

PART 2

WORKING WITH THE COMMUNITY

Village Involvement in the Rehabilitation, Social Integration, and Rights of Children with Disabilities

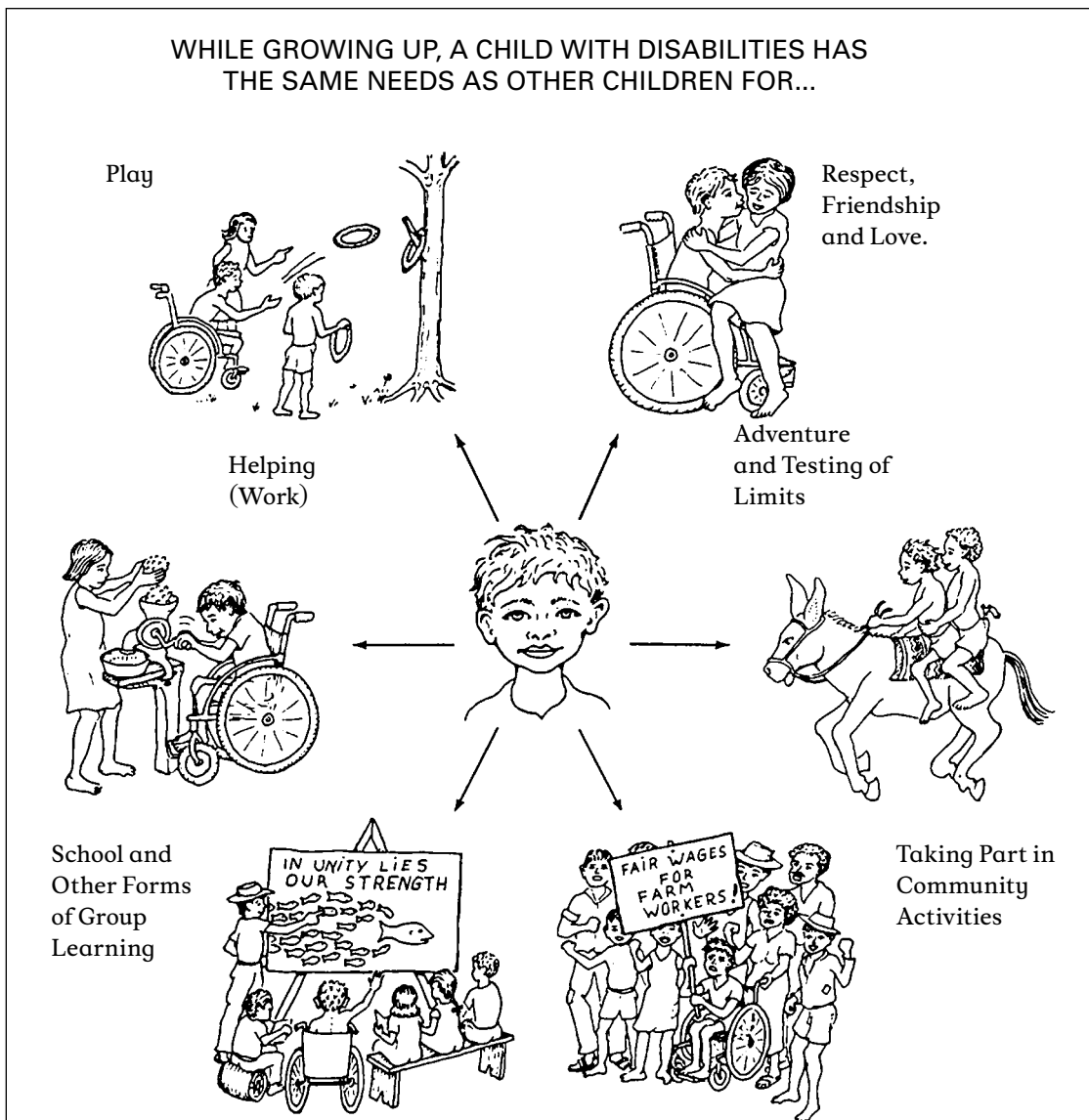




Children with Disabilities in the Community

In PART 1 of this book, we discussed ways of working with individual children according to their particular disabilities. However, a lot of what can make life better—or more difficult—for a child comes not from the child's disability itself, but from the way that people in the family and community look at and treat the child.

In this part of the book (PART 2) we look at ways to actively involve members of the community—people with disabilities, their families, concerned adults, schoolchildren, and others—in meeting the needs of children with disabilities and in helping them find a meaningful place in the community.



In every society, children with disabilities have social needs like those of children without disabilities. They need to be loved and respected. They need to play and explore their world with other children and adults. They need opportunities to develop and use their bodies and minds to their fullest ability, whatever that may be. They need to feel welcome and appreciated by their family and in their community.

Unfortunately, in many communities, people with disabilities—including children—are not given the full chance they deserve. Too often people only see their disability and not the person who they are.

DIFFERENT COMMUNITIES REQUIRE DIFFERENT APPROACHES

The way people treat people with disabilities differs from family to family, community to community, and country to country.

- **Local beliefs and customs** sometimes cause people to look down on people with disabilities. For example, in some places, people believe that children are born with disabilities because their parents did something bad, or displeased the gods. Or they may believe that a child was born “defective” to pay for her sins in an earlier life. In such cases, parents may feel that to correct a deformity or to limit the child’s suffering would be to go against the will of the gods.
- **Lack of correct information** often leads to misunderstanding. For example, some people think that paralysis caused by polio or cerebral palsy is “catching” (contagious), so they refuse to let their children go near a paralyzed child.
- In many societies, children who have seizures or mental illness are said to be possessed by the devil or evil spirits. Such children may be feared, locked up, or beaten.
- **Failure to recognize the value and possibilities of people with disabilities** may lead to their being neglected or abandoned. In many countries, parents give their children with disabilities to their grandparents to bring up. (In return, many of these children when they grow up take devoted care of their aging grandparents.)
- **Fear of what is strange, different, or not understood** explains a lot of people’s negative feelings. For example, in communities where polio is common, a child who limps may be well accepted. However, in a community where few children have physical disabilities (or where most who do are kept hidden), the child with a limp may be teased cruelly or avoided by other children.
- **How severe a disability** is often influences whether or not the family or community gives the child a fair chance. In some parts of Africa, children with polio who manage to walk, even with braces or crutches, have a good chance of becoming well accepted into society. The opposite is true for children who never manage to walk. Even though most could learn important skills with their hands and perhaps become self-sufficient, the majority of non-walkers die in childhood, largely from hunger or neglect.
- **Where poverty is extreme**, a child’s disability may seem of small importance. When this family → in Sri Lanka was asked about their child with a disability, the mother said her biggest worry was that the roof of their hut leaked. The village rehabilitation workers organized neighbors to help build a new roof. Only when the basic needs of food and shelter were met, could the mother give attention to her child’s disability.



(Photo: Philip Kgosana, UNICEF, Sri Lanka.)

Overprotection

Certainly not all children with disabilities are neglected or treated cruelly. In Latin America (where this book was written) a child with disabilities is often treated by the family with an enormous amount of love and concern. It is common for parents to spend all of their money trying to cure their child, or to buy her vitamins or sweets, even at the cost of hardship for the other children.

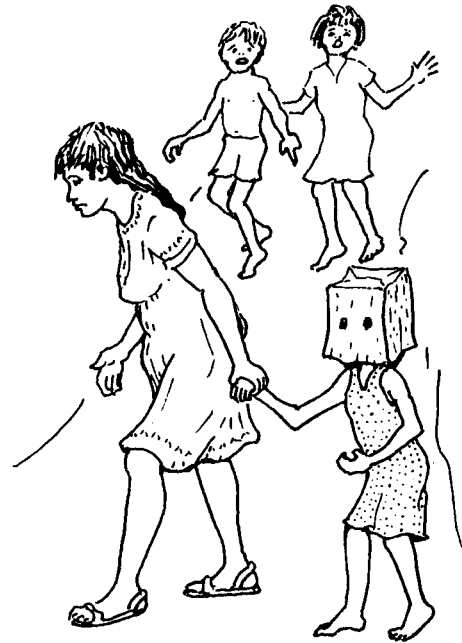
Providing too much protection is one of the biggest problems in Latin America and elsewhere. The family does almost everything for the child, and so holds her back from developing skills and learning to care for herself. Even a child with a fairly mild disability is often not allowed to play with other children or go to school because her parents fear she will be teased, or unable to do as well as the others.

Even in Latin America, where families usually provide loving care for children with disabilities, some parents may seem to keep their children hidden away. They may feel shame or fear judgment from the community, or may be trying to protect their children from cruel treatment. But when communities do not see people with disabilities participating — working, playing, relating freely with others — it may cause people to think they cannot, and should not. Bringing parents together in support groups and encouraging more rehabilitation activities that include the whole community (see Chapter 45) can help.

In the village of Ajoya, Mexico, people used to stare at, turn their backs on, or express their sorrow for the occasional child with disabilities whom they saw. But now things have changed. Ajoya has become the base of a community rehabilitation program (PROJIMO) run mainly by young people with disabilities.

In Ajoya, children with disabilities and their parents are now comfortable about being seen in public. Children with and without disabilities play together in a “playground for all” built by the village children with their parents’ help. The community has helped build paths and ramps so wheelchair riders can get to the stores, to the village square, in and out of some homes, and to the outdoor movie on Saturday nights.

Mari, a young woman with paraplegia (paralyzed from the waist down), first came to Ajoya from a neighboring village for rehabilitation. She soon became interested in the village program and decided to stay and become a worker. Mari took over the record keeping, began to interview and advise children with disabilities and their families, and learned to make plastic leg braces. She became one of the most important and respected members of the PROJIMO team.



In one Latin American border town, a mother brought her child to a clinic with her head covered by a paper bag—to hide the condition of her mouth (cleft lip).

But Mari did not want to go back to her own village. She said, “The people don’t treat me like myself anymore. They don’t even treat me like a person. They treat me like a cripple, a nothing.” People with disabilities are often misunderstood by community members who only see their disability and do not realize that they have a lot to contribute to the community. They can feel alone and isolated as a result. When people with disabilities are accepted and supported by their communities for their talents and skills, each community is stronger. It is important to engage in consciousness raising activities to dispel myths about disabilities, reduce fear, and increase acceptance of people with disabilities. For examples of ways to do this, see Chapters 46 and 47.

The PROJIMO team began to visit Mari’s village and encouraged the families of children with disabilities there to organize. The village children have helped build a “playground for all,” and adults have built a small rehabilitation post next to it. So, things have begun to change in Mari’s village too. The “different world” has begun to grow and spread.



Mari helps another girl with a spinal cord injury with her exercises.

In PART 2 of this book we look at ways to help the community respond more favorably to children with disabilities and their needs. Usually, of course, a village or neighborhood does not decide, on its own account, to offer greater assistance, acceptance, and opportunity to people with disabilities and their families. Rather, **people with disabilities and their families must begin to work together, to look for resources, and to re-educate both themselves and their community.** Finally—when they gain enough popular understanding and support—they can **insist on their rights.**

The different chapters in PART 2 discuss various approaches and possibilities for bringing about greater understanding of the needs and possibilities of children with disabilities in their communities. We start by looking at what people with disabilities and their families can do for themselves and each other. We look at possibilities for starting a **family-based rehabilitation program**, and the importance of starting **community-directed rehabilitation centers** run by villagers with disabilities themselves. We explore ways to include village families and school children. Finally, we look at specific needs of the child with disabilities growing up within the community—needs for group play, schooling, friendships, respect, self-reliance, social activities, ways to earn a living or to serve others; also needs for love, marriage, and family.

EXAMPLES, NOT ADVICE

In this part of the book, which deals with community issues, we will try mostly to give examples rather than advice. When it comes to questions of attitudes, customs, and social processes, advice from any outsider to a particular community or culture can be dangerous. So as you read the experiences and examples given in these pages, do not take them as instructions for action. Use, adapt, or reject them according to the reality of the people, culture, needs, and possibilities within your own village or community.

Each community is unique and has its own obstacles and possibilities.