Sumter, Suwannee, Union)
1000 N E 16th Avenue, Building G
Gainesville, Florida 32601
(904) 395-1005

HRS District Four (includes Baker, Clay, Duval, Flagler, Nassau, St Johns, Volusia)
5920 Arlington Expressway
P O Box 2417I
Jacksonville, Florida 32231
(904) 723-2050

HRS District Five (includes Pasco, Pinellas)
2255 East Bay Drive
Clearwater, Florida 33516
(813) 536-5911

HRS District Six (includes Hardee, Highlands, Hillsborough, Manatee, Polk)
400 W Buffalo Avenue
Tampa, Florida 33614
(813) 272-2540

HRS District Seven (includes Brevard, Orange, Osceola, Seminole)
400 W Robinson, Suite 801
Orlando, Florida 32801
(305) 423-6208

HRS District Eight (includes Charlotte, Collier, DeSoto, Glades, Hendry, Lee, Sarasota)
12381 Cleveland Avenue S
Ft Myers, Florida 33907
(813) 936-2211

HRS District Nine (includes Indian River, Martin, Okeechobee, Palm Beach, St Lucie)
111 Georgia Avenue
West Palm Beach, Florida 33401
(305) 837-5078

HRS District Ten (includes Broward)
201 W Broward Boulevard
Ft Lauderdale, Florida 33301
(305) 467-4298

HRS District Eleven (includes Dade, Monroe)
401 N W 2nd Avenue
Miami, Florida 33128
(305) 377-5058

"The real meaning of life is
to give oneself to a cause
that will outlast it."
William James

SECTION 7: FACING YOUR FUTURES TOGETHER

Thanks to recent changes in laws and the availability of more information, society is now more willing to accept children with disabilities and their families for what they are: people with hopes and needs much like everyone else. And, as more and more emphasis is placed on community services instead of state schools or residential facilities, the child or adult with disabilities is able to function more successfully in a "normal" environment.

Throughout this guide you have read about what kinds of events you can expect for your child and what services you can find to help deal with your child's special needs. It may be easy to get so involved with day-to-day care that you forget that there really is a "bigger picture," a life for you and your child apart as well as together. This section will explore a few of these future areas for you and your child.

Adolescence and Sexuality

Even if your child is very young, you can see frequent signs that he or she is growing and changing. You may notice the increases in weight, or mobility, or efforts to talk. You may observe your child developing a unique personality. Or you may be aware that clothes are outgrown more quickly. At any rate, your infant will one day be a child, who will one day — soon — be a teenager and young adult.

What can you expect as your child matures? To begin with, a child with a disability follows the same development schedule as any other child, except that it may take more time to advance from one stage to another. During adolescence, the developmental tasks for all young people include strengthening a sense of identity, assuming the appropriate male or female sexual role, and achieving some measure of independence (de la Cruz and LaVeck, 1973).

Many people have great difficulty with the behavior of their children during adolescence, particularly with the area of a child's developing sexuality. When the child is mentally or physically disabled, dealing with sexual feelings and behavior may be even more difficult. It helps to remember that sexuality is a part of all human development and should be considered a normal part of growth.

Sometimes a conflict develops between the rights and needs of parents and the rights and needs of children. As a parent you may be afraid of your child's sexual interest or activity. Yet your child has a right and need to express sexual feelings, in both physical and emotional ways. You may want to protect your child from harm or criticism by the community. You may be afraid of pregnancy, abuse or exploitation of your child. Or you may believe that your child may simply not be capable of managing a relationship that might possibly include sex.

Your child may share your fears, but learning to cope with his or her own sexuality is an important step in the learning process. Obviously, there are real issues to be faced as your child matures. Yet there are no easy solutions.

Happily, there is much more openness today about these issues. Some organizations that work with children and adults with disabilities offer workshops and discussion sessions about sexuality, birth control, rights and privacy, instruction about sex, marriage, having children and parenting. Your child's educational program also may cover some of these topics.

Or, once again, as a parent you may need to find new sources of information that will help you and your child through this time.

Adult Relationships

The problems of day-to-day living which come with a disability are often time-consuming, frustrating and complex. In spite of these daily challenges, there are many people with serious disabilities who not only manage to survive but do so as capable, proud and happy individuals.

The world of a person with disabilities is made up of people — family, friends, teachers, therapists, doctors and brief encounters with strangers. Sometimes it may seem tempting for both the person with a disability and the parent(s) to keep other people out, but no person, disabled or not, can live alone. The interaction of people is important to your child's eventual acceptance as a part of your community.

Once your child reaches adulthood, he or she may want to live apart from you and other family members. There are many safe ways for him or her to do this and the rewards in self-esteem and independence are usually large.

As an adult, the person with a disability will continue to need people, including a supportive family, as well as friends. His or her adult relationships may even include marriage and a family. While it is true that limitations may come from disabilities, it is not true that a person with a disability must be a limited person. This is particularly meaningful when it comes to the relationship of one adult to another.

Employment / Financial Independence

An adult with a disability may have some difficulty in finding or keeping a job, but this is mostly due to the prejudice of employees and/or co-workers. This, too, is changing as more individuals with disabilities enter the work force and function successfully on their jobs.

As mentioned earlier in this guide, your son or daughter has the right to work at a job of his or her choice according to ability. There are many opportunities for employment, many jobs that can be performed easily by a person with a disability. As a parent, you can look forward to a time when your child will be at least partially self-supporting.

Building a Life For Yourself

One of the best things you can do for your child is also the best thing to do for yourself: get on with life. Certainly, you will have to adapt to the demands and needs of a child with disabilities. But that doesn't mean that you must abandon your life as you knew it before you were aware of your child's disability. By making use of the many services available to you, your child and other family members, each person in your family will be better able to lead his or her own life.

Genetic Counseling

If you are thinking about having another child, you may be worried about your chances of having another child with a disability. This is a natural concern that may be removed through "genetic" counseling. A genetic clinic studies the genes in the body's cells. Often a disability is passed from parent to child by a certain gene or found in misformed cells. A genetic study can help parents understand the risks they may take if they decide to have another child. It is then up to the parents themselves whether to have another baby.

There are several genetic counseling centers in Florida. Appointments usually are made by referral from your personal doctor. Or you can make the appointment yourself. Call the HRS District Office serving your county for the name of the center nearest you.

Many parents find that the birth of another child does much to ease the pain and dismay felt when their "special" child was born.

Potential Growth

Not everyone faced with the difficult task of raising a child with a disability is able to manage it. But those parents who continue to work at providing care and affection to their child may receive many rewards for their effort. Perhaps it is not surprising that these rewards are in personal growth and development.

Many parents report the satisfaction they feel when their child succeeds at even a minor task. They tell of their renewed appreciation of the little things in life. Or are reminded of how important their own relationships are. Many parents build warm friendships with other parents of children with disabilities. Many feel that their lives were drastically changed — for the better — by having a child who helped them learn patience, tolerance, acceptance, as well as joy in day-to-day accomplishments. Pleasure in your child's growth and pride in your personal ability to meet the sometimes painful demands of your child's development or health are two more of the rewards you may discover.

The list might well be endless but a final point might be the joy and satisfaction of those parents who, through love and hard work, help their children to adapt and adjust to live happy, fulfilled lives in a difficult world.

Your Contribution to Society

Mr. Don Boyd, the parent of a child who has mental retardation, has described three stages of thinking through which every parent goes: (1) Why did this happen to me? (the stage of self-pity and selfishness); (2) What can I do for my own child and my family? (the stage of facing one's own problem); and (3) What can I do for others? (the stage of working to help others) (French and Scott, 1967).

Most parents arrive at this third or "community consciousness" stage when they realize that they are concerned not only about their own child but also about others who are similarly disabled.

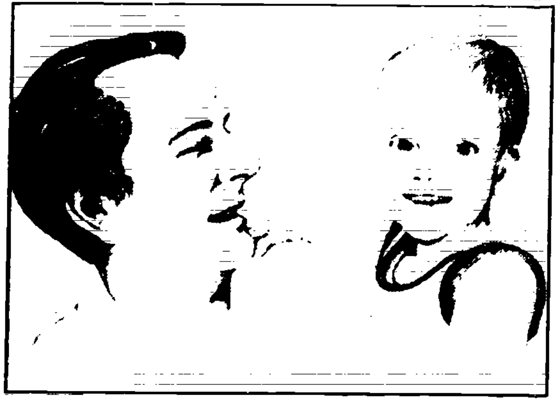
These parents believe that their child's life could be more useful if, because of his or her disability, one small step could be taken to meet the overall problem. This would be the lasting good that comes from and because of their own efforts to help their child.

Many of the books written about disabilities are authored by a parent of a child who is disabled. Much of the legislation which protects the rights of the disabled was written and lobbied for by their parents. Special programs are developed and run by these parents. Organizations are formed, agencies supported, and research is funded by parents of children with disabilities. And there is more, much more.

You, too, may have an important contribution to make. Perhaps that is why you have been entrusted with a child who needs so much. Through this guide you have found many ways to get started on the path to well-being for your child. Remember that all journeys begin with a single step. We hope that this guide will encourage you to take that first step toward your child's future as well as your own.

"Sometimes we are apt to regard as limitations qualities that are actually the other person's strength."

Eleanor Roosevelt in *You Learn By Living*



SECTION 8: APPENDICES

A. Department of Health and Rehabilitative Services / Program Areas

Aging and Adult Services

- Information & Referral
- Abuse Prevention Services
- Senior Activity Centers
- Meals Programs
- Home Health Care and Other In-Home Services
- Placement Services
- Community Care for the Elderly
- Displaced Homemaker Services
- Transportation
- Adult Day Care
- Counseling and Other Support Services

Alcohol, Drug Abuse and Mental Health

- Emergency Counseling
- Inpatient
  - Hospitals — Long- and Short-Term Care
- Outpatient
  - Counseling
  - Partial Hospitalization
  - Day / Night Care
- Consultation and Education
- Screening Assistance to Courts
- Halfway Houses
- Follow-up Care for Discharged Mental Patients
- Specialized Services for Children and Elderly
- Alcohol Abuse
  - Detoxification
  - Evaluation
  - Residential Services
  - Day / Night Care and Treatment
  - Outpatient Services
    - Treatment
    - Counseling
    - Rehabilitation
    - Halfway Houses
- Court and Law Enforcement Liaison Services
- Employee Assistance Programs
- Community Consultation, Education and Prevention Programs

Children's Medical Services

- Clinics
  - Pediatric
  - Specialty
- Referral Centers
- Regional Centers
  - Renal
  - Diabetes
  - Genetics
  - Perinatal
  - Spinal Cord Injury
- Special Statewide Programs
  - Infant Screening
  - Child Abuse
  - Rheumatic Fever

Children, Youth and Families

- Dependency / Delinquency Intake
- Prevention and Diversion Services
- Specialized Family Services
- Protective Services for Children
- Crisis Homes and Emergency Shelter Care
- Child Day Care Services
- Detention (secure and non-secure)
- Commitment Programs for Delinquent Youth
- Residential Centers and Programs
- Non-residential Programs
- Community Control and Furlough
- Mental Health Services
- Adoption and Related Services
- Foster Care

Developmental Services

- Evaluation of persons with —
  - Retardation
  - Epilepsy
  - Cerebral Palsy
  - Autism
  - Other Developmental Disabilities
- Family Counseling and Assistance
- Home Care / Equipment Assistance
- Group and Foster Homes
- Community Facilities
- Intermediate Care Facilities for Mentally Retarded
- Cluster Facilities
- Residential Care — Sunland Centers
- Training and Education Programs
- Vocational Training
- Medical Care
- Transportation
- Counseling
- Day Care

Economic Services

- Aid to Families with Dependent Children
- Food Stamps
- Refugee Assistance Program
- Low-Income Energy Assistance Program
- Disaster Relief
- Supported Work Assistance Program and Work Incentive Program

Health

- Personal Health
- Non-Communicable Disease Services
  - Cardiovascular Disease Services
  - Hypertension Services
  - Diabetes Services
  - Cancer Services
  - Anticonvulsant Medication Services
  - Nursing Care at Home Services
  - Surveillance / Investigations
- Socio-Behavioral Services
  - Health-Risk Reduction Services
- Nutrition Health Services
  - Women / Infant / Children Supplemental Food Program
- Family Planning Services
- Maternal Health Services
  - MIC Projects: Maternal Lay Midwives
- Infrant / Child / Adolescent Health Services
  - Children and Youth Project
  - MIC Project: Infants
  - EPSDT Services
  - School Health Services

  - Special Surveillance
- Adult Health Services
- Dental Health Services
- General Personal Health Services
- Communicable Disease
  - Control Services
  - Immunization
  - Venereal Disease Services
  - Surveillance / Investigations
- General Public Health
- Vital Statistics Services
  - Vital Records Disposition, Certification and Compliance Services
- Environmental Health
  - Consumer Safety
  - Occupational Health Services
  - Consumer Product Safety
  - Emergency Medical Services
- Food Hygiene Services
- Housing Public Facilities and Conveyance Services
  - Group Care Facilities Services
  - Housing and Public Building Safety and Sanitation Services
  - Trailer Park and Camps Services
- Water and Waste Service
  - Private Water System Services
  - Public Drinking Water Services
  - Bottled Water Services
  - Swimming Pool and Bathing Places Services
  - Individual Sewage Disposal Services
  - Public Sewage Services
  - Solid Waste Disposal Services
- Environmental Surveillance / Control Services
  - Sanitary Nuisance Services
  - Rabies Surveillance / Control Services
  - Arbovirus Surveillance Services
  - Rodent Control Services
  - Arthropod Control Services
  - Water Pollution Services
  - Air Pollution Services
  - Radiological Health Services
  - Toxic Substance — Hazardous Materials Services
- General Environmental Health Services

Health Planning and Development

- Comprehensive Health Planning
  - Statewide Health Planning Coordination
  - Planning, Research and Development
- Community Medical Facilities
  - Architectural and Engineering
  - Developmental and Monitoring
  - Regulatory Review and Planning
- Cooperative Health Statistics

Medicaid

- Nursing Home Care
- Pharmaceutical Support
- Medical Care
  - Inpatient
  - Outpatient

Vocational Rehabilitation

- Medical Evaluation
- Vocational Adjustment
- Treatment
- Hospitalization
- Counseling and Guidance
- Artificial Limbs and Appliances
- Equipment for Jobs
- Financial Assistance while in Rehabilitation Program
- Job Placement
- Transportation
- Post Employment Services

B. Reference List

Biklen, Douglas. *Let Our Children Go: An Organizing Manual for Advocates and Parents.* Human Policy Press, Syracuse, 1974

Buscaglia, Leo. *The Disabled and Their Parents: A Counseling Challenge.* Charles B. Slack, Inc.; New Jersey, 1975

de la Cruz, Felix F., and LaVeck, Gerald. *Human Sexuality and the Mentally Retarded.* Brunner / Mazel, Inc.; New York, 1973

French, Edward L., and Scott, J. Clifford. *How You Can Help Your Retarded Child.* J. P. Lippencott Company, Philadelphia and New York, 1967.

Kushner, Harold S. *When Bad Things Happen to Good People.* Avon Books, February, 1973.

C. Florida Statutes Relating to the Rights of Persons with Disabilities

This overview of relevant Florida and federal statutes is designed to provide quick information about the legislatively expressed interest of our government in its citizens with handicapping conditions.

ACCESSIBILITY

Florida Statute 193.623
Provides that any renovation to existing buildings in order to provide access to persons with handicaps shall not increase the property value of that building for ad valorem tax purposes.

Florida Statute 255.21
Provides for all buildings to be used by the general public to be made accessible to persons with handicaps. Prescribes standards for building and remodeling such facilities.

Florida Statute 255.211
Provides that all state-owned buildings be accessible (see 255.21) and display internationally recognized symbol for wheelchair users.

Florida Statute 163.3177(f)4
Provides sites for specialized housing, including group homes, in a comprehensive land use act.

TRANSPORTATION

Florida Statute 234.211
Provides for the use of public school buses to be used by non-profit agencies for the transportation of specified groups.

Florida Statute 236.083(1)
Mandates the transportation of students with physical handicaps to and from school, irrespective of where they live.

Florida Statute 316.1955
Provides for special parking places for certain disabled persons to be provided by governmental agencies

Florida Statute 316.1956
Provides for parking spaces designated for disabled persons by nongovernmental agencies

Florida Statute 316.1964
Exempts certain persons with handicaps from parking fees

Florida Statute 320.0842
Provides free motor vehicle plates to be issued to veterans confined to wheelchairs

Florida Statute 320.0843
Allows for distribution of motor vehicle license plates stamped with the international wheelchair user symbol

Florida Statute 335.075
Provides minimum standards for design and construction of streets; sidewalks; curb ramps; etc

Florida Statute 399.035
Provides for accessibility to passenger elevators to be made for persons with physical handicaps, and for the design of such elevators

Florida Statute 553.45 - 553.49
Defines "physically handicapped person" and provides for accessibility of entrances and exits to certain types of public buildings, defines types of accessibility (ramps, paths, restrooms, etc) and lists modifications and waivers to these requirements

ELECTIONS

Florida Statute 97.061
Provides for special voter registration for persons with disabilities

Florida Statute 97.063(1)(e)(2)(3)(4)(5)(6)(7)
Allows persons with physical disabilities to vote by absentee ballot and gives provisions for such participation

Florida Statute 101.051
Provides for special assistance in voting to certain persons with physical disabilities and specifies procedures for such

Florida Statute 101.715
Provides that all polling and election sites be made accessible to persons with handicaps.

Florida Statute 320.0848
Provides for special parking permits for persons with handicaps

Florida Statute 413.07
Requires traffic to stop for individuals using a white cane or guide dog

Florida Statute 427.011 - .018
Establishes the Florida Coordinating Council on the Transportation Disadvantaged and provides funds to purchase services

EDUCATION

Florida Statute 228.2001
Prohibits discrimination against students and employees in the state system of public education; provides for equality of access to programs and courses, requires the development and implementation of programs to meet special needs and to encourage participation of handicapped individuals

Florida Statute 229.832
Directs the Department of Education to establish regional diagnostic learning resource centers for exceptional students

Florida Statute 229.834
Directs regional learning resource centers to provide services to both public and non-public school students

Florida Statute 229.8361
Establishes the Florida Council for the Hearing Impaired

Florida Statute 230.23
Directs local school boards to provide appropriate special instruction for exceptional students, for exceptional student placement programs, and for parent notification of such placements

Florida Statute 230.2317
Establishes a multi-agency network to provide education, treatment, and residential services to emotionally disturbed students

Florida Statute 230.33
Directs local district superintendents to recommend plans for special education classes, instructors, equipment, and facilities for exceptional students

Florida Statute 232.13
Directs HRS to report to all district superintendents the names and pertinent information for all exceptional children in each district who require special services or programs

Florida Statute 233.056
Provides coordinating unit and instructional materials for hearing and visually impaired students in Florida public schools

Florida Statute 242.331
Establishes the Florida School for the Deaf and the Blind

Florida Statute 959.25
Establishes the Exceptional Child Education Program for youthful offenders and wards of HRS and mandates meaningful compensatory educational programs for them

INSURANCE

Florida Statute 440.49
Establishes a fund to reimburse insurers of employers who hire the handicapped if a handicapped employee sustains an on-the-job injury which is made worse by the existence of a handicap

Florida Statute 626.9541(1)(g)1,2
Prohibits discrimination between individuals of the same actuarial class in rates charged for life insurance, annuities, accident; disability; and health policies

Florida Statute 626.95419(1)(o)5
Prohibits additional charges for and policy cancellation of automobile insurance to those persons with handicaps who have the ability to drive

Florida Statute 626.9705
Prohibits insurers from discriminating against those with severe disabilities. Requires that insurers sell life and / or disability insurance, regardless of severe disability.

Florida Statute 627.644
Provides that insurance companies cannot unfairly refuse health insurance or charge unfair premiums to individuals with handicaps

Florida Statute 627.6486
Provides for the State Comprehensive Health Association to insure all residents, regardless of pre-existing health conditions

Florida Statute 627.6576
Prohibits discrimination against handicapped individuals joining group policies.

EMPLOYMENT

Florida Statute 23.161 - 23.167
The Human Rights Act — forbids discrimination because of any handicapping condition, establishes the Human Relations Commission and defines membership, powers, and functions provides that discrimination in employment is illegal

Florida Statute 110.105
Provides that the employment policy of the State of Florida shall be non-discriminatory.

Florida Statute 110.215
Modifies requirements for examinations conducted by state agencies for visually and hearing impaired citizens

Florida Statute 205.162
Allows exemptions from business licensing requirements for certain persons with disabilities.

Florida Statute 205.171
Allows exemptions for business and occupational licensing requirements for certain disabled veterans

Florida Statute 212.08(7)(h)(2)
Exempts sale or rental of guide dogs and food for such dogs from sales tax in certain circumstances

Florida Statute 240.335
Provides for non-discrimination on the basis of handicapping condition for the granting of salaries to employees of Florida community colleges

Florida Statute 295.07
Provides for preference to be given to disabled veterans for employment

Florida Statute 760.10
Lists all unlawful employment practices, including provisions for hiring and dismissal; compensation, terms and privileges of employment

ACCOMMODATIONS

Florida Statute 196.101; 196.031; 196.202; 295.16.
Allows for homestead exemptions for persons who are totally disabled at certain rates established in the statute; exempts certain property of persons with handicaps from taxation; exempts disabled veterans from certain fees relating to their homes.

Florida Statute 286.26
Provides that all public meetings be made accessible to persons with handicaps.

Florida Statute 413.08
Provides for equal accommodations to all persons with physical handicaps in housing and employment

Florida Statute 413.08(4)(a)(b)(c)
Provides the right to equal housing accommodations to persons with visual or hearing impairments Also provides that these persons have the right to house guide dogs within their property at no extra expense

Florida Statute 413.08(1)(2)
Provides equal privileges and accessibility to any visually or hearing impaired persons to be accompanied by a guide dog on all common carriers, places of public accommodations, or public facilities

GENERAL LEGISLATION

Florida Statute 393
The Florida Retardation Prevention and Community Services Act — includes prevention plans, community care facilities, legal definitions, establishes the Group Living Home Trust Fund

Florida Statute 394
The Florida Mental Health Act — provides definitions and objectives for HRS Mental Health Services; establishes patient rights, facilities, and residential care for disturbed children

Florida Statute 413.011 - .08
Blind Services Program — establishes the Division of Blind Services, provides for records, services, products, and purchases of the division; provides legislative intent, traffic exemptions, equal accommodations, guide dogs; and identification cards for persons with visual handicaps

Florida Statute 413.20 - .504
Establishes the Vocational Rehabilitation Program and provides regulations, administration, benefits and duties and responsibilities of the Department of Health and Rehabilitative Services.

Florida Statute 413.601 - .605
Establishes general rehabilitation programs, programs for persons with spinal cord injuries, nursing home programs, and the Council on Spinal Cord Injuries.

IDENTIFICATION

Florida Statute 322.051
Provides that identification cards be issued to persons who are not licensed to drive a vehicle

Florida Statute 413.091
Provides for identification cards to be issued to persons with visual impairments

D. RELEVANT FEDERAL STATUTES

TITLE XVI — of the Social Security Act of 1935. Provides supplemental financial assistance for persons who are elderly or handicapped.

TITLE XIX — of the Social Secuity Act of 1935. Establishes Medicaid assistance for the care and treatment of persons with low income and serious medical problems

TITLE XX — of the Social Act of 1935 Provides federal funding of such services as day care, special living arrangements, employment programs, counseling, information and referral when no other forms of funding are appropriate.

PL 95-602 — Federal Disabilities Services and Facilities Construction Act. Provides funding for services, facilities construction, protection, and advocacy for persons with severe and chronic disabilities whose needs cannot be met by generic community services.

PL 94-142 — Federal Education for All Handicapped Children Act. Provides funds for states to obtain or provide a free, appropriate education for all handicapped children.

SECTION 504 — Federal Vocational Rehabilitation Act (PL-103). Prohibits discrimination against disabled persons in programs receiving federal assistance, including education, housing, employment, and access to public services.

SECTION 202 — U.S. Housing Act of 1959. Provides direct loans for the construction or renovation of housing facilities to serve elderly and disabled citizens.

SECTION 8 — U.S. Housing Act of 1959. Provides rent subsidies for low income, handicapped and elderly persons.

PL 98-527 — The Developmental Disability Act of 1984 which extends language under PL 95-602.

E. RESOURCES

AUTISM

National Society for Autistic Children
1234 Massachusetts Avenue, N.W., Suite 1017
Washington, D.C. 20005

CEREBRAL PALSY

National Easter Seal Society
2023 W. Ogden Avenue
Chicago, Illinois 60612

United Cerebral Palsy Association
66 East 34th Street
New York, New York 10016

EPILEPSY

Epilepsy Foundation of America
4351 Garden City Drive
Landover, Maryland 20785

GENERAL

The Florida Developmental Disabilities Planning Council
1317 Winewood Boulevard, Building 1, Suite 309
Tallahassee, Florida 32301
(904) 488-4180

National Easter Seal Society for Crippled Children and Adults
2023 W. Ogden Avenue
Chicago, Illinois 60612

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, New York 10605

The Association for the Severely Handicapped
7010 Roosevelt Way, N.E.
Seattle, Washington 98115

Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091

American Coalition of Citizens with Disabilities
1200 15th Street N.W.
Washington, D.C. 20005

National Center for Law and the Handicapped, Inc
1235 North Eddy Street
South Bend, Indiana 46617

LEARNING DISABILITIES

Association for Children with Learning Disabilities
4156 Library Road
Pittsburgh, Pennsylvania 15234

Orton Society
8415 Bellona Lane
Towson, Maryland 21204

MENTAL RETARDATION

National Association for Retarded Citizens
2501 Avenue J
Post Office Box 6109
Arlington, Texas 76011
(817) 261-4961

American Association on Mental Deficiency
5101 Wisconsin Avenue, N.W.
Washington, D.C. 20016

President's Committee on Mental Retardation
Department of Health and Human Services
Office of Human Development Services
Washington, D.C. 20201

Down Syndrome Congress
1640 Roosevelt Road
Chicago, Illinois 60608

PHYSICAL IMPAIRMENTS

American Foundation for the Blind
15 West 16th Street
New York, New York 10011

National Association for the Visually Handicapped
305 East 24th Street
New York, New York 10010

National Association for Parents of the Visually Impaired
2011 Hardy Circle
Austin, Texas 78757

American Speech and Hearing Association
10801 Rockville Pike
Rockville, Maryland 20852

Helen Keller National Center for Deaf-Blind Youth and Adults
111 Middle Neck Road
Sand Point, New York 11050

Gallaudet College for the Deaf
Kendall Green
Washington, D.C. 20002

National Association of the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910

American Cleft Palate Education Association
331 Salk Hall
University of Pittsburgh
Pittsburgh, Pennsylvania 15261

SPINA BIFIDA

Spina Bifida Association of America
343 South Dearborn Street, Suite 317
Chicago, Illinois 60604
(800) 621-3141

For a current list of addresses of organizations that deal with your child's particular disability, write to:

National Institute of Neurological and Communicative Disorders and Stroke (NINCOS)
Office of Scientific and Health Reports
Building 31, Room 8A-06
Bethesda, Maryland 20205

HRS

DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES

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