



EACH OF US  
**REMEMBERS...**

PARENTS OF CHILDREN  
WITH CEREBRAL PALSY  
ANSWER YOUR QUESTIONS



# EACH OF US REMEMBERS... THE DAY WE LEARNED OUR CHILD HAD CEREBRAL PALSY

For some of us, the diagnosis came as a complete surprise. We'd noticed that our baby wasn't doing some things at the same age as other babies we knew, but we thought that, given time, she would catch up. For others of us, the diagnosis of cerebral palsy simply confirmed what we had already suspected: our child had a problem that wasn't going to go away with time.

It didn't matter, however, whether we were surprised or we were somewhat prepared for the diagnosis; the words *cerebral palsy* still came as a shock. The doctor kept on talking but we were numb. If we had known someone with cerebral palsy, our minds were picturing how cerebral palsy had affected that particular child or person. Even if we asked questions, it was hard to remember the answers. Our minds were racing but our hearts were standing still: *"Please, please ... not my baby. Not my little boy. Not my daughter. This isn't happening to me. No, this can't be true. Please—not my kid!"* But it *was* our baby—our son, our daughter—who had cerebral palsy, it *had* happened to us, and sooner or later we had lots of questions to ask about this thing called cerebral palsy—like why, and what, and how.

It also seemed as though we had to learn a new language. The doctors, nurses, therapists and social workers who talked with us used words like "spastic," "quadriplegia," "low tone ... high tone," "choreoathetosis," and "dyskinesia." A list of these and other terms is included at the end of this booklet. You may want to look at it now to help you understand the terms that may have been used in your child's diagnosis, but you won't need to use the list to understand this booklet.

We wrote this booklet because we wanted to share with you what we've learned about having a child with cerebral palsy. We've tried to answer many of the questions we asked in the first few weeks after the diagnosis was made. We hope that you will find it helpful: not only because it answers questions you have but also because it will help you realize that you are not alone as you, your baby and your family get on with the business of raising your child who has cerebral palsy.

**"There's a lot I don't understand...but I do know this. We can give him a good life—and we can make him happy."**

**"I wish I had known then what I know now...that he would have friends, go to school, be invited to birthday parties. I wish I had known how much help there is available and how supportive people would be."**

**"It's taken a long time— but I've reached the point where I feel blessed instead of hurt."**

# GENERAL INFORMATION

## MY CHILD HAS CEREBRAL PALSY. WHAT IS IT?

The words *cerebral palsy* are just that-words. They tell you something you probably already know about your child—maybe he has difficulty holding his head up or maybe her arms and legs are very stiff. “*Cindy was born in a family with a lot of other kids. I started noticing she couldn't sit up or crawl or do anything they were doing. We knew something was wrong, but I didn't want to use that word—cerebral palsy. I still don't.*”

Cerebral palsy is a movement and posture disorder. It is not a disease. Instead, cerebral palsy is a condition that is the result of damage to the brain. The damage is non-progressive, which means that the damage doesn't get worse. As explained in the book *Children with Cerebral Palsy*:

*“Cerebral palsy is a catchall term for a variety of disorders that affect an infant's ability to move and to maintain posture and balance. The injury does not damage the child's muscles or the nerves connecting them to the spinal cord--only the brain's ability to control the muscles.” \**

Although the damage does not get worse, without therapy the effect on the muscles could lead to more stiffness or to less muscle tone.

Cerebral palsy affects somewhere between two and five children out of every thousand. Each year, between 8,000-9,500 babies born in this country have cerebral palsy, and there are 500,000 people with cerebral palsy in the United States today.

Like any children, no two with cerebral palsy are exactly alike. Depending on what portion of the brain was damaged, cerebral palsy might affect only one side of your child's body, or it might affect only your child's arms or just his or her legs. Some children

with cerebral palsy are very stiff: --“*Trying to sit and hold Susan is sort of like trying to fold a skateboard on your lap!*” Other children with cerebral palsy are very loose or floppy; and still others may be a combination of both.

## WHY DOES MY CHILD HAVE CEREBRAL PALSY?

This is a good question that's hard to answer. Cerebral palsy is caused by damage to the brain, but exactly how and why the damage occurred is sometimes difficult to pinpoint.

In fact, in about 50 percent of the children with cerebral palsy, the cause of their cerebral palsy isn't known.

Sometimes there are problems with how a baby's brain

develops before he or she is born. As the baby's brain grows and develops, there may be difficulties in the number of brain cells produced, or there may be problems in the way the different parts of the brain communicate with each other. Brain abnormalities like these are called “developmental malformations,” and what causes them is often not known. They may be caused by genetic disorders, by chromosome abnormalities, or by problems with the supply of blood to the fetal brain as it is developing. If the brain abnormalities involve the portion of a child's brain that controls movement, the result is cerebral palsy.

Other times cerebral palsy is the result of an injury to the child's brain before, during or after birth. These injuries can be caused by premature birth, difficult deliveries, medical complications in the newly born infant, or trauma to the brain.

**“I needed to deal with my own feelings of personal responsibility associated with her prematurity. Was it something I did, or didn't do, or should have done differently? It's part of wanting to know the cause—just like some people want to know the diagnosis.”**

\* Geralis, *Children with Cerebral Palsy*, p. 2

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The damage may be caused by lack of oxygen or poor flow of blood in the brain; by bleeding into the brain; by infection such as with a virus; or by medical complications such as severe jaundice, very low glucose levels or other metabolic disorders.

As a parent, it is natural to want to know as much as possible about what happened and why. Your obstetrician and your child's pediatrician may be able to explain the most probable cause of your child's cerebral palsy, or you and your doctors may need to consult with specialists—neonatologists or pediatric neurologists, or a neurodevelopmental pediatrician—to discover what happened in your child's case.

**“When Aric was born, I thought he was going to grow up to be a wrestler in high school like his Daddy. Now I know he is not going to be a wrestler; he's going to be president of IBM!”**

### IS MY BABY GOING TO DIE?

No, not from cerebral palsy. Cerebral palsy is not fatal. People do not die from cerebral palsy. It is not a disease, and children who have cerebral palsy are not sick. Children with cerebral palsy grow and learn. They attend school, graduate, go to college or pursue vocational training, move out to live on their own, and join the workforce. Adults with cerebral palsy get married, have families and are active members of their communities.

### CAN MY CHILD'S CEREBRAL PALSY BE FIXED OR CURED?

The answer to this question is also no. The actual damage that happened in your child's brain is not something that gets "repaired." Advances in medicine, surgery and therapeutic treatments, however, have made the condition easier to *manage*.

If your child is only mildly affected by cerebral palsy, sometimes the undamaged portions of the brain can take over some of the impaired functions. In most cases, however, you and your child learn to work "around" his or her limitations so that your child can get on about the business of being a happy,

healthy little kid who just happens to have a disability.

### DOES MY CHILD ALSO HAVE AN INTELLECTUAL DISABILITY?

Maybe, maybe not. Although cerebral palsy and a cognitive or intellectual disability may both be present, one is not automatically linked to the other. Instead, like all children, children with cerebral palsy have a wide range of intelligence and school performance. If the learning areas of your child's brain were affected, or if your child's movement or language ability interfere with learning, there can also be school problems. Many children with cerebral palsy, though, have average or above average intelligence and school performance.

### CAN I OR ANYONE ELSE "CATCH" CEREBRAL PALSY?

No, cerebral palsy is not contagious. It is *not* a disease, and no one can "catch" cerebral palsy from someone who has the condition.

A child born without cerebral palsy may "acquire" the condition before the age of five as the result of a head injury, or because of oxygen deprivation to the brain, or from meningitis.

### MY DOCTOR TELLS ME THAT WE WON'T KNOW FOR A WHILE HOW MILDLY OR HOW SEVERELY AFFECTED OUR BABY IS. WHY? WHEN WILL WE KNOW?

Doctors are often reluctant to make predictions because the brain of a very young child has a much greater ability to repair itself than does an adult's brain. Although a very young child may experience movement problems, the undamaged areas of a child's

brain may be able to take over some of the functions of the damaged areas. Also, as your child develops and grows, you may notice changes in how your child uses his or her muscles. In general, by the time

**“I wanted to know, 'Will she get worse?' And I wanted to know how this would affect her mentally.”**

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your child is two or three years old, you will have a good idea of what your child can and cannot be expected to do. This *doesn't* mean that children with cerebral palsy won't continue to improve or make progress in their ability to control their muscles after they are two or three. With help from physical, occupational and speech therapy and special education, they can—and they do!—learn new skills throughout childhood.

### WILL MY OTHER CHILDREN DEVELOP CEREBRAL PALSY? IF WE HAVE ANOTHER CHILD, WILL THAT CHILD ALSO HAVE CEREBRAL PALSY?

Although it has been known to happen, it is rare for more than one person in a family to have cerebral palsy. It is almost never an inherited condition, i.e., one passed on through the parents' genes. Twins might both have this condition, but, just as often, one twin will have cerebral palsy and the other will not. Children already in the family will not develop cerebral palsy, nor is it likely that other children born after this baby will have cerebral palsy. Men and women who have cerebral palsy are no more likely than any other parents to have a child with cerebral palsy.

### WHAT WILL THE FUTURE HOLD FOR MY BABY?

People with cerebral palsy go to school, make friends, have jobs, get married, have babies and raise families, drive cars, compete in sports, and rent apartments or own their own homes. Federal law requires that children with cerebral palsy (or any other disability) be given a free, appropriate public education and that they receive the services they need to help them with problems that affect their ability to learn. Another federal law—the Americans with Disabilities Act (ADA)—prohibits discrimination against children and adults with disabilities. These laws protect your child and your family's civil rights. They are intended to ensure that you and your child have access to places of

**“Mark's in a regular classroom with a full-time aide, and I hear all the time about how well he fits in, how great he's doing, and what a terrific kid he is!”**

public accommodations such as stores, restaurants, movie theaters, museums, day care centers and recreation programs. In addition, the ADA requires that public transportation and telecommunication systems be accessible by people with physical, speech, hearing, visual or cognitive disabilities. This law also prohibits employers from discriminating against qualified persons because they have a disability.

Advances in technology have opened up a whole new world for children and adults with cerebral palsy. Children as young as eighteen months of age are using computers to learn, explore, control and interact with the world

around them. For children with cerebral palsy, computers can be the pencil and crayons, scissors and blocks that help them keep pace with their peers socially, emotionally and cognitively. For instance, children unable to dress themselves can practice dressing a bear on the computer screen—and they can even put the underpants

on over the overalls like any other toddler just learning these skills. Specially adapted computers can become the voice for children who have difficulty speaking, and the vocabulary programmed into these communication devices can be adapted to meet each child's particular needs. Words like "Ernie," "Bert" and "Big Bird" can be added for preschoolers or the word "yuck!" can be added for a five-year-old. Powered wheelchairs and motorized child-sized jeeps and fire engines provide independent mobility for children who have difficulty walking. Many children with cerebral palsy, however, do not need any adaptations at all in order to keep up with the other children in their classroom.

**“Even special, personalized words of contempt can be programmed into the computer—i.e. ‘mommy is a mudface!’ or ‘!# @&.’ Let's face it. Every kid learns to use cuss words.”**

As a result of all these legislative, medical and technological advances, the future for children with cerebral palsy is a lot brighter today than it was even twenty years ago. Men and women who were once "hidden" in residential facilities or nursing homes are now living, with or without assistance, in their own

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apartments or townhouses in their community. Modifications to the worksite coupled with changes in the laws and in employers' attitudes have opened the way for adults with cerebral palsy to hold down challenging, competitive jobs. Exactly how much each child with cerebral palsy will achieve and how independent and self-sufficient he or she will become will vary depending on that child's physical and intellectual abilities, but all children with cerebral palsy now have the potential to lead productive, satisfying and fulfilling lives—just like any other child.

## SORTING IT OUT

### EVER SINCE WE LEARNED THAT OUR BABY HAS CEREBRAL PALSY, MY (HUSBAND/WIFE) HAS BEEN NUMB, ANGRY, SAD, SHOCKED, CONFUSED, WITHDRAWN, FRANTICALLY BUSY....WHAT'S HAPPENING?

What's happening is that you and your spouse—and other family members—are going through a process ... a normal process of understanding what has happened to you and your baby. Each of us responds to the knowledge that our child has cerebral palsy in his or her own way. Your spouse may react very differently from you, and that's OK. Some parents need to ask hundreds of questions right away in order to come to grips with what the diagnosis means for them, for their baby, and for their family. Others need to withdraw for a while and sort out their feelings. It's not unusual for one parent to react in one way, and the other parent to react quite differently. Both parents need permission to cope in his or her own way.

You may feel fiercely protective and intensely loving toward your little one. You may feel angry and resentful that this thing called cerebral palsy happened in your family. At times you will probably feel deeply sad. You may pretend that your baby is not one bit different from any other baby on earth except, of course, that your baby is cuter and sweeter. You may feel numb or that your life has been put on hold. You may find yourself caught up in the "what if's" and "if only's." And you may find yourself experiencing these feelings—sometimes even all of them—in one day!

*"One of the toughest feelings I had to admit was the resentment I felt toward my child. There were days when I think I actually hated her for making my life so difficult ... for taking so long to eat ... for being so heavy ... for having another seizure when I thought*

*we'd finally gotten medication leveled off ... for having to sell my car so we could pay the hospital bills. It isn't a pretty emotion—but I know I'm not the only parent who has experienced it!"*

Perhaps one of the biggest misconceptions is that dads don't feel the same things that moms feel or that they don't have the same need to cope or to talk it out. *"We came home from the diagnosis, and all I wanted to do was talk. But George carried Matt to the garage, hopped on the riding mower, and off they went. Didn't he hear anything the doctor said? I watched for a long time until I saw his shoulders shaking up and down. I knew then that he felt what I was feeling."*

**"As a pediatrician, I know some mothers have stated—not necessarily to me—that their sadness and feelings of being overwhelmed genuinely felt to them like it would drive them to the grave—literally."**

*"I remember getting to know a dad who brought his boys to the program. I was surprised at the tender feelings he had for his twins. He worried about the same things I did: Would other kids be cruel to them? Would they be able to live independently? Why did this have to happen to them? He was so kind and loving and gentle. He was always willing to stop and talk but he never came into the parent center with the moms. Maybe he felt out of place. I don't know."*

All these feelings and reactions are normal and common. It may take a month to accept the fact that your baby has a disability, or it may take several years. Sooner or later, however, the intensity of your reaction will lessen and your life will continue on. You'll have good days, and you'll have rough days...but mostly you'll have ordinary days like any other family. *"I never think about Randy having cerebral palsy unless we're at the doctor or the dentist or the clinic. When we're at home together, he's my son—just a little boy."*

## **SORTING IT OUT**

### **HOW MUCH SHOULD I TELL MY PARENTS AND MY BROTHERS AND SISTERS? WHEN IS THE RIGHT TIME?**

*"My parents didn't respond the way I thought they would, or maybe they didn't respond the way I wanted them to. It took a while before I understood that they wanted for me the perfect life I wanted for my son. Of course they were hurting. They hurt for their child and their grandchild, and they didn't know how to begin making anything better."*

The people who love you and care about you are feeling many of the same emotions you feel...pain, fear, confusion, disappointment, worry. Finding a way to give information without overwhelming your family and friends isn't easy. One family found that any mention of their daughter's disability brought on serious criticism from her grandparents: *"They said we were overcritical of her...we were looking for something that wasn't there...we weren't giving her a chance. It was so hurtful that it got to the point where we stopped telling them she was going to therapy, but 'sneaking off' like that didn't feel right to us. For now, her grandparents know that she's going to therapy but they don't go there with us even though they live near. Maybe they will sometime in the future."*

Some grandparents, aunts and uncles are hesitant at first to pick up, play with or babysit for their granddaughter or nephew with cerebral palsy because they are afraid that they might do something wrong or somehow hurt the baby. Once they learn more about cerebral palsy, the way it affects their baby and what they can do to help out, they are then usually able to focus on the child, instead of the condition.

*"After Jamie was born, my mother would come over and take the other two kids for*

*an afternoon but she never offered to take Jamie. It wasn't until I asked her to sit for all three kids so I could go to a doctor's appointment, that she finally told me she was terrified that something would happen and that Jamie would die! I took Jamie to the doctor's appointment with me, but after that I had Mom come over and I showed her how I take care of him. At first it seemed funny for me to be teaching my Mom how to take care of a baby-she raised four herself-but now when she takes the kids, she takes all three of them. And sometimes she just takes Jamie, so I can do things with the older kids."*

Family members can also become additional "eyes, ears and hands." Your family may surprise you with their resourcefulness as your baby grows and needs certain things- like toys that can be picked up or operated by one hand or play clothes with Velcro closings or elastic waistbands that a 3-year-old can "put on by myself!" One grandfather became so good at adapting toys and furniture to meet his grandson's particular needs that he was "recruited" by a local UCP affiliate to do the same for other children in their early intervention program.

It is helpful to teach grandparents (and other family members) how to recognize progress in youngsters who respond differently from the children they have raised. Unless they learn to wait for responses that may come more slowly and learn to read the subtle signals from your child, they may become frustrated when they don't get the type of responses they've come to expect from all children.

Not all family members respond or react the way you hope or would like. Family members and friends are no different from the rest of society: some are able to accept and help; others can't and don't. If it happens that your friends and relatives are not able to give you and your family the support you need, you still are not alone. Parents of other children who have disabilities are a tremendous resource—a resource you can use regardless of whether or not your family and friends are helpful. We tell you how to contact these families later in this booklet.

**"I wanted support and understanding. Mostly I got sympathy."**

**"There are times when I feel sorry for my son. Then I look at him and I see a typical two-year-old with a smile on his face that I cannot resist."**

## SORTING IT OUT

### HOW CAN I EXPLAIN CEREBRAL PALSY TO MY OTHER CHILDREN SO THAT THEY CAN UNDERSTAND? HOW WILL THEY FEEL ABOUT THE BABY HAVING CEREBRAL PALSY?

Answer your other children's questions as simply and honestly as you can. If you don't know the answer, say so. Children pick up on everything that happens around them, so it's not a good idea to try to "protect" the children from knowing that you are concerned about something. For one thing, it doesn't work: they know something isn't right and that Mommy and Daddy are sad and

**"It's a mistake to cater to your child's disability. It looks so much like favoritism and, to your other kids, it really is a type of favoritism."**

worried. When children aren't told what is happening, they often become more worried or think that they have done something wrong or imagine that something terrible is going to happen to them.

A matter-of- fact statement-- *"the baby has a problem with the way her muscles work and that's why I've been feeling sad and worried"*—followed by an explanation of what is going to happen next-- *"she's not sick and she's not going to die, but she does need extra help to learn how to (crawl, turn over, hold her bottle ...)* so that's why we have been taking her to the doctor a lot " —will relieve your other children's anxiety. Your willingness to talk about what is happening will also make it easier for them to ask you questions and tell you what may be worrying them.

How children feel about having a brother or sister with a disability like cerebral palsy depends a lot on their age. Preschoolers are likely to regard any new baby as a not-so-welcome intruder and resent the demands the infant makes on their parents' time. They may also feel guilty or that they are somehow to blame for the baby having cerebral palsy.

Remember that preschoolers think that the entire world revolves around them—that everything that happens occurs for them or because of them.

School age children may swing from being fiercely and militantly protective to being mortally embarrassed about their brother or sister with cerebral palsy—often in the same day. Again, your willingness to talk about what is happening and your matter-of-fact acceptance of how they are feeling will go a long way toward helping all your children adjust to any situation.

*"I asked my five brothers and sisters how they felt about growing up with a sister who has cerebral palsy. They all said it was no big deal, except that they claimed that I never got punished. (I certainly don't remember that! I think I was just better behaved than they were!) We never had those big family discussions about it—I'm not sure they're so great. I'm sure my parents answered their questions as best they could, but the bottom line was always 'This is your sister and that's how she is.' One of my sisters describes my having cerebral palsy as a 'non-issue.'"*

Remember, too, that your baby with cerebral palsy wasn't born into a vacuum: he or she was born into a family—and the other members of the family have rights and needs too. The happiest and most successful adults with disabilities tell us that their parents had high expectations for them and treated them no differently than any other child. "My mom expected the same from me as from all of my other brothers and sisters. I had to clean my room every Saturday, including dusting the window sill. Mom cut me a break when it came to cleaning in the corners—but I was expected to clean everything else."

The world is not going to end and you are not a horrible, uncaring parent if you modify your baby's routine to fit in with the needs of the rest of the family, including yourself! If it's time to take your four-year-old to a birthday party and your two-year-old's resistance to having his jacket put on is making his arms more spastic than usual, wrap him up in a blanket and go off to the birthday party! You can always put the jacket on when you get to the party, and like any other two- year-old, he'll probably delight in wearing it indoors.

## SORTING IT OUT

### EVER SINCE OUR BABY WAS DIAGNOSED AS HAVING CEREBRAL PALSY, IT SEEMS AS THOUGH OUR FRIENDS ARE TREATING US DIFFERENTLY. AM I IMAGINING THINGS?

Probably not. Your friends, like you, need time to adjust to the fact that your baby has a disability. Like you, they may respond in lots of different ways. Some will bombard you with "helpful" advice about treatment, "cures," diet, and experts. You may get tired of hearing optimistic stories about the cousin who wore braces for a few years and then outgrew the problem, etc. *"I know then that they feel badly and they want to feel better, so I just say, 'That's good to know' or something like that. It lets us all off the hook."* Others will say nothing at all and may even seem to avoid you. *"If they ask how the baby is doing, I tell them.. If they don't, I know they don't really want to know or aren't ready to hear."*

What you don't need right now is the added task of educating your friends about cerebral palsy or helping them deal with their feelings. What you do need is their support—and it will help them help you if you simply tell them what you need: "Will you watch the big kids while I take the baby to therapy?"

"Will you watch the baby while I take the other kids out for ice cream?" and even "I'm not up for company right now, but I promise I'll call you when I'm ready."

One family found that, by setting the tone and going on the offensive, they were able to influence their friends' receptivity. *"I remember when the people at work found out about our son. I had this feeling that they didn't know what to say or do. So I brought my boy to work with me one day so they could all see what a great kid he is. After that, everything was fine."*

Another father began writing poems to his son. All the feelings he had never been able to say aloud came easily in his "talks" with his child. Eventually he shared the poems with his wife, his family, and his close friends. These private "conversations" sparked long, passionate talks as people found they could relate to what he had written. The "conspiracy of silence" had been broken by the relative quiet of a volume of poetry.

*"At Ryan's sixth birthday party, I looked around at all the wonderful people who had stuck by us. The ones who had faced our pain and our fear and our anger. I felt such overwhelming love for them. Ryan may lack some basic skills, but this child has the ability to sift gold from sand."*

### HOW DO I HANDLE IT WHEN PEOPLE SAY THINGS LIKE "WHAT'S WRONG WITH YOUR BABY?" OR "YOU'RE SO SPECIAL" OR "IT COULD BE WORSE" OR "GOD WOULDN'T GIVE YOU SOMETHING YOU COULDN'T HANDLE." THEY MEAN WELL, I GUESS, BUT THEY JUST DON'T UNDERSTAND.

You're right. They don't understand. They don't understand that while it could have been worse, what you're dealing with right now is that it could have been better. They don't understand that you're not special; you're just ordinary people trying to cope with a child who has special needs. And they don't understand that sometimes you may feel like screaming or running away. As for answering the question, "what's wrong with your baby?" or the even ruder statement "hey, there's something wrong with your baby!"—how you answer it depends on how you feel at that particular moment, whether you have time to talk, and even on who is asking the question. It's OK not to answer sometimes or to walk away. You don't have to "be perfect" or "a saint." *"I don't always answer rude adults, but I always answer curious children."*

One couple says that they don't use the term cerebral palsy. They explain that their daughter has a problem that affects her muscles: *"I find that most people have misconceptions about cerebral palsy anyway, so I try to describe Shannon, not cerebral palsy."* They also feel that because there are such wide variations among people with cerebral palsy, just saying that she has cerebral palsy doesn't clarify their daughter's diagnosis for anyone.

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Another couple agrees: *"Cerebral palsy is part of our son's physical being—like the color of his eyes and his hair, but it has nothing to do with his soul—with **who** he is."* One woman feels frustrated when people obviously notice that her son has a disability but do not ask or talk about it. She points out, *"It's unbelievable how little people really know and understand about cerebral palsy. I took Larry to pick up his sister at school, and a woman pointed to his AFO's [lightweight plastic devices worn on a child's ankles and feet to support ankles and/or stretch leg muscles] and said, 'Is that something to hold his socks up?' I couldn't believe it, but I'm glad she asked. It gave me a chance to tell her a little bit about CP."* Another parent might deal with the question by simply saying, "Yes, they hold his socks up" which they happen to do, although that's not the reason they're worn!

However you decide to respond on any particular day, it's important to remember that it is not required that you educate the rest of the world. *"It's OK to tell people that it's none of their business. Although your child's disability is in public view, it is a private issue."*

As you find ways that are natural and comfortable for you to relate to family and friends, don't forget the most important relationship: **the one you have with your spouse.** Moms and dads are sometimes so busy with their children that they forget to talk to each other—or they try to protect one another from intense feelings or fears. When one father first heard the diagnosis, he happened to be alone. He went home and thought about it for a week before he told his wife. *"And I was furious with him for keeping it from me. I didn't want to be protected."* Perhaps because of that start, this couple has shared everything since: *"We set aside 15 minutes at the end of the evening when we talk ... about anything that we're afraid of or worried about or facing. It's the way we keep in touch."*

**"It's OK to have a life! Frantically working on disability stuff doesn't make the disability go away."**

It's important, too, to do some things that have nothing at all to do with cerebral palsy—to go dancing, or pursue your hobbies, or whatever else it is that gives you pleasure. Otherwise, your whole life will become wrapped up in disability.

## ALL OF THIS IS PRETTY OVERWHELMING. HOW CAN I COPE?

As you begin working through your own feelings and helping friends and family adjust, you'll find some coping mechanisms that work better than others. Each of us has his or his own way of coping, and we've found that the ways we cope often change over time. You'll know when a particular method of coping is working for you because the problem or worry should begin to ease up, not intensify.

Talking and sharing is a common coping mechanism. You may find that it helps to talk with family, friends, your spouse, in prayer, or with a counselor. Joining a support group of other parents whose children have disabilities really helps, too. Some of the strategies these other parents have discovered might work for you, too, but even more important is the fact that they are, or have been, exactly where you are right now—and they understand in a way that your best friend, or your father, or your sister simply does not.

It also helps to talk with parents whose child is several years older than yours. Parents whose child with a disability is a year or two older than yours can tell you how to go about getting the services your child needs. They can also share their stories with you: the funny ones, the sad ones, the angry or frustrated ones. They can tell you how they juggled all the demands on their time and energy—and they can be there for you, in person or by phone, when you just want to let off steam or need a boost in morale. If you can't find "experienced parents" to talk to who have a child with cerebral palsy, then talk with parents whose child has spina bifida or Down syndrome or another type of disability.

**"Work was definitely a help to me. I could walk out the door and leave everything behind for a little while. But Cathy was there 24 hours a day."**

## SORTING IT OUT

The details and specifics of each disability may be different, but when it comes to talking about what is going on, parents of kids with disabilities have more things in common than they have that are different. You will want to meet and talk with other parents whose children have cerebral palsy at some time in the not-too-distant future, but what is important right now is to find some parents you can talk with frankly and openly. Having the friendship and support of another parent who has traveled the road before you is a tremendous source of support—and often a wealth of information.

*"I left Molly's classroom in tears one day when another kid snatched a toy away from her. I wanted to grab it out of his little hands and give it back to her. Molly was so defenseless— why didn't his Mom stop him? I felt a little better when I talked to a Mom who'd been through the program a few years before us. She remembered the same thing happening to her child and pointed out that this was pretty typical two-year-old behavior. She said Molly is probably figuring out her own way to deal with it."*

Some parents cope by reading everything they can about their child's disability, attending a class dealing with special education or child development, or by questioning professionals. On the other hand, limiting information to only what you can deal with at one time is also a way of coping.

Sometimes, becoming involved with a project can be a helpful way to cope: *"I liked going to the Center for Sharon's therapy because I always found someone empathetic to talk to. Then Dan started going with me. He found out that they could use standing frames, and he began spending his time there building some for the kids."*

Crying... educating other people ...confronting issues ...going to work ...working around the house ... adapting things for your child to use ...talking about it ... refusing to talk—or even think-about it for a while... all of us have used these ways of coping at one time or another. What's important to remember is that there is no right way or wrong way to cope. Be gentle with yourself, and give yourself time to explore and figure out what works best for you.

## THERE IS SO MUCH I DON'T KNOW ABOUT HAVING A CHILD WITH CEREBRAL PALSY. HOW AM I EVER GOING TO LEARN IT ALL?

No baby comes with an instruction manual or a wear-and-care label attached, but that doesn't mean new parents have to figure it all out for themselves. There are books they can read; doctors, nurses and other professionals they can ask; and classes they can take. They can also compare notes with other parents to see how they handled a certain problem. The same thing applies when your baby has a disability. *"There's no magic or special skill involved, just love, and maybe a little determination!"*

Some helpful books about cerebral palsy in particular, and about disabilities in general, are listed in the bibliography at the end of this booklet. Your child's doctor(s) and other professionals can answer a lot of your questions, and there are a number of early intervention programs available that will help your child make progress. Although you can learn a lot from books and from professionals, not everything you read and learn will apply to your baby. No two kids with cerebral palsy are exactly alike, so it's important to watch and see what happens with your child.

**"What I really wanted was someone who would listen without judging me or my child."**

One of the best ways to learn about raising a child with cerebral palsy is by talking to other parents of children who have disabilities. One way to get the names of other parents whose children have disabilities is by calling the United Cerebral Palsy affiliate closest to you. Another is by contacting the Parent-to-Parent program in your state. The national office of United Cerebral Palsy (800-872-5827) or the National Information Center for Children and Youths with Disabilities (1-800-999-5599) can help you find the UCP affiliate, Parent-to-Parent program, or other organization serving your community.

# WHAT HAPPENS NEXT?

## WE KEEP HEARING TERMS LIKE “HIGH RISK,” “AT RISK,” AND “DEVELOPMENTAL DISABILITY.” WHAT DO THEY MEAN?

When medical personnel use the terms "high risk" or "at risk," they mean your baby has experienced some events that could cause an injury to the brain and affect a baby's ability to function. Some of these risk factors are premature birth; maternal bleeding prior to delivery; premature separation of the placenta from the uterus; very slow fetal heartbeat during labor; difficult and/or prolonged delivery; breathing problems or poor blood flow to a baby's brain after birth; seizures; meningitis or other viral infection; or hemorrhages (bleeding) in an infant's brain. When one or more of these risk factors are present, it is a warning to medical personnel to watch closely to see if the infant has a disability that will affect the way he or she develops. But remember, a risk factor is not an absolute! The term *developmental disability*, as defined by the federal government, means that a child has a disability that began before the age of 22 and is expected to continue indefinitely. Finally, the term *developmental delay* simply means that your child's development is behind other children his or her age and that it takes your child longer to learn new skills.

## OUR DOCTOR TOLD US THAT OUR BABY NEEDS "EARLY INTERVENTION SERVICES." WHAT ARE THEY AND WHAT CAN THEY DO FOR OUR CHILD?

Early intervention services provide that "extra boost" of therapy, education and support that children with disabilities very often need to get on with the process of learning what they need to learn. Babies learn by first figuring out how their bodies move—and then by putting that knowledge into practice by exploring the world around them. When a baby has cerebral palsy, however, it's going to take him or her longer to figure

out how things work. The old "thumb or foot in the mouth" method of exploring how your body works may take a long time to master—or may not work at all— if your arms and legs are very stiff, or very floppy, or move about involuntarily. For instance, babies with cerebral palsy may need specialized seats or positioning devices to help them sit or hold their heads up; or they may need help from physical, occupational and speech therapists to learn how to "work around" the effects of their cerebral palsy.

**“They kept calling her a 'high risk' baby. We thought that meant she was at risk for seizures.”**

**“For about two years after the diagnosis, I used to fall asleep at night without a dream for him. I have so much hope now. So many dreams.”**

Early intervention services are extremely effective in helping babies with cerebral palsy. They can make a significant difference in how your child develops physically, cognitively and socially. "At no other stage of life does a child learn and develop as quickly as he does during the first few years of his life. Through early intervention, infants and young children with cerebral palsy can be helped to develop more normal posture, muscle tone, and movement patterns; they can be taught the movements they will later use in feeding, bathing, and dressing themselves and in doing school work; and they can learn through play and teaching experiences that are adapted to their specific needs."\*

**“Early intervention was the best thing I could have done for Tyler. It was a very positive time in our lives. They didn't take him from me and do something and then hand him back. I was welcome to stay, and we all worked together.”**

In addition to working with your child at an early intervention program or center, you may want to ask an early intervention specialist to observe you and your baby at home. The specialist may be able to give you tips on how to use what you have at home to the best advantage, or to suggest other equipment or adaptations you may be able to obtain.

\* Geralis, op. cit., p. 263

## WHAT HAPPENS NEXT?

Federal law now requires that states provide services for infants and children who have disabilities or who are at risk for developing disabilities. Services provided for infants are called "early intervention services," while children between ages three and five receive preschool "special education services."

Eligibility requirements for early intervention vary from state to state, but most children diagnosed with cerebral palsy qualify for early intervention services.

*"Kelly wasn't diagnosed until she was eighteen months old. When I asked her pediatrician about programs for her, he said*

*there wasn't anything out there—that there wasn't anything to be done. I changed pediatricians ... and now I'd like to take Kelly back and show the first one what early intervention did for her!"*

Early intervention services can include physical and occupational therapy, speech therapy, medical services, social services and infant education. These services are provided in many different ways: in your own home, in an early intervention center, at a clinic—or through a combination of home, center or clinic. To find out how early intervention services are provided in your community, you can check with your child's doctor or contact your school system. You may also call your local United Cerebral Palsy affiliate or other local disability-related organization such as the Easter Seal Society or The ARC (formerly known as the Association for Retarded Citizens). Contact United Cerebral Palsy's national office at 1-800-872-5827 ([www.ucp.org](http://www.ucp.org)); or call the National Information Center for Children and Youths with Disabilities ([www.nichcy.org](http://www.nichcy.org)) at 1-800-999-5599 to find an organization near you.

**EVERYONE—THE DOCTORS, THE THERAPISTS, THE SOCIAL WORKER, THE INFANT TEACHER—KEEPS ON TELLING ME TO DO THIS, OR THAT I MUST DO THAT, OR THAT MY BABY HAS TO HAVE THIS PIECE OF**

**EQUIPMENT, OR THAT THESE ARE THE GOALS FOR THE NEXT FEW MONTHS. WHO'S IN CHARGE HERE? WHO GETS TO DECIDE?**

You are in charge, and you get to decide. It's your baby, after all, and no one knows your little one as well as you do. Furthermore, no one knows better than you do what your family needs or how it works. Babies don't exist in a vacuum; they are born into families, and families, like babies, have their own "personalities," needs and styles. You, as the parent, are the person in charge of your family, and it's your *right* as well as your responsibility to make the people working with you and your baby aware of family routines and favorite family activities like going camping or eating out at restaurants once a week as well as the schedules and needs of other family members- including yourself!

*"Cindy had physical therapy at 1:00 three days a week. I'd pick up her brother at preschool at 11:30, rush home and try to feed them both, drop Randy off at my neighbors where he **wouldn't** take a nap, drive to the Center for therapy, dash back home, pick up Randy who would be overtired and crying, put both kids down for a nap, wake them up at dinner time, try to get Randy to go to bed at a reasonable time (even though he wasn't tired since he'd had a late nap!). The next morning, of course, I had to pry him out of bed to go to preschool—which made him grumpy and irritable. It was awful, and I thought I'd go crazy!"*

*I was so upset one day, that I started crying while Cindy was having PT. The physical therapist asked what was wrong, and I told her. She told me that she thought she could switch Cindy's time with another kid who came for therapy in the morning—and she did! Now, Cindy goes to therapy while Randy is in preschool, and it makes all the difference in the world!"*

When your baby is enrolled in an early intervention program, someone on the program staff may be assigned to be your service coordinator. Your service coordinator could be a social worker, a therapist, a teacher, a nurse, an administrator or, in some cases,

## WHAT HAPPENS NEXT?

parent of a child with a disability who has been trained to work with other parents. His or her job is to help you and your baby get all the services you need. For example, he or she may help you file for insurance, apply for financial assistance or other programs for which you are eligible, or refer you to other programs in your community that might be helpful to you and your family.

Although it is great to have someone helping you figure out what is best for you, your baby and your family, you as parents are the ones who are ultimately in charge. That's why it is important that you *always* feel free to call the service coordinator assigned to your family or, if necessary, someone else at the program- to ask questions about the services your baby is getting, to see if insurance papers or applications for other programs have been filed, or to learn about meetings or workshops that might interest you.

Be persistent. Ask for what you need and, if it seems to be taking a long time to get what you ask for, ask again. Sometimes the answer may be "no" but it is *always* OK to ask. Even when the answer is "no"—because your family or your baby doesn't meet the eligibility requirements, or because a particular service isn't offered by the early intervention program—keep on asking for what you need. If you're turned down one year, ask again next year. Eligibility requirements change; new laws are enacted to respond to public needs; programs add new services; and services become available at other agencies and programs in your community. You may not find out about these changes if you don't ask.

*"I used to worry that I was coming on too strong-that people would see me coming and think 'Oh, no, here she comes again!' But it's not like that, really.*

*We're all trying to do what is best for this little guy, and the teachers don't seem to mind even though we don't always agree."*

It's important to remember that all the people working with your baby are really working for and with you. It doesn't matter who is actually paying their salary—whether it is the insurance company paying for the doctor visits, or the early intervention program paying for the teachers and therapists. You and your child have a right to receive the services provided by these professionals, and it is part of their job to do their best to meet your needs.

## THE STAFF AT THE EARLY INTERVENTION PROGRAM WERE TALKING ABOUT AN IFSP. WHAT IN THE WORLD IS THAT?

Welcome to the "Club"! We promised you that this booklet would not use a lot of technical words or medical terms—and it

doesn't—but parents of children with disabilities very quickly learn to use and recognize a lot of initials! An IFSP is a written plan that spells out the services your child needs to grow and develop as well as the services your family needs to help the process along. The letters IFSP stand for Individualized Family Service Plan. Say that three times quickly, and you'll understand why we call it an IFSP!

**"Parents need to know that their first job is to love their children, to love themselves, and to take care that life does not become such a crusade that it can't be enjoyed."**

As we said earlier, early intervention services are important for children with cerebral palsy or other disabilities. The federal government recognized how important early intervention is and passed a law, Individuals with Disabilities Education Act (IDEA), that supports early intervention services for infants from birth to age three with or at risk for delayed development. Under this law, programs are required to assess your child and determine his or her strengths and needs, plus your family's strengths and needs. Based on this information, goals or outcomes for your baby and your family will be developed, and services planned that will meet those needs and achieve those goals. The assessments should be done

## WHAT HAPPENS NEXT?

both formally and informally. The people evaluating your baby's development should use formal—or standardized—tests, such as the Brazelton Neonatal Behavioral Assessment Scale or the Bayley Scales of Infant Development, to determine what your baby can and cannot do. They should also use informal methods like visiting you and your baby in your

home and asking you and other family members to fill out checklists or answer a series of questions.

Once the assessments have been completed, the results should be shared with you and your spouse, and a time should be set for you

to meet with staff from the early intervention program to develop a plan for meeting your child and your family's needs. You and the other people at the meeting will make up the *team* that is responsible for making the best possible plan to help your baby grow and develop.

The people from the early intervention program who attend this meeting could include doctors; physical, occupational or speech therapists; psychologists; social workers; early intervention specialists or infant teachers; and representatives from other community programs or agencies. Parents have the right to invite anyone *they* want- another family member, a friend, another parent of a child with a disability-to come to the meeting. It's a good idea to bring a "support person" along with you, (especially to take notes) because all those professionals gathered together in one room can be pretty overwhelming! It also helps to have someone else there who knows and sees you, your child and your family in ordinary, everyday life.

Someone from the early intervention program will be the Team Leader who will run the meeting. He or she will either introduce the other people in the room or ask them to introduce themselves. All of you will take turns talking about what your baby can and cannot do easily. If you don't understand something, *say* so! Professionals use a lot of initials, words and

phrases as a sort of shorthand when they talk to each other-and they often forget that the rest of the world doesn't talk like that. Remind them.

*"Sometimes in these IFSP meetings, I start to feel stupid. I don't always understand what these people are talking about, and I feel embarrassed about asking a lot of questions. But then I say to myself, 'if it weren't for me and my kid, they'd all be out of a job!' and I ask questions until I'm satisfied that I know all I need to know."*

Many parents have found it helpful to bring along a "Parents Report" that talks about their child's strengths—how hard she tries to master a certain skill, his sunny disposition, the little games their baby has discovered to play with family members, how the baby always seems to know when it's time for the older kids to come home from school - anything and everything that makes your baby unique. Although the

assessments are supposed to include what your baby does well and although your baby's strengths are supposed to be discussed as well as his or her weaknesses, all too often most of the discussion at this meeting focuses on what your baby *cannot* do and the services he or she

**"Early intervention was like this safe, little cocoon for us. We were surrounded by people who saw the wonderful, positive things Ryan was doing. They encouraged him to do more."**

needs to overcome these problems. This can be very discouraging, to say the least, and having a "Parents Report" with you can help you keep your perspective. Information in your Parents Report can help you suggest ways the professionals can build on your baby's strengths. It can also help them see your child as a whole-instead of focusing only on legs that are too stiff or on an upper body that is too floppy!

As a team all of you will decide which skills your baby needs to learn first. Maybe she is having trouble sucking so her feedings go very slowly. Perhaps your son has trouble sitting up or holding onto toys. Or maybe your "little one" is beginning to weigh "a ton and a half" but isn't able to walk and must be carried everywhere.

## WHAT HAPPENS NEXT?

Appropriate IFSP goals would include help from physical, occupational and speech therapists to increase your baby's ability to use and coordinate his/her muscles; assistance in discovering the most appropriate position to hold the baby while feeding her or the best method of helping your son sit up; therapy to increase your baby's ability to pick up a toy or move around; infant groups where your baby can learn by playing with adapted toys and with other babies; and help in getting the right type of stroller so that the "little big one" doesn't have to be carried all the time.

Other appropriate IFSP goals focus on family needs. You may want to meet and talk on a regular basis with a support group of other parents whose babies have cerebral palsy. Or you may need "time off" from taking care of your baby—to spend time alone with your other children, to spend time alone with your spouse or family members or friends, or to spend time alone—period. (Actually, we *know* you need "time off," and we strongly recommend that you find a support group.) You may also need help in getting financial assistance, medical insurance, transportation, day care, adapting your home, getting specialized equipment and a lot of other

**"I remember they shared information with us about early intervention when we were in neonatal but, at that time, I didn't really think we needed it."**

things. IFSP goals to meet these needs could include a referral to a parents group at the program or elsewhere in your community; respite care in which a trained caregiver is sent to your home to take care of your baby or where you are given funds to hire someone a few hours a week; and assistance from a social worker to help you apply for financial assistance. Think about the things your family needs to make life a little easier. What are your dreams for your child? What are your concerns and worries? Tell the people at the IFSP meeting as much as you can about what you need and want, so that the plan you decide on can be tailored to your baby and your family. Remember, by law, the IFSP is supposed to be family-centered, family- focused and family-friendly.

Someone at the meeting will be taking notes on all the goals suggested for your child as well as writing down all the services your child and family will need to receive in order to achieve these goals. The person assigned to take notes could be the Team Leader or another one of the professionals, or it could be the support person you've invited to attend the meeting with you. At the beginning of the meeting, you'll be asked to initial the IFSP form to show that you were present. At the end of the meeting, after the goals have been written out and the services needed to achieve these goals have been listed (including the dates when the services will begin and how long they will continue), you will be asked if you agree with the plan made for your child.

If you agree, you will be asked to sign your name on the form. You *do not* have to sign the form

*that day.* This whole process—meeting all the people on the team, hearing about what they have observed about your baby, and listening to all of their suggestions—can be pretty confusing. It's perfectly OK to take a day or so to think about what you've heard before "officially" signing the IFSP. One experienced parent points out that she has made it her policy to *"never to sign off on the day of the meeting. Even when I get every single thing on my 'wish list', I still don't do it. I need time to think about what's best for my kid and what works for my family. So I take my copy of the form home and think about it that night and, so far at least, I've gone back in the next day or so and made it official."*

Even after you've signed the IFSP and your child's early intervention services have started, your IFSP can be changed. The law requires that the IFSP be reviewed every six months, but you can request a review at any time if your needs or your child's needs change.

**"I was looking for answers, so I kept asking questions. When I didn't get definitive answers, it made me angry. I finally realized that the doctors and specialists don't always know."**

## WHAT HAPPENS NEXT?

### HOW DO I GET HELP TO PAY FOR MY BABY'S THERAPY AND EQUIPMENT?

What you will need first are written prescriptions or plans for each therapy your child needs (for instance, speech, occupational, and/or physical therapy). You will also need a prescription for each piece of equipment (for example, ankle-foot orthoses or a special stroller with seating and positioning inserts). Then, with these papers in hand, you can tap into a funding stream that may pay for it. Some programs that fund medically necessary equipment and services are described below. Most of these programs have eligibility requirements that depend on your income and/or on the extent of your child's disability. Your service coordinator, social worker, medical providers or early intervention staff can help you identify programs for which you may be eligible. Even if you don't think that you and your child meet the eligibility requirements, it's a good idea to apply anyway. Eligibility requirements change, and your child might become eligible in the future. If you haven't applied, however, there is no way the agency can locate you to tell you that your child has become eligible for funding or services. Also, because eligibility requirements may change and because new programs are created, it's a good idea to check with the funding agencies at least once a year to see if you now qualify or if there is a new program or service for which you might be eligible.

**"They told us he would be severely handicapped, but I was seeing really good things.... cooing, giggling, responsiveness to me and his brothers."**

### Health Insurance

Your employer can provide you with information about your insurance coverage—or you can call your insurance provider directly to obtain written information about what benefits your health insurance policy provides. Ask about limits or "caps" on the amount of money your insurance will pay for treatment of certain conditions. Some insurance plans have a "lifetime" limit or maximum amount they will pay; once that has been reached, no further insurance payments will be made regardless of

medical need. If your insurance plan has a cap of, say, \$250,000 as a lifetime maximum, you may want to find other funding sources for your child's therapy and equipment and save your insurance to pay for on-going chronic health problems.

If your insurance provider denies you payment over the phone, ask for the denial in writing. Then, with the written denial in hand, you can go to another funding source, such as your state's Early Intervention Program, or to a state agency to see if they will cover it. You can also file a complaint with your state's Insurance Commissioner and ask that the denial be investigated; it may turn out that your claim *should* have been paid.

If you are applying for health insurance or you are changing from one health insurance provider to another because you have changed employers, check the insurer's benefits with regard to "pre-existing conditions." Some health insurance policies will not cover costs related to conditions (like cerebral palsy) that were in effect before you enrolled in their insurance plan—and some will not cover the person with a pre-existing condition at all. Other policies require a lengthy waiting period (usually 12 months) before they will pay for costs related to the pre-existing condition. In order to provide insurance for persons with pre-existing conditions, some states offer "high risk" insurance pools or have *open enrollment* plans. Contact your State Insurance Department for information and assistance on your state's insurance laws, rights and companies.

### SSI Eligibility: Children

As soon as your child has been diagnosed as having cerebral palsy, you may want to consider applying for Supplemental Security Income (SSI) for your baby. SSI is a federal cash assistance grant that makes monthly payments to eligible individuals. You can get an application and make an appointment for an interview at your local Social Security Administration office. Call 1-800-772-1213 [Voice] or 1-800-325-0778 [TTY] to be connected to the office nearest you, or look in the phone book under United States Government, Social Security

## WHAT HAPPENS NEXT?

Administration ([www.ssa.gov](http://www.ssa.gov)). Eligibility for SSI depends on your family income and assets *and* on the degree of your child's disability. You will need documentation from a physician about how severely your baby's cerebral palsy affects his/her ability to function independently, appropriately, and effectively in an age-appropriate manner.

Even if you don't think you are eligible on the basis of your child's disability or because of your income, it's probably a good idea to file an application anyway and go to the eligibility interview. Furthermore, if your application is turned down—and your income is not too far above the SSI income cutoff level or your child's cerebral palsy keeps him/her from doing most of the things other babies the same age do—you should probably appeal the ruling. Many families have had to appeal two or three times before their child was deemed eligible to receive SSI. Another reason for making and keeping the appointment with your local Social Security Administration (SSA) office is that, if your appeal is granted, SSI payments are made retroactive to the *date of your first appointment* with the SSA office. This means that you will receive a check covering the payments you would have received if they had started on the date of your first appointment with SSA.

If you are found to be eligible for SSI, in all but 12 states, your child is automatically eligible for Medicaid. Medicaid is a joint state-federal health insurance program. (Sometimes you will hear people talk about “Title XIX” or “Title 19” or “M.A.” or Medical Assistance (or Medi-Cal in California)—this is the same thing as Medicaid.) Pregnant women and newborn babies up to the age of one year with incomes equivalent to 133% of the federal poverty index are eligible for Medicaid. As of early 2002, 133% of the federal poverty index is an income of approximately \$23,475 for a family of four (higher in Alaska and Hawaii). Some states offer what is called a “*Katie Beckett*” waiver for families whose income is too high to be eligible for Medicaid *but* whose child would have to be placed in an institution unless he or she receives an intensive level of services and supports in order to stay at home. Ask your Medicaid agency if your state offers a “Katie Beckett” waiver

and if your child qualifies.

### EPSDT (Early Periodic Screening, Diagnosis and Treatment)

EPSDT is a Medicaid program to identify and treat health problems faced by children from birth to 21 years of age so that illness or more serious difficulties can be prevented through early intervention. EPSDT provides treatment and other measures, such as physical, occupational and speech therapy, as well as the equipment needed to correct or ameliorate any physical or mental “defects” or chronic conditions identified through the screening. EPSDT can cover eyeglasses, hearing aids, wheelchairs, braces and orthoses, augmentative communication devices, environmental controls etc. Contact your local Medicaid office to learn more about EPSDT.

### Programs for Children with Special Health Care Needs

Under the Maternal and Child Health Programs ([www.amchpl.org](http://www.amchpl.org)), states receive federal funds to provide rehabilitation services not otherwise covered by Medicaid for children under the age of 16. The goal of this program is to promote family-centered, community-based, coordinated care for children with special health care needs. Services under this program are provided on a sliding-scale fee.

### Part H of IDEA (Individuals with Disabilities Education Act)

The federal government recognizes the importance of early intervention services for infants and toddlers with disabilities and their families. Through Part H of the Individuals with Disabilities Education Act, the federal government provides funds for states to coordinate a wide array of early intervention services for children between the ages of birth through 36 months and their families. As part of this program, a service coordinator will help you get the services, family support, equipment and other things your family and your child need. This program is still in its early stages and may not yet be fully implemented in your state. Contact your state's Parent Information

## **WHAT HAPPENS NEXT?**

and Training Program ([www.taalliance.org](http://www.taalliance.org)) to check on the status of the Part H Early Intervention Program in your state.

### **United States Tax Code**

Medically- necessary expenses paid for out-of-pocket (not paid for or reimbursed by insurance) can be deducted from your federal income tax when they exceed 7.5 percent of your adjusted gross income. Medical expenses can include fees for visits to the doctor; prescription drugs; purchases of medically necessary equipment and devices; transportation costs (including round-trip mileage) for trips to the doctor, clinic or therapists; hotel/motel costs for medical treatment that requires an overnight stay; and the cost of insurance, including after-tax employee contributions to employer health plans. See your tax advisor for information and assistance in taking this deduction.

# GLOSSARY

**ADAPTIVE EQUIPMENT** - Equipment offering special support which is adapted to your child's special needs.

**AFO (ANKLE FOOT ORTHOSES)** - A short leg brace worn inside the shoe which extends up to the calf. Made of lightweight plastic.

**AMBULATORY** - Having the ability to walk.

**ASPHYXIA** - Lack of sufficient oxygen and circulation of the blood resulting in possible brain damage and a loss of consciousness.

**ASYMMETRICAL** - When one side of the body differs from the other.

**ATAXIC** - Having unbalanced, jerky movements.

**ATAXIA** - A condition in which damage to the cerebellum results in an unbalanced gait.

**ATHETOID** - Having involuntary or uncontrolled writhing movement.

**ATONIC** - Relating to lack of normal muscle tone.

**AUGMENTATIVE COMMUNICATION** - The use of signs, gestures, pictures, communication boards or computers to supplement a child's ability to speak.

**BITE REFLEX** - A reflex which causes an infant to close his mouth tightly; for example, when his gums or teeth are touched.

**BRAIN STEM** - Portion of the brain between the cerebellum and the spinal cord.

**CENTRAL NERVOUS SYSTEM** - The brain and spinal cord. The part of the nervous system primarily involved in voluntary movement and thought processes.

**CEREBELLUM** - Part of the brain that helps coordinate muscle activity and control balance.

**CEREBRAL PALSY** - A movement and posture

disorder resulting from a nonprogressive defect of the brain (brain damage).

**CHOREOATHETOSIS** - A form of cerebral palsy which causes variable muscle tone and involuntary movements of the limbs.

**CLONUS** - Rapid, rhythmic movements (alternate muscle relaxation and contractions) which result from spastic muscles.

**CONGENITAL** - Present at or before birth.

**CONTRACTION** - Momentary tightening or shortening of a muscle.

**CONTRACTURE** - Shortening of muscle fibers resulting in a decrease of joint mobility.

**DEVELOPMENT** - The process of growth and learning during which a child acquires skills and abilities.

**DEVELOPMENTAL DISABILITY** - A handicap or impairment beginning before the age of twenty-two which may be expected to continue indefinitely and which causes a substantial disability.

**DEVELOPMENTALLY DELAYED** - Having development that is slower than normal.

**DIPLEGIA** - A type of cerebral palsy in which spasticity primarily affects the legs.

**DYSKINESIA** - A general term for involuntary movements.

**DYSTONIA** - Slow, rhythmic, twisting movements.

**EARLY INTERVENTION** - The specialized way of interacting with infants to minimize the effects of conditions that can delay early development.

**EQUINUS** - Walking on toes due to a shortening of the calf muscles.

**EXPRESSIVE LANGUAGE** - The ability to use

## GLOSSARY

gestures, words, and written symbols to communicate.

**FINE MOTOR** - Relating to the use of the small muscles of the body, such as those in the face, hands, feet, fingers, and toes.

**FLOPPY** - Having weak posture and loose movements.

**FLUCTUATING TONE** - Having a combination of low and high muscle tone.

**GAG REFLEX** - A reflex that causes a child to gag or choke when his palate or tongue is touched.

**GENETIC** - Inherited.

**GROSS MOTOR** - Relating to the use of the large muscles of the body, such as those in the legs, arms, and abdomen.

**HEMIPLEGIA** - A type of cerebral palsy in which only the right or left side of the body is affected.

**HYPERTONIA** - An increased tension or spasticity of the muscles. High tone.

**HYPOTONIA** - Decreased tension of a muscle. Low tone.

**INTELLECTUAL DISABILITY** – Children with an intellectual disability learn more slowly than other children, but having an “intellectual disability” does not indicate a specific level of mental ability. The level of mental function may not be identifiable until a much later age.

**INTRACEREBRAL** - Within the brain.

**INTRACRANIAL** - Within the skull.

**INUTERO** - Referring to the period during fetal development.

**INVOLUNTARY MOVEMENTS** - Uncontrolled movements.

**I.Q. (INTELLIGENCE QUOTIENT)** - A measure of cognitive ability based on specifically designed standardized tests.

**KAFO (KNEE ANKLE FOOT ORTHOSES)** - A long brace of lightweight plastic with hinges at the knee joint which offers support to the whole leg.

**KINESTHETIC** - Relating to the ability to perceive movement.

**LEARNING DISABILITY** - Difficulty processing certain types of information in a child with normal intelligence.

**LOW TONE** - Decreased muscle tone.

**LOWER EXTREMITIES** - The legs.

**MONOPLÉGIA** - Type of cerebral palsy in which only one limb is affected.

**MOTOR** - Relating to the ability to move oneself.

**MOTOR DELAY** - Slower than normal development of movement skills.

**MOTOR PATTERNS** - The ways in which the body and limbs work to make sequenced movement.

**MUSCLE TONE** - The amount of tension or resistance to movement in a muscle.

**NEUROMOTOR** - Involving both nerves and muscles.

**OCCUPATIONAL THERAPIST (OT)** - A therapist who specializes in improving the development of the fine motor and adaptive skills.

**ORTHOTICS** - Lightweight devices made of plastic, leather, or metal which provide stability at the joints or passively stretch the muscles.

**PHYSICAL THERAPIST (PT)** - A therapist who works with motor skills.

**POSTURE** - Positioning or alignment of the body.

## GLOSSARY

**PRIMITIVE REFLEXES** - Early reflexes that usually disappear after about six months of age.

**QUADRIPLEGIA** - A type of cerebral palsy in which the whole body is affected.

**RANGE OF MOTION (ROM)** - The degree of movement present at a joint.

**RECEPTIVE LANGUAGE** - The ability to understand spoken and written communication as well as gestures.

**REFLEX** - An involuntary movement in response to stimulation such as touch, pressure, or joint movement.

**RIGIDITY** - Extremely high muscle tone in any position, combined with very limited movements.

**SCISSORING** - Crossing legs together when standing or being held upright.

**SEIZURE** - Involuntary movement or changes in consciousness or behavior brought on by abnormal bursts of electrical activity in the brain.

**SPASTIC** - Having increased muscle tone (stiff muscles) resulting in difficult movements.

**SPEECH/LANGUAGE PATHOLOGIST** - A therapist who works to improve speech and language skills, as well as to improve oral motor abilities.

**TACTILE** - Relating to touch.

**TACTILE DEFENSIVENESS** - Abnormal sensitivity to touch.

**THALAMUS** - A portion of the brain involved in refining movement of the muscles.

**THERAPIST** - A trained professional who works to overcome the effects of developmental problems.

**TONGUE PROTRUSION REFLEX** - A reflex that causes the tongue to forcefully push food out of the mouth.

**TONIC** - Having continuous increased muscle tone.

\* The Glossary reprinted here has been excerpted, with permission, from the Glossary appearing in *Children with Cerebral Palsy: A Parent's Guide*, Elaine Geralis, editor; Woodbine House, 1991.

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## LET'S BE FRIENDS!

### HOW TO COMMUNICATE WITH PERSONS WHO HAVE DISABILITIES

1. Treat your friends who have disabilities just like you would any other friend.
2. When you talk for more than a few minutes with a friend who uses a wheelchair or crutches, sit down in front of the person so you are at eye level. This way your friend won't have to lean his or her head way back in order to see you.
3. If your friend has trouble seeing, remember to say your name when you talk to them the way you would if you called them on the phone: "Hi, Mary. It's Sandy." When a bunch of you are talking in a group, it's a good idea to say each person's name when you talk to him or her. This way your friend can tell who's saying what.
4. If you want to talk to a friend who has trouble hearing and your friend isn't looking at you, tap your friend on the shoulder or wave your hand. Look directly at your friend and speak clearly and slowly.
5. Some people who are deaf or who have trouble hearing can understand what you are saying by watching how your lips move. This is called lip-reading. For your friends who lip-read, make it easy to see your lips. Keep your hands and food away from your mouth when you are speaking.

Some people who have a problem with hearing use their hands to talk. This is called signing or sign language. Ask your friends who use sign language to teach you how to sign some words.

6. Listen carefully when you're talking with a person who has a hard time speaking. Be patient and wait for your friend to finish.  
  
Never pretend to understand if you can't. Instead, repeat what you did understand and wait for your friend to say more. After a while, you will be able to understand easily what your friend is saying.
7. Leaning or hanging on a person's wheelchair is a lot like leaning or hanging on a person and might bother him or her.
8. Before you help people who have a disability, ask if they want or need help. If they say "yes," ask how you can help and then do what they tell you.
9. When you meet a person with a disability, it is OK to shake hands. People who have trouble using their hands or who wear an artificial hand or arm can usually shake hands. (Shaking hands with the left hand is OK, too.)
10. Relax. Don't be embarrassed if you say something like "See you later" or "Did you hear about this?" or "Let's take a walk" when you know that your friend can't really see, or hear or walk. It's OK; they know what you mean.

**Each of Us Remembers...** was written by parents of children with cerebral palsy who want you to know that you are not alone. The book began with a Parent Focus Group who talked about what they really wanted and needed to know when they first learned that their child had cerebral palsy. The members of this Focus Group include Sue and Dave Burdicko, Kevin and Amy Cook, Mimi Hunt, Patti Leventhal, Kathy Landin, Tina Murray, Barbara Revay, and Jeff and Traci Schwartz.

Others, including adults with cerebral palsy, read and commented on the book, adding their own stories and perspectives. Many of these are also parents of children who have cerebral palsy or another severe disability: David Bauer, Jim Hollahan, Sharon Meek, Helen Reisner, Jenifer Simpson, Fran Smith, Leon Sternfeld, M.D., Bonnie Wooten Webb and Sally Weiss, United Cerebral Palsy Associations, Inc.; Andrew J. Baumgartner, Margaret Bayles and Karen Rehm, UCP of the North Shore (MA); Peter A. Blasco, M.D., Center for Children with Chronic Illness and Disability; Philippa H. Campbell, Ph.D., Family Child Learning Center (Tallmadge, OH); Judy Howard, M.D., UCLA Intervention Program; Donna Roberts, UCP of [Greater] Indiana; and Lory Valuet, UCP of MetroDetroit.

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