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## Chapter 15

# Support for Parents and Caregivers

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**A**s a parent or caregiver of a young child who is blind, you need support and information that is useful for your family and your community. Although families and communities are different around the world, many of the challenges of taking care of a young child who is blind or cannot see well are the same, no matter where you live. This chapter talks about how many families in different places:

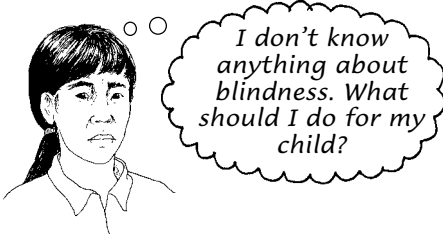
- feel when they learn their child is blind or cannot see well
- cope with the extra responsibility of having a blind child
- join together to support each other and to improve the lives of their blind children
- work as a group to get their community to support children with disabilities

As with the rest of this book, the information in this chapter is for you to adapt for your family and community.

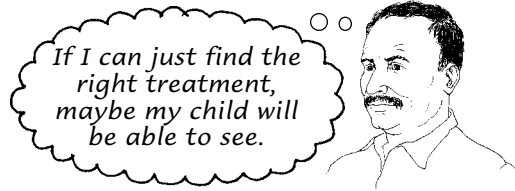
## When you first learn your child cannot see well

Learning that a child cannot see well or is blind can be very upsetting for parents and family. It is normal to feel upset by the news of your child's disability and to continue to feel different emotions in the months that follow. You and your family may feel:

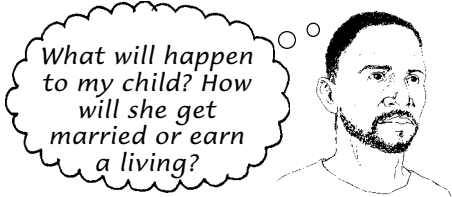
- worry about what to do



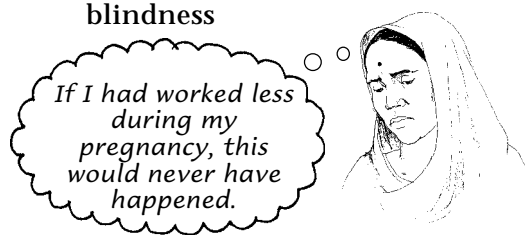
- denial (refusal to believe that your child will never see as well as other children)



- fears of what it means to be blind and fears about the future



- guilt about what you might have done to cause the blindness



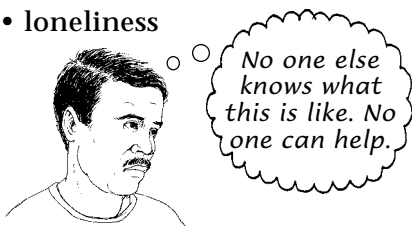
- sadness, helplessness, or no feelings at all (depression)



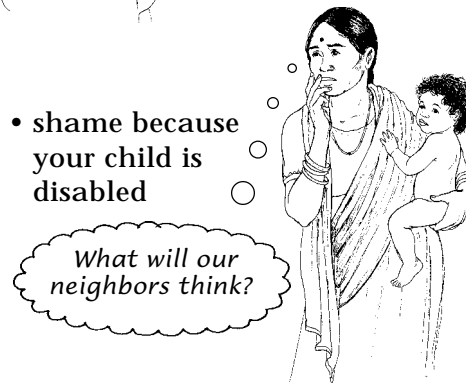
- anger at what has happened



- loneliness

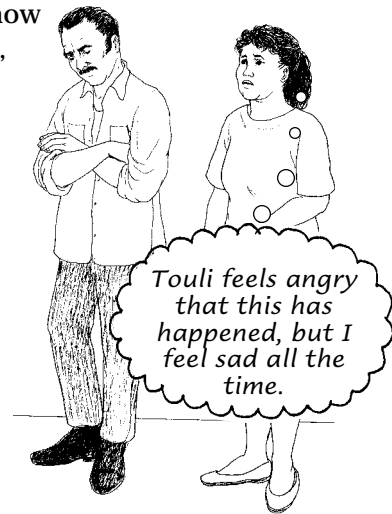


- shame because your child is disabled

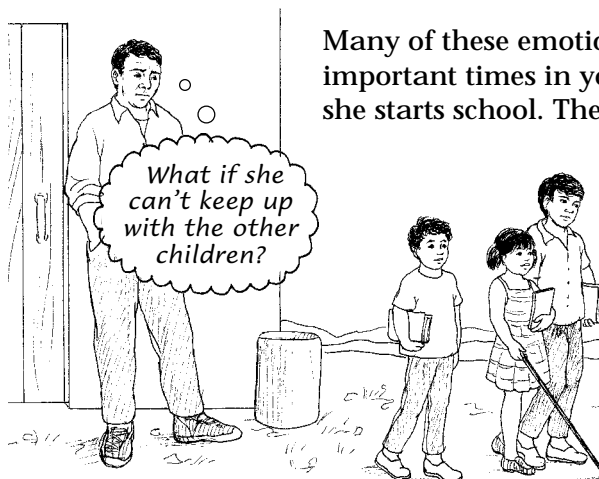
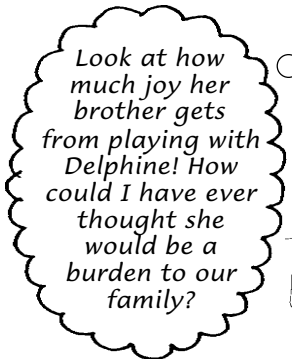


As a parent, you may find it comforting to know that these strong emotions can help you cope, and at the same time can help you begin to take action to help your child. For example, denial may keep you from feeling overwhelmed by the sudden changes in your life. Some parents say that anger or frustration has given them energy to help their child and to reach out and help other families of children with disabilities.

You, your partner, and your family will probably feel some of these emotions and react to them in different ways. It is best to let each person feel the emotions in his or her own way, without judgment.



These emotions will slowly become less strong. Over time, you will begin to realize that your child has the same needs for love, affection, discipline, and learning as other children. And, like all children, she will give you much support, pleasure and joy. The fact that she cannot see well will become less important.



Many of these emotions will probably return at important times in your child's life, like when she starts school. The fact that they come back does not mean something is wrong. It just means that you are going through another period of adapting to your child and her disability. Usually the emotions will be less strong than the first time you had them.

## Managing the stress of caregiving

All parents and caregivers need to find ways to manage stress. Parents and other family members work very hard caring for young children.

If one of the children cannot see well or is blind, then there is even more work.

Besides caring for the child, family members also need to be teachers, to help their child learn what other children naturally learn through sight.

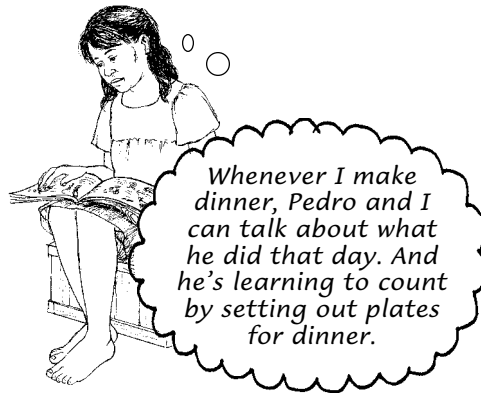
At times it can be difficult to cope with this extra work. Here are some suggestions from families about different ways that have helped them manage:



### BE REALISTIC

Try to be realistic about how much time you and others can spend working with your child.

Try adapting activities so they fit more easily into your daily life and take less time.



Try breaking large tasks into smaller, easier tasks. This way you will see progress and not get discouraged.

I want Pradeep to learn to dress himself.



Why not teach him one thing first - like how to take off his shirt?



## CARE FOR YOURSELF

Everyone needs time for themselves once in a while. But often parents do not take any breaks because they have so much work to do. If you get so tired that you do not feel well, then you cannot help your child.

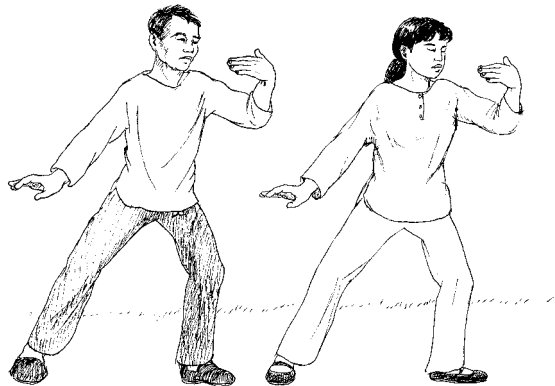


To help yourself relax, take some slow, deep breaths. Try not to think about all the things you have to do, just for a while.



**meditation**

Many communities have developed beliefs and traditions that help calm the body and mind, as well as build inner strength. Practicing these traditions may help you take care of yourself.



**tai-chi**

### TALK WITH YOUR FAMILY

Everyone in a family plays a role in a child's life. Each person caring for a child, especially one with special needs, may have different

ideas about the best way to raise and help that child. It is important to find time to talk together. This will help everyone understand how others feel. And if one of you is feeling tired or discouraged, the others may be able to help.



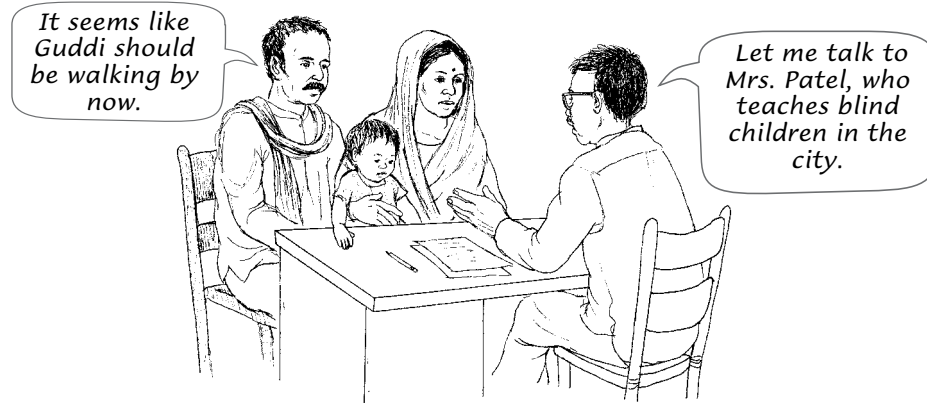
### ASK OTHERS FOR HELP

You do not need to do all the activities with your child by yourself. Everyone in the family can help — so can friends and neighbors.

If you are feeling tired or discouraged, often just talking with another person can help. Try to find someone you can talk with often.



Talk to a blind adult, a health worker or school teacher, or someone who teaches children who are blind. This will be especially helpful if your child does not seem to be learning new skills after several months.



## The power of parents working together

Working with other parents of children with disabilities can help in many ways. Working together can provide an opportunity to:

- share feelings and information
- give each other ideas about activities to help the children and the best ways to adapt activities for a particular child
- share ideas to help fit a child's activities into family and community life
- work together to make the community more friendly, safe, and supportive for children with disabilities



If you know there are other parents like you, but there is no parents group in your area, you may decide that it is up to you to start one. Some of the strongest, most active parents groups began because of one person's idea. As a group, parents can work together to solve problems. Parents working together can do more than if they each work alone.



*Our group sent someone to talk with the National Association for the Blind in the city. Now a field worker who knows about blindness comes to some of our meetings.*

## STARTING A GROUP

Find 2 or more parents who want to start a group. If you do not know other parents whose children cannot see well, you may want to include parents of children with other disabilities. A health worker may know of parents in nearby communities.

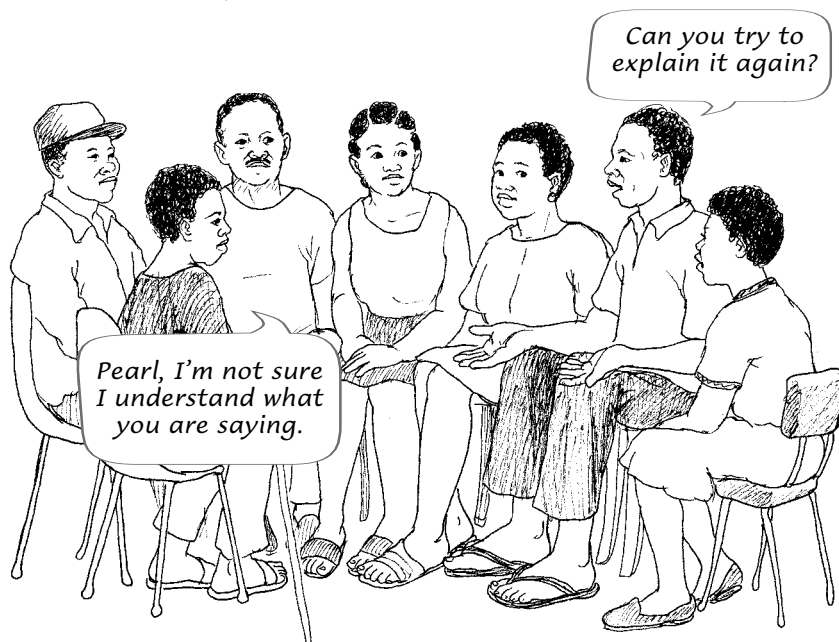
Plan when and where to meet. It helps to find a quiet place, like a school, health post, cooperative, or place of worship. At the first meeting, discuss why you are meeting and what you hope to do.

Probably one person will be the leader of the first few meetings. But it is important that no one person makes decisions for the group. Everyone should have a chance to talk, but try to keep the discussion focused on the main reasons for the meeting. After the first few meetings, take turns leading the group. Having more than one person lead each meeting will help shy members participate.

## LEARNING TO SUPPORT EACH OTHER

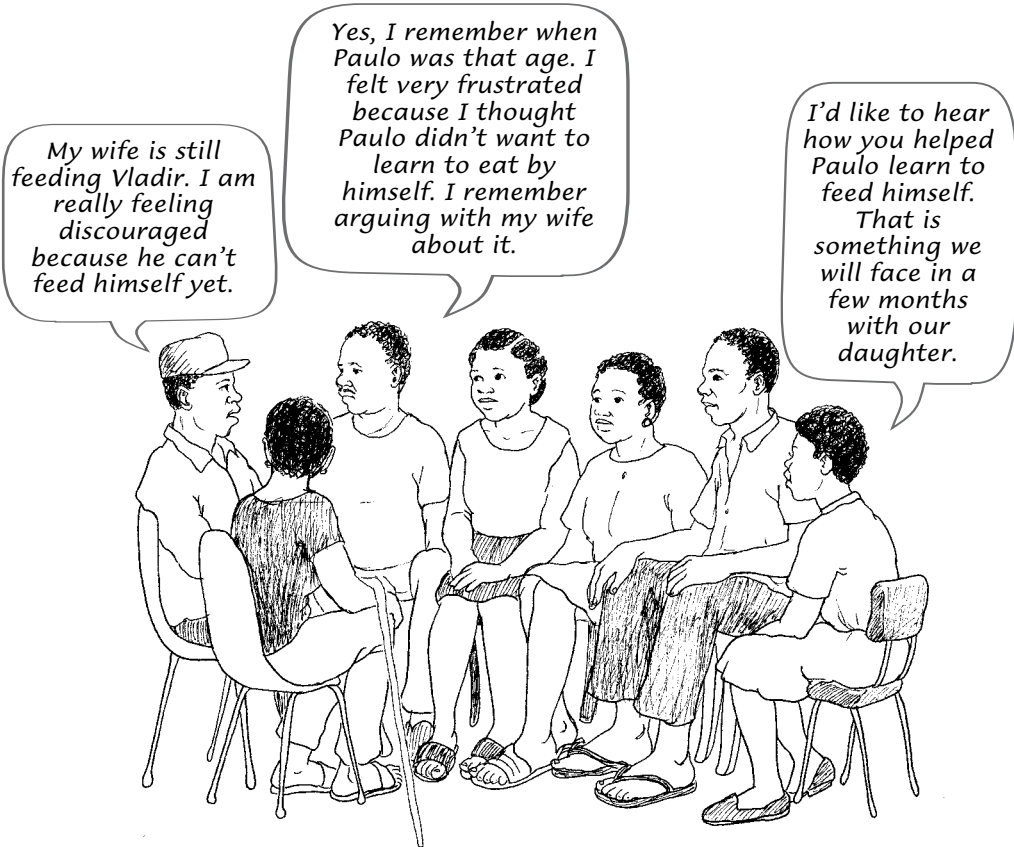
Even when parents know each other well, it may take time to feel comfortable talking about feelings, experiences, and the challenges of raising a child with disabilities. These things take practice. Here are some suggestions for helping group members feel comfortable and trust one another:

**Listen carefully to what others say, without judging it.** Think about how you want others to listen to you, and then try to listen to them in the same way.





**Try not to tell other people what to do.** You can help others understand how they are feeling, and share your own experiences. But everyone must make their own decisions about the best way to care for their children.



**Respect each person's privacy.** Never tell others what the group talks about unless each person says that it is okay.



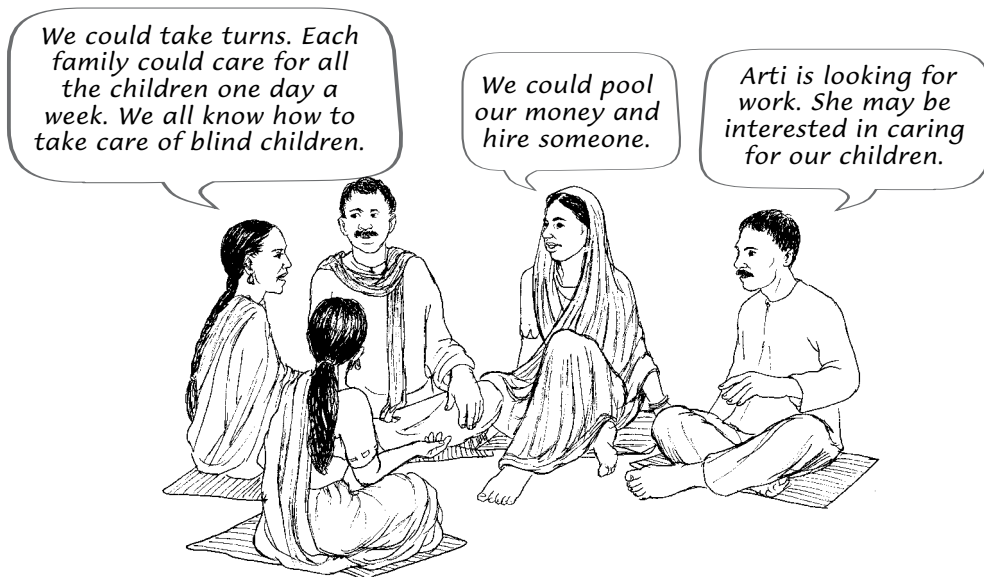
## PLANNING FOR ACTION

When parents work together they can take action to solve many problems. Here are steps for taking action that other parents groups have found useful:

1. Choose a problem that most people in the group feel is important. Although many changes are probably needed, your group may be more effective if it works on one at a time. At first, pick a problem that your group has a good chance of solving quickly. Then, as the group learns how to work together, you can work on more complicated problems.



2. Decide how you want to solve the problem. List many ways the problem could be solved, and then pick the one that best uses your group's strengths and resources.



3. Make a plan. Members of the group will need to do different tasks to get the job done. Try to set a date when each task should be finished.

*Mishri and Guddi, can you find out if other families in the village need child care?*

*I'll find out how much we would need to pay someone.*

*I'll ask Arti if she has taken care of blind children before and how much she would charge.*

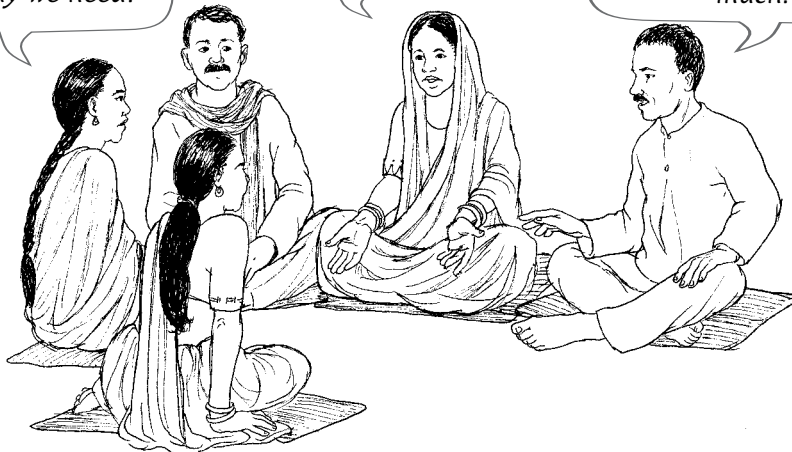


4. When you meet together, talk about how the work is going. Adjust your plan as needed if difficulties arise.

*How is the schedule working out? Do we have care for each day we need?*

*No, we need someone else for 2 days each week.*

*Arti says she has never worked with blind children, but is eager to learn. And she won't charge too much.*



## WORKING TOGETHER FOR CHANGE

Parents groups work on many kinds of projects. They may try to improve the economic conditions of families, the attitudes of communities, the government's laws and services for blind children — all as a way to help their children.

Most blind children come from poor families. To get more resources for their children, a parents group can:

- find ways to get funding for new projects to help children with disabilities
- help parents develop new job skills
- offer workshops on ways to teach and help children with disabilities
- develop groups and camps for the brothers and sisters of children with disabilities

**These mothers learned how to sew clothing so they could earn more money, work closer to home, and spend more time with their children.**



Parents groups can work to make the community more friendly and safe for all children with disabilities. Often, involving your neighbors in fixing safety problems in the community (see Chapter 9) is a good way to begin building solidarity with people with disabilities.

Many parents groups have worked to educate the rest of the community about disabilities. They use discussion groups, workshops, radio programs, newsletters, billboards, street theater, and posters to help others understand more about disabilities.



Other parents groups have worked on projects to help children with disabilities become more active members of the community. For example, your parents group can:

- organize sports events that include children with disabilities.
- build a playground for all children (see Chapter 13 “Becoming Part of the Community”).
- start a child-care center where children with disabilities can be cared for together with other children (see Chapter 14 “Getting Ready for Child-Care and School”).

Some parents groups have worked to improve government programs and laws for children with disabilities. Your group can:

- contact people in government, like the ministers of health and education. Tell them about services your community needs, or about laws needed to protect children with disabilities.
- get well-known people, like entertainers or athletes, to speak out in solidarity with children with disabilities.
- write letters, pass around petitions, or organize protests if government officials do not improve conditions for disabled children.
- educate and involve newspaper, radio, and TV reporters in your campaigns.



Parents groups have also worked to prevent blindness and other disabilities. For example, many children become blind because they do not eat enough foods with vitamin A (see Chapter 16 “Why Children Lose Their Vision and What We Can Do”). Your group may want to raise awareness about the causes of blindness, or grow vegetables that can prevent blindness.

Here is a story of how one parents group, Los Pipitos, is working to change the lives of children with disabilities.

### Parents Are the Heart of Los Pipitos

In Nicaragua, there are more than 200,000 children with disabilities. Poverty is the most frequent cause. Eye problems and other disabilities often happen when children do not have enough to eat and live in crowded homes where infections spread easily.

Before 1987 there were few services for children with disabilities in Nicaragua. Then, 21 parents decided to form a group to “change the world.” They called the group “Los Pipitos,” which is a term of affection for children throughout Nicaragua. Los Pipitos now has more than 20 parents groups throughout the country. Together, these parents have become leaders in a national campaign to help children with disabilities.

*We share our children's lives — their achievements and setbacks — and feel a deep sense of injustice when others reject them.*



*That is why parents and families are at the heart of Los Pipitos.*



*We reach out to other parents to bring them together, to share ideas, and to support each other.*

Los Pipitos parents groups have:

- held workshops for parents on raising children with disabilities
- trained health workers about how to know the extent of a child's disability
- advised the Ministry of Health on the services needed by children with disabilities

All of these activities are part of Los Pipitos' dream to build a society that helps children with disabilities develop their full potential. Parents are the key to making this happen.

