

PART 2

WORKING WITH THE COMMUNITY

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





Starting Village-Based Rehabilitation Activities

CHAPTER

45

TOP-DOWN OR BOTTOM-UP?

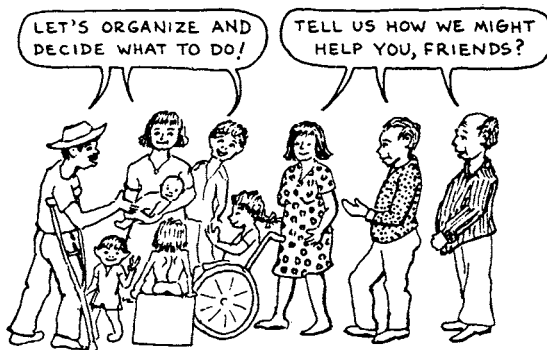
Around the world today there are many examples of what have sometimes been called “community-based rehabilitation programs.” Some of these are imposed upon the communities they serve. They may work well or not so well. We call them “top-down.” Others arise from within the community. We call them “bottom-up.”

Top-down: Chain of command

Top-down programs or activities are mostly planned, started, organized, and controlled from outside the community: by government, by an international organization, or by distant “experts.” And the local leaders are usually persons in positions of authority, influence, or power.



Bottom-up: Equality in decision-making



Bottom-up programs or activities are those that are largely started, planned, organized, and controlled locally by members of the community. Much of the leadership and direction comes from those who need and benefit most from the program's activities. In brief, the program is small, local, and “user-organized.”

Community participation is important to both top-down and bottom-up programs. But it means something different to each:

In top-down programs, people are asked to participate only in ways that have already been decided from above. For example, a decision might be made by a team of foreign specialists that certain persons in each community be selected as “local supervisors.” The local supervisors are taught several pre-decided “packages” of cookbook-like information. Each supervisor then instructs a given number of “local trainers” (family members of the person with a disability) how they must train each particular person with disabilities. Thus community participation, from the viewpoint of the experts, means “getting people to do what we decide is good for them.”

In bottom-up programs, community participation means something else. The program develops within a village or neighborhood, according to the needs and wishes of its members. It may take an outsider with some knowledge in rehabilitation and skill in organizing people to help get things started. But it is the people themselves, especially people with disabilities and their families, who make the decisions about their own program. They can learn from other programs and from the experts. But they do not simply copy or follow others. They pick and choose from whatever advice and information they can get in order to plan activities that fit the needs and possibilities of their particular village, and their particular children.



In the village of Ajoja, Mexico, over 60 families participated in building a cement walkway from the rehabilitation center to the main street.

There are advantages and disadvantages to both types of program. For a central government, a standardized, top-down approach is easier to introduce, administer, and evaluate in many communities at the same time. But in primary health care, it has become clear that these programs frequently fail or have serious weaknesses, mainly because they do not have enough popular leadership, understanding, and personal commitment. These are especially important for rehabilitation. Every child with disabilities is different and has her unique combination of needs. An imaginative, problem-solving approach is essential. If decisions and plans come pre-packaged from above, rehabilitation measures often do limited good and sometimes even harm.

When a program is organized from within the community, there is a greater sense of equality, and of arriving at decisions together. People do not just follow instructions. They consider suggestions. They want to know why. This greatly increases the chances that exercises, aids, and activities will really fit the individual needs of the child. It also makes rehabilitation more interesting, meaningful, and valuable for all concerned. It helps both parents and children become more independent.

This approach to rehabilitation has the advantage of flexibility and adaptability that comes from being organized and controlled locally. Planning is a continuous learning process that responds to the changing needs, difficulties, and possibilities within the community. Especially when people with disabilities and family members play a leading role, participants at every level are likely to develop a spirit of respect, friendliness, and equality that keeps a program human and worthwhile.

Above all, a program organized by those it serves decentralizes and redistributes power: people who have been powerless begin to find strength through unity. You can never be sure where things may lead, how far people may go in terms of taking charge of their own lives or in demanding their rights.



On the following pages we look at community rehabilitation activities and programs organized from within the communities they serve. This is where our own experience lies. For a different approach with more of the planning from above, we suggest you see the World Health Organization's *Training In the Community for People with Disabilities* along with the supplementary materials (see p. 637).

STARTING IN A VILLAGE—WHERE TO BEGIN?

Rehabilitation of people with disabilities within a village or neighborhood usually has two major goals:

1. To create a situation that allows each person with disabilities to live as fulfilling, self-reliant, and whole a life as possible, in close relation with other people.
2. To help other people—family, neighbors, school children, members of the community—to accept, respect, feel comfortable with, assist (only where necessary), welcome into their lives, provide equal opportunities for, and appreciate the abilities and possibilities of people with disabilities.

One of the best ways to bring about better understanding and acceptance of people with disabilities is to involve both people with and without disabilities in shared activities. The next few chapters discuss selected community activities that can help improve people's understanding and respect for the disabled community. These can be introduced either as part of a rehabilitation program, or independently by concerned persons such as parents, school teachers, or religious leaders. Some of these activities, in fact, have proved to be good ways to create interest and open discussion with local people about starting a small community-based program.

There are many possibilities for getting people in a village or neighborhood more actively involved. Often a good way to start is to **call a meeting to bring together people with disabilities and their families**. Sometimes one or more leaders in the community happen to have a child or close relative with disabilities. These persons, with a little encouragement, may take the lead in organizing other families of children with disabilities, or in starting a local rehabilitation program.

It makes sense to **start where people express their biggest concern**. For example, in Peshawar, Pakistan, a community program for children with cognitive delay was started because families of these children expressed a strong need. In Nicaragua, a group of revolutionaries with spinal cord injuries started a program to produce low-cost wheelchairs to meet their particular needs, in Mexico, village health workers with disabilities started a community program for children with disabilities and their families. Today, these 3 programs have all expanded their coverage to include a far wider range of disabilities than they started with.

Some children have several disabilities, so it is hard to limit attention only to certain ones. We must try to meet the needs of the whole child, within the family and within the community. However, it often works best to start in a **small and fairly limited way, wherever people are ready**. Let things grow and branch out from there, as new concerns arise and new people become involved.



In a community program everyone helps out. Here the mother of a boy with polio sews cloth to form “stockings” for use under plaster casts.

Who gets things started?

Within a community or neighborhood there will often be persons eager to become involved in starting rehabilitation activities or even a program. All it may take is something to “spark the idea.” This spark can be in the form of a person, a pamphlet, or even a radio program that triggers people’s imaginations with ideas or basic information.

For example, we know of one village medic with paralysis due to polio who received a WHO magazine with an article on “Rehabilitation for All.” As a result, she began to organize the villagers to build a simple rehabilitation playground. In a similar fashion, CHILD-to-child activity sheets have sometimes inspired teachers to conduct activities that help school children to prevent certain disabilities or to behave toward children with disabilities in a more friendly, welcoming way.

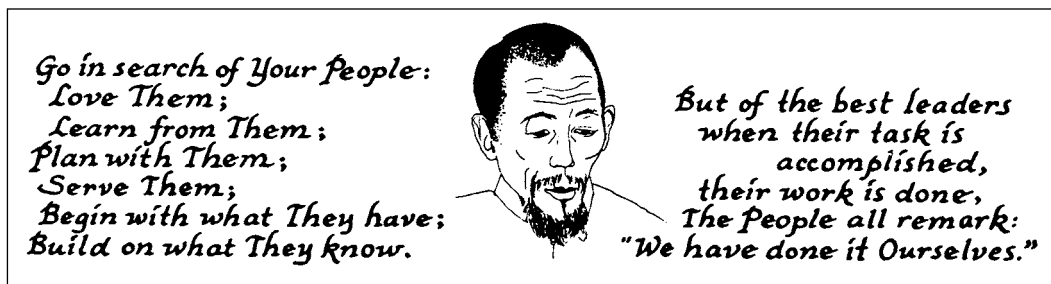
Often, to get things started, it takes a person with some background in rehabilitation and in community work, to stay for a while in a village or neighborhood. Her role is to bring together people with similar needs, helping them to form a plan of action and to obtain the information and resources they need.

Such a person is sometimes called an “agent of change.” She need not be a highly-trained professional in rehabilitation or social work. In fact, persons who have professional degrees often have the hardest time accepting that parents and people with disabilities can and should be the primary workers and decision makers in a community rehabilitation program.

What is necessary is that the agent of change respects the contributions that all community members can make and is committed to helping them join together to meet their needs and defend their rights.

The agent of change should be a counselor, not a boss; a provider of information and choices, not orders or decisions. Especially if such a person comes from outside the community, her role is to stay in the background, to help the people make their own decisions and run their own program. This is necessary to create a rehabilitation program grounded in the community it will serve.

Staying in the background, however, is easier said than done, especially for an agent of change who is deeply committed. To make sure that a program is run by the people, not by outsiders, it is often a good idea that agents of change and any visiting professionals not be present all the time. Instead, they should encourage the program to continue without them. Perhaps the final test of an agent of change’s success is to leave the community forever, without her absence being much noticed. These ideas are said beautifully in this old Chinese verse:



A good example of this process can be found in *Community-based Rehabilitation in the Bolivian Amazon* (see page 637).

To help start a program for the people with disabilities, it often works out better if the agent of change is also disabled. This helps make the outsider an insider.

People with disabilities as leaders and workers in rehabilitation activities

Some of the most exciting and meaningful community rehabilitation activities in various parts of the world are those that are led and staffed by people with disabilities. When the leaders and workers in a program are disabled, they can be excellent role models for children with disabilities and their parents. When they see a team of people with disabilities working together productively, contributing to their community, and enjoying themselves in the process, it often gives both family and child a new vision and hope for the future. This alone is a big first step toward rehabilitation.

Another reason for recruiting leaders and workers who are mostly people with disabilities (or their relatives) is that they are more likely to work with commitment, to give of themselves. From their own experience, they understand the challenges, needs, and possibilities of people with disabilities. Because they, too, have often experienced rejection, misunderstanding, and unfair treatment by society, they are more likely to become leaders in the struggle for a fairer, more fully human community.



Workers with disabilities give an example to children with disabilities that they can lead a full life. Polo Leyva, a person with paralysis due to polio, has become a skilled welder and wheelchair maker.

Examples of community rehabilitation programs run by people with disabilities are in Chapter 55.

Kinds and levels of village-based activities

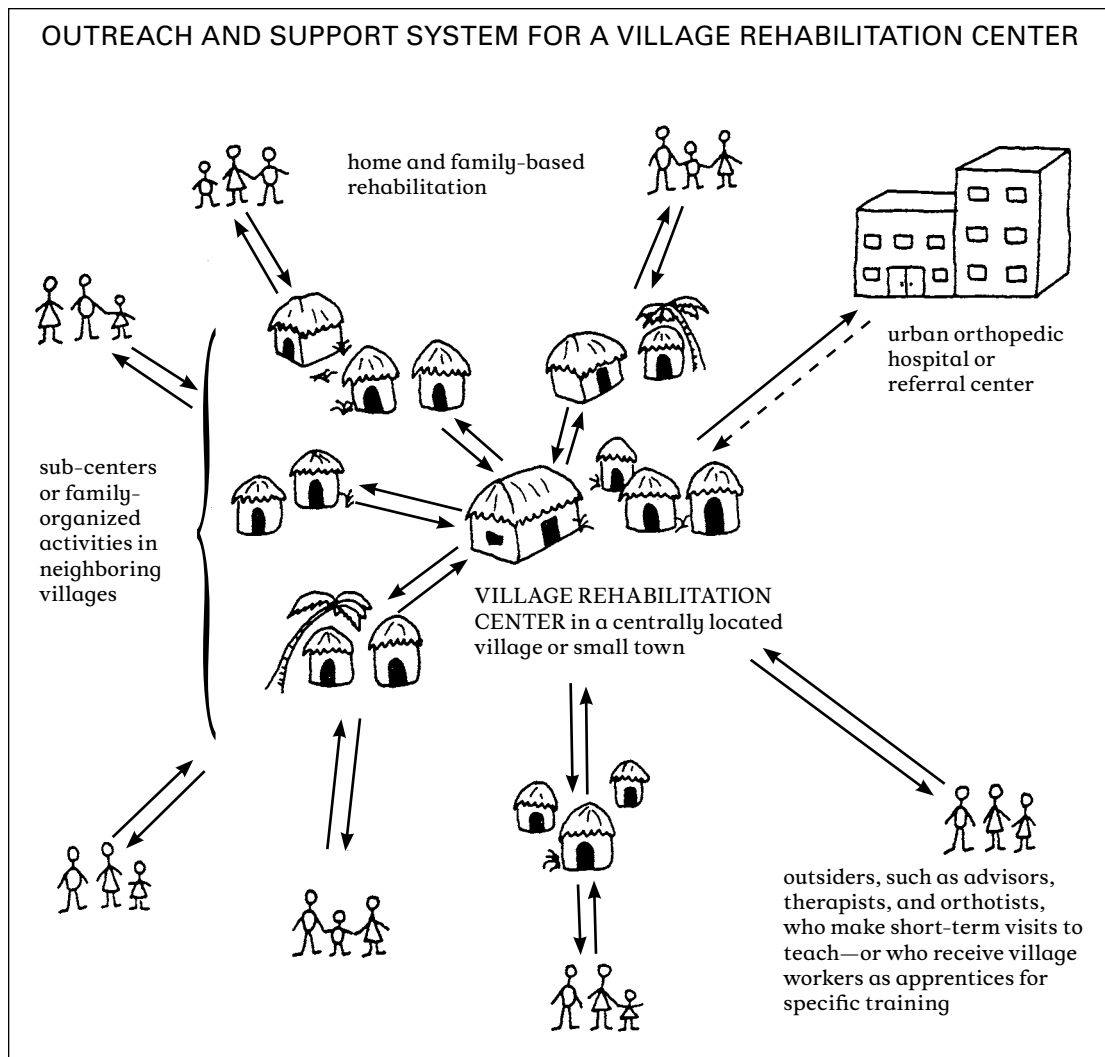
There is no formula or blueprint for starting a village rehabilitation program. How things get started will depend on various factors: the size of the village, the number of children with disabilities and the nature of their disabilities, the interests and talents of parents and other persons, the resources available, the distance and difficulties for getting specific rehabilitation services elsewhere. Also consider the possibilities for getting assistance from rehabilitation therapists and other professionals, craftspersons, health workers, schoolteachers, and people with other skills that could be helpful.

It is important that most rehabilitation activities take place at home with the family members as the primary rehabilitation workers. And even where plenty of money and professional services are available, the home and community are still the most appropriate place for most of the rehabilitation of most children with disabilities.

For home-based rehabilitation to be effective, parents need community support, friendly encouragement, and carefully selected and prepared information from rehabilitation professionals. Community support can be developed through meetings open to everyone interested in working together to improve life for people with disabilities. Involving neighbors in a project like building a playground for all children can also build support and encouragement for rehabilitation in the community (see Chapter 46).

At times, parents will need assistance from rehabilitation and medical workers with different skills. A good arrangement, perhaps, is a referral chain, starting with rehabilitation in the home with guidance from a small community center run by local, modestly trained workers. If possible, the center has close links with the nearest low-cost or free orthopedic hospital and professionally-run rehabilitation center, to which the relatively few children with disabilities requiring surgery or complex therapy can be referred. Outside professionals (orthotists, therapists, and others) can help by making periodic teaching visits to village rehabilitation centers. They can also invite village workers to visit and apprentice with them in their city shops and clinics.

Some villages will be too small or lack the resources to start their own community rehabilitation center. However, it has been found in several countries that once a modest center in one village opens, the word spreads. Children with disabilities and their families soon begin arriving from surrounding villages. In time the rehabilitation team may be able to help people with disabilities and their families in neighboring villages to organize their own sub-centers. Workers with disabilities from these sub-centers can learn by apprenticing at the original center.



The above “ideal” is more or less the way Project PROJIMO in Mexico works, although with certain difficulties and obstacles.

The role of a villager-run rehabilitation center

Some of the most important rehabilitation activities take place with the family in the home. Others take place in the school, the marketplace, the village square, and, when necessary, in the nearest orthopedic hospital. The key to helping all this happen can be the village rehabilitation center. (See the next page.)

A rehabilitation center run by trained villagers with disabilities, together with the families of children with disabilities, can provide a wide range of services. These may include training and support of families, community activities, non-surgical orthopedic procedures, and making orthopedic and rehabilitation aids. The program need not try to do everything at first, but can start with what seems most important and gradually add new skills and activities as needs and opportunities arise.

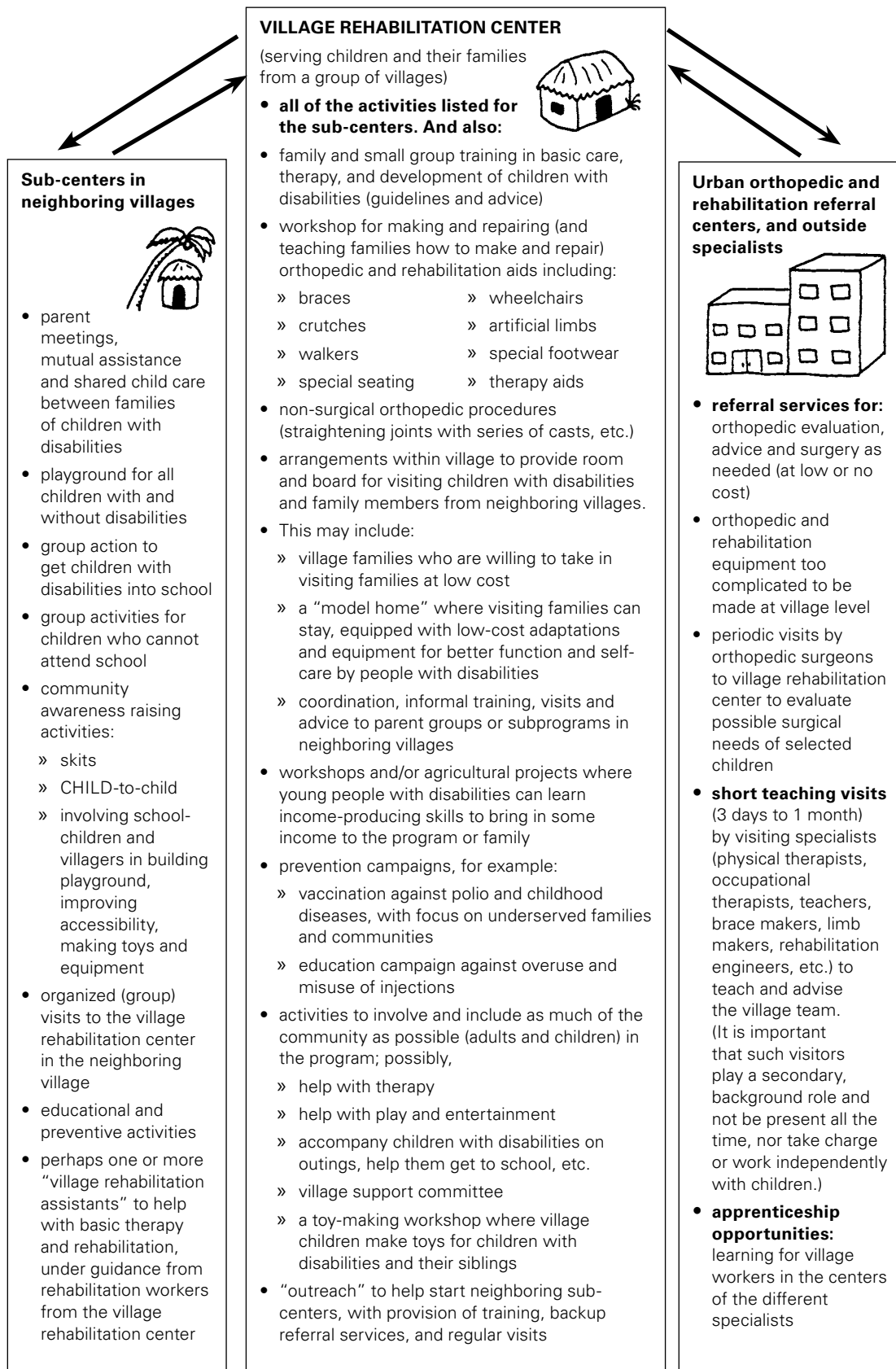
Eventually, a community team can gain considerable skill in many areas. For example, the village team of PROJIMO is able to adequately attend the needs of about 90% of the children with disabilities it sees (except for children with vision or hearing loss, for whom its services are still not adequate). Only about 10% need referral to orthopedic hospitals or larger rehabilitation centers. Visiting experts have found that at times the therapy or aids provided by PROJIMO are more helpful than those previously provided to the same children by professionals in the cities.

The chart on the following page gives an idea of possible activities and functions of a village rehabilitation center. It also lists activities of possible “sub-centers” in neighboring villages, as well as referral and support services needed from urban orthopedic and rehabilitation centers, and outside specialists.



Organizing the community to build a “playground for all children” is one of the best ways to increase participation and to integrate children with and without disabilities in a way that everyone enjoys.

POSSIBLE ACTIVITIES AND FUNCTIONS OF REHABILITATION CENTERS AT DIFFERENT LEVELS



The importance of community-run rehabilitation centers

In an attempt to get the focus of rehabilitation out of big institutions and into the home, some community-based rehabilitation programs have tried to manage without any kind of local rehabilitation centers. Local supervisors make home visits and work directly with families of people with disabilities. However, when additional assistance or aids are needed, the local supervisor often has nowhere to turn. She has to send the person with disabilities to professionals in the city. For reasons of distance, cost, fear, or failure of the support system, these referrals too often do not work out. As a result, rehabilitation is often incomplete, and people get discouraged.

Of course, referral to large city hospitals or centers will still be important for selected individuals. However, there are several **strong arguments in favor of setting up a small village or community-based rehabilitation center run by local concerned persons:**

1. It is a visible, practical, low-cost base for coordinating rehabilitation activities in the home, and for providing back-up services outside the home.
2. It can produce a wide range of rehabilitation equipment and aids quickly and cheaply, using local resources, with participation of families, schoolchildren, and local craftspersons, when possible.
3. It can include a “playground for all children” and organize activities to encourage understanding and interaction among all children.
4. It can provide meaningful work and training experience for local, otherwise often untrained and unemployed people with disabilities. It gives the families of children with disabilities and other villagers the chance to see and appreciate the rewarding role people with disabilities can have in a community.
5. Although the best place for day-to-day rehabilitation is often the home, there are families for whom this may be very difficult. These include families in which one or both parents have left or are dead, or have drinking problems, or where step-parents or other family members are cruel to the child, neglect her, or abuse her sexually (a fairly common problem). In many homes, the family does the best it can. But the extra work of trying to care for a child with severe disabilities may simply be too much for the family that has to work long hours just to survive. Under any of these circumstances, special care at a community center may be of enormous benefit to both the child and the family.
6. If many small community centers join to form a network, they can exchange ideas and learn from each other. Or different centers can specialize in producing different supplies or equipment. For example, one village center might make wheelchairs, another toys, and another low-cost plaster bandage for casting. Then different centers or programs can supply each other at low cost.

Home-based rehabilitation often works much better with the help of a local, community-run center.

How small, local programs spread to new villages and areas

Bottom-up programs tend to spread through popular demand. As the news of the program travels from family to family and town to town, even a small program based in a single village can reach far in its impact. For example, Project PROJIMO is based in a village of less than 1,000 and has a staff of a dozen villagers with disabilities. In its first 4 years, PROJIMO has attended to the needs of over 1,000 children with disabilities from over 100 towns and villages and the slums of several large cities. (Since roughly one child in every 100 people has a moderate to severe disability, PROJIMO is in effect serving a population of over 100,000.)

There are various ways that bottom-up or people-centered programs tend to spread. We speak of their growth as “organic” because they grow and spread in a living, whole sort of way, like seeds into trees.

In Project PROJIMO, some of the young people from neighboring communities, who first come for rehabilitation, decide to stay and to work for a while in the program. In the process they learn skills which they can use to help in the rehabilitation of other persons when they return to their own communities. In some cases, other villages and village-based health programs have sent young people with disabilities to apprentice with PROJIMO for several months, in order to help start similar activities on return to their communities.

Another people-centered program that started small and has spread to many other towns is the Community Rehabilitation Development Program in Peshawar, Pakistan. This is discussed on p. 520.

ACTIVITIES IN THE COMMUNITY TO WIN INTEREST AND UNDERSTANDING

Group activities in a village or neighborhood can help improve understanding of and interaction with children with disabilities. Social gatherings of children with disabilities and their families are a place for these families to connect for support. Gatherings that include the larger community can help change attitudes about children with disabilities and help people become more familiar with their experiences and realities. These social gatherings can be an important first step for the four particularly useful activities discussed in the next 4 chapters:

- A “Playground for all children”
- CHILD-to-child activities
- Popular theater
- A children’s workshop for making toys



Playground for all children—PROJIMO

Any of these activities may be used to gain people’s interest and involvement when starting a community rehabilitation program. Or they can be used to increase understanding even where no special program is planned. For example, the workers in a village with a rehabilitation center can visit neighboring villages and put on skits or puppet shows about disability prevention. They might also talk with school teachers, local health workers or concerned parents about developing CHILD-to-child activities, or organize local children to build a “playground for all children.” Project PROJIMO took a truckload of school children to a neighboring village to help the children there build their own playground. Nearly 100 children and adults built the playground in one day.

After these 4 chapters, we will explore other aspects of social integration and opportunities for people with disabilities.