

The Child with Several Severe Disabilities

CHAPTER 33

Some children have a combination of severe disabilities. For example, a child may have severe cognitive delay and have little or no physical control of his body. He may also have vision or hearing loss, have seizures, or have difficulty swallowing. Or he may have any combination of these disabilities—and perhaps develop severe behavior problems.

Caring for children with multiple and severe disabilities is never easy; they need an enormous amount of time, patience, and love. In most communities, parents and close family members will be the main care providers. But parents will need a lot of support from the community in order to care adequately for the child. Unless parents have help, they are likely to find that the continual demands of caring for their child are too much. Even the most loving parents, after months and years of continuously caring for a child with severe disabilities, can easily become frustrated and angry. This is especially true when the child shows little progress or response, and grows up to be a physical adult with the needs of a young child.



A child with multiple disabilities, including severe cerebral palsy, vision loss, seizures and cognitive delay.

It is not uncommon for a parent who for years has poured love and attention into a child with severe disabilities to suddenly hit the child or in other ways begin to neglect or mistreat him.

Before we blame the parent for this, we should try to put ourselves in her position. She has given the child her total love and attention for years. She has waited for a change, for a smile, for some return of warmth and love. But the child remains like a newborn baby, becoming stiffer, more fussy, and more difficult to lift and care for as he grows. Any human being can only give so much without receiving something in return, some sign of recognition or appreciation. In time, the parent is overcome by the unfairness of the situation: the lack of appreciation, the constant demands, the lack of help, the hurt. She reaches her limit and hurts the child in return. Rather than blame her, we should try to understand her. Above all, **we should look for ways to help both the family and child—if possible, long before the mother or other family members reach their limit.**

COMMUNITY SUPPORT

There are many ways in which the community can give assistance to the family of a child with severe disabilities. In poor countries—and especially in the rural areas—most support and assistance for these families will likely come from the communities themselves.

It is very important that the family have rest periods from caring for their child with severe disabilities. Such rest periods often make the difference between whether or not family members can successfully handle difficulties and continue to treat the child in a loving, supportive way. In some cases, it may be better to provide day care in the child's own home. The community may be able to provide either volunteers or paid care providers. Whatever the case, it is often too much to expect the family of a child with multiple severe disabilities to care adequately for the child unless the community offers generous help and support.



In areas where a community rehabilitation program exists, the program can play an important role. It will usually be neither desirable nor possible for the program to take complete or continual care of a child with severe disabilities. Yet, the program may be able to help in several ways:

- The community rehabilitation workers can regularly visit the home of a child with severe disabilities and give suggestions, assistance, and friendship.
- They can help make or provide special seating or equipment that can help the family to manage the child more easily.
- They can teach the family ways to help stimulate the child's development and can plan with the family a step-by-step approach toward reaching realistic goals.
- Perhaps they can start something like a day care center where rehabilitation workers, parents of children with disabilities, other concerned parents in the community, or unemployed young persons can take turns caring for the children with disabilities for part of the day. This could be done on a volunteer basis. Or money to pay for caretakers could be raised by the community, either through donations, raffles, bake sales, musical events, or other fund-raising activities.

For more information on community rehabilitation programs, see Chapter 45.

In some countries, children with severe disabilities may be taken care of in special care centers, or institutions. This may be because of difficulties in the home situation, or because a child with multiple disabilities requires more time, skill or resources than the family can handle. If you or a community member is struggling to care for a child with a disability, reach out to your local organizations or institutions for assistance.

CARING FOR THE CHILD WITH SEVERE DISABILITIES

In deciding how to care for and work with the child who has a combination of severe disabilities, it is important to evaluate as best you can both her disabilities and possibilities. Especially in the very young child, this may not be easy. You must be ready to see new signs and change your evaluation. This, in turn, may change your plan for working with the child, so as to best help her to develop whatever skills and responses are possible.

In evaluating and planning activities with the child, try to be realistic. Do not expect too much, because this can lead to disappointment. But at the same time, do not expect too little.

For example, a child with a serious physical disability who also has hearing and/or vision loss may appear to have cognitive delay simply because her ability to experience and respond to things around her is very limited. The child may, in fact, have a lot more mental capacity (or possibility) than she appears to have. It would be wrong not to look for ways of reaching, developing, and appreciating her mind. However, this may take great patience and creativity by those caring for her.

SOME GOALS IN CARING FOR A CHILD WITH MULTIPLE SEVERE DISABILITIES:

1. To help her to be physically comfortable, clean, safe, and well-fed.
2. To help her with positioning and exercise to prevent further deformity, and to make caring for her easier.
3. To help her learn whatever basic skills she can—in developing head and hand control, and in some form of communication. Also, to help her learn to interact with others in a way that her needs are met and her behavior is acceptable.
4. To make caring for the child easier and more enjoyable for those who are responsible for her.
5. To assure her that she is loved.

Much of the information and suggestions in Chapters 34 and 35 on early stimulation and development may be helpful for the child with multiple disabilities. Look for areas of development where the child seems to be most ready or to have possibilities. Then work out a plan of activity, stimulation, and rewards that will take the child forward one small step at a time. Some of the suggestions included in Chapter 40, "Ways to Improve Learning and Behavior," may also help. However, you will need to apply them with much patience and repetition.

To help meet the needs of the child with multiple disabilities you will also find useful information in the chapters on the different disabilities that affect the child.

Special seating and positioning, discussed in Chapter 65, may help the child to have more control of her body. This can make feeding, basic communication, and other activities easier.



Special seating can help the child with severe disabilities by supporting him in a position where he has better control.



A child who takes longer than others in learning to use her mind and body needs extra help. Learning to twist and to roll, and to lift up on her arms and turn, are important early developmental steps. Here a rehab worker first helps loosen up a child by slowly swinging her hips from side to side.



Then she encourages the child to lift up and turn to follow an object she wants.

CAUTION: Breastfeeding is healthier than bottle feeding. It is usually better to use a toy or rattle to draw the child's attention rather than a bottle.