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## Chapter 14

# Support for parents and caregivers

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All over the world, parents and other family members work very hard caring for their young children. And when a family has a child who cannot hear, there is the extra responsibility of making sure he gets everything he needs to grow well. The extra work will make a big difference to the child, but it can be very stressful and tiring for the parents. This chapter has information to help families and caregivers of deaf children find ways to cope with their situation and care for themselves as well as for their children.



Because we share our lives with our children, everything that happens to them affects us deeply. Many families with deaf children feel helpless or fear the future. If parents join together to support each other, they can improve the lives of their deaf children. They can also work as a group to get their community to better support all children who have hearing problems.

## When you first learn your child cannot hear well

Learning that a child cannot hear well or is deaf can be very upsetting, even for families who have relatives who are deaf or cannot hear well. This is natural. You may have feelings of:

- worry about what to do



*I don't know anything about deafness. How could I possibly help my child?*

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

*How will my child get married or earn a living?*



- denial



*My child will hear well if I just find the right treatment.*

- anger at what has happened

*It's not fair that this happened to my family.*



- loneliness



*No one else knows what this is like. No one can help.*

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

*If I had eaten better during my pregnancy, this would never have happened.*



- shame because your child is deaf



*What will our neighbors think?*

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

*I feel so hopeless...*



- accepting it as fate or punishment

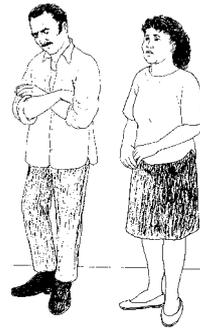
*We can't do anything to change a curse. It is just our fate.*



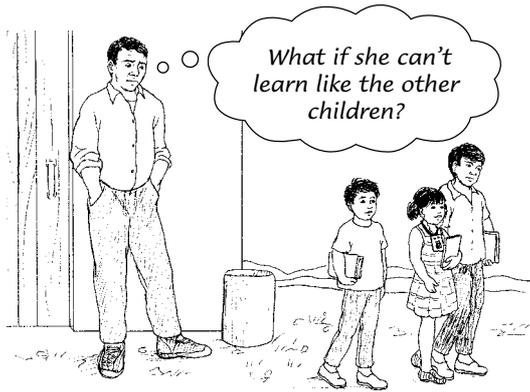
## Understanding your emotions

Parents, other family members, and caregivers will react to the emotions they feel in different ways. It is best to let each person feel the emotions in his or her own way, without judgment.

Emotions such as worry, loneliness, or fear will become less strong as time passes. You will come to realize that a child who cannot hear well has the same needs for love, affection, discipline, and learning as other children.



*Touli feels angry that the baby is deaf, but I feel sad all the time.*



*What if she can't learn like the other children?*

These emotions will return to you at important times in your child's life, like when she starts school. This does not mean something is wrong. It just means you are going through another period of adapting to her deafness.

These strong emotions can help you take action to make your child's life better. For example, loneliness may encourage you to reach out to deaf adults in your community or to other families with deaf children. Anger may give you energy to help organize other parents to persuade the government to provide education for deaf children.

When you accept that your child cannot hear well, you can begin to love your child as she is. And, like all children, she will give you much support, pleasure, and joy!

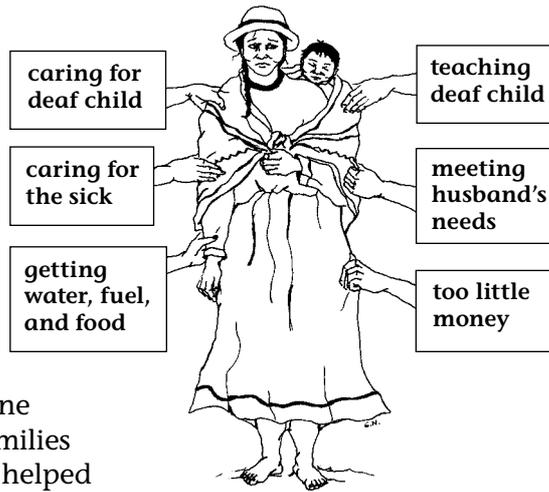
*Look at how much fun they are having! How did I ever think Delphine would be a burden to our family?*



## Managing the stress of caregiving

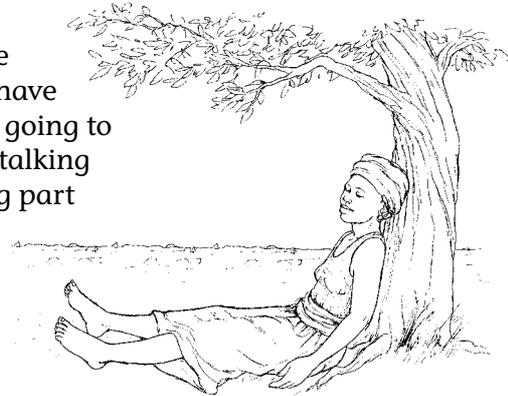
Being a parent of any child is hard work. And if your child cannot hear well or is deaf, then there is even more work. For example, families must teach deaf children things that other children learn on their own, from hearing people talk.

It can be difficult to find time and energy for this extra work. This page and the next one have some suggestions from families about different ways that have helped them manage this stress.



## CARING FOR CAREGIVERS

Parents and other caregivers will be able to look after children better if they also have some time to relax. Simple things — like going to the market, visiting friends or relatives, talking with friends, having a massage, or being part of a community group — can all be helpful. Remember, you can help your children more when you feel well.



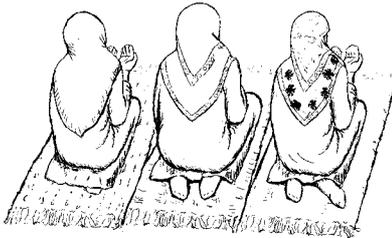
Sometimes it is helpful for a group of parents to get together to talk with each other about any difficulties they may be having. If some have difficulty saying things to others in a group, perhaps they can make up songs, poems, or stories about their situation. Drawing and painting pictures can also help some people express their thoughts and feelings without using words.

**Remember to care for each other. Being a parent is hard work.**



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

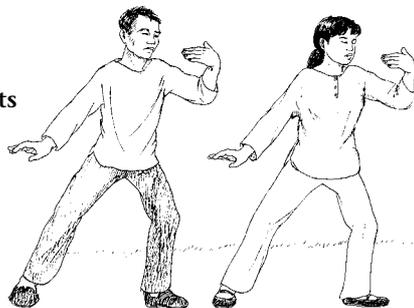
prayer



meditation



exercise or martial arts



## Parents' groups

### A parents' group changes Irlandita's life

A mother in Nicaragua, named Rosa, began to suspect something was not right with her daughter Irlandita. Irlandita did not respond when her name was called, and only reacted to very loud noises.

Worried for her daughter, Rosa took Irlandita to a doctor when she was 16 months old. The doctor was very cold to her, and said only, "Your child can't hear anything. Bring her back when she's 5 years old and we will see if anything can be done for her." Rosa left feeling more frightened and lost than she had been before the visit.

On the way home she met a friend who suggested that she make an appointment with Los Pipitos, a community organization. Los Pipitos was started by a group of parents who wanted their children with disabilities to have the opportunity to develop fully.



Although the doctor and staff at Los Pipitos gave Rosa the same diagnosis — that her daughter was deaf — they also gave her hope for the future. They explained how with special help and extra support from her family, Irlandita could develop just like a child who hears normally. With the support of other parents at Los Pipitos, Rosa began to feel confident that she could make a difference in Irlandita's life.

Now Rosa is an active member of Los Pipitos and she works to give other parents the same help and friendship that she herself found when she needed it.

Thanks to the support of her family, and the care given at Los Pipitos, Irlandita is an expressive, caring, happy, intelligent, and confident girl. She can communicate and is able to attend a regular school.

*With the help of Los Pipitos and a lot of effort at home, we have come a long way in 3 years. To other parents I would say, 'I could do it, and you can too! Try!'*



## STARTING A GROUP

If you know there are other parents with deaf children in your community, but there is no parents' group in your area, it may be 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 of the Deaf in the city. Now a field worker who is deaf regularly visits our village.*



- Find 2 or more parents or caregivers who want to start a group. If you do not know other families with deaf children, you may be able to find parents of children with other disabilities. Or a health worker may know of parents in nearby communities.
- Plan when and where to meet. It helps to choose a place where everyone will be comfortable talking, perhaps a room in a school, health center, 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. Try to keep the discussion focused on the main reasons for the meeting. After the first few meetings, take turns leading the group. Having different people lead each meeting will help shy members participate.

## LEARNING TO SUPPORT EACH OTHER

Even when people know each other well, it may take time to feel comfortable talking about feelings, experiences, and the challenges of raising a child who is deaf or cannot hear well. These things take practice.

*Why should we share our troubles with the whole neighborhood?*



*Omar, who can help us better than our friends? At least we all can face these problems together.*



Here are some suggestions to help group members feel comfortable and to trust in each other:

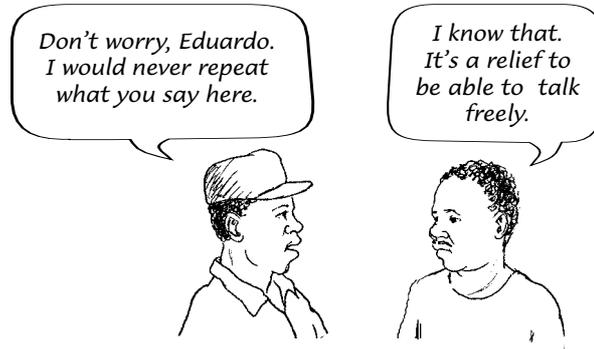
**Listen carefully to what others say, without judging them.** Think about how you want others to listen to you, and then try to listen to them in the same way.



**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 is okay.



## Planning for action

Parents working together can take action to solve many problems. Here are some useful steps for taking action:

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 problem 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.



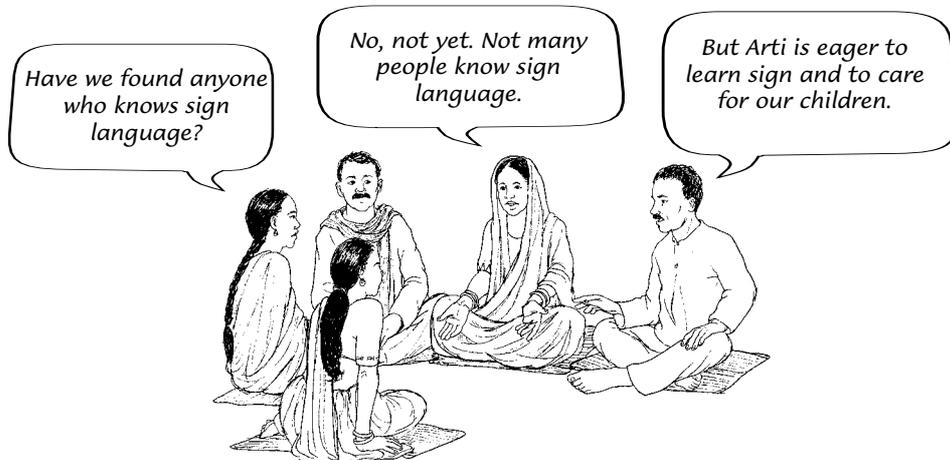
2. Decide how you want to solve the problem. List many ways the problem could be solved and then pick the one that best uses your group's strengths and resources.



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



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



## A GROUP WITH FEW RESOURCES CAN STILL MAKE A DIFFERENCE!

We believe the whole community — neighborhood, village, city, or nation — is responsible for supporting families with children who have disabilities. But sometimes it takes parents working together to make the larger community take that responsibility. As the following story about a group of determined parents in South Africa shows, when people cooperate and put their resources together, they can overcome obstacles and make something where there was nothing!

### Building resources — the power of determination

In a city in South Africa, children with learning disabilities rarely played with other children or attended school. Many parents could not work outside the home because the local day care centers did not want to include their children. The centers told the parents who approached them, “You cannot tell us what to do!” and “We have no facilities for teaching these children.”

A group of parents — all unemployed mothers, many with little or no formal education — got together and decided they must do something for these children and their families. They decided that 1 or 2 of them would look after all the children so that the others would be free to look for work.

*We had no funding, no special resources. We agreed that parents would send something with their children — half a cabbage, a carrot, or a potato — whatever we could manage.*



*With these ingredients, those of us who were caring for the children would cook soup.*

The mothers organized a schedule for caring for the children. One of them volunteered to cook. One became a teacher. Others looked for work that they could do at home. Parents who managed to find work began to contribute a little to those who cared for the children and to the growing day care center. One parent who worked began to buy books for the children.

A social worker heard about the group and came to see what they were doing. She was able to get the local government to give some money to pay the mothers who took care of the children.

With the only resource the mothers had — determination — they were able to establish a day care center for their children, and they were also able to earn a living!

## 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, or the government's laws and services for deaf children — all as a way to help their children. To get more resources for their children, a parents group can:

- find ways to get funding for new projects to help deaf children.
- help parents develop new job skills.
- offer workshops on ways to teach and help their children.
- share information about hearing aids.
- organize sign language classes.
- bring hearing and deaf people together.

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



Many parents' groups work to educate the rest of the community about deafness. They often work together with people who are deaf. The groups use workshops, radio programs, newsletters, billboards, street theater, and posters to help others understand more about deafness.

Some parents' groups work to improve government programs and laws for children who are deaf. They contact people in the government, like the ministers of health and education. They tell them about services their community needs, or about laws needed to protect children who are deaf or have hearing problems. They write letters, pass around petitions, or organize protests if government officials do not improve conditions for their children.

