Love, Sex, and Social Adjustment

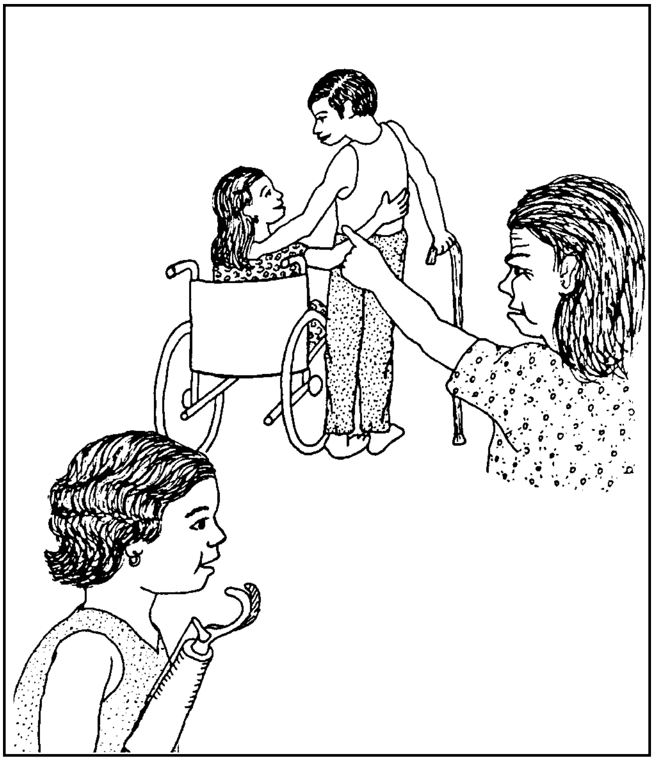
CHAPTER 52

In the village of Ajoya, the home of Project PROJIMO, young people with disabilities happily go to dances and outdoor movies together. They are not ashamed to let people know that they have a close or loving relationship. Some who have grown to know and care for each other through the Project have married and now have children.

All this is fairly much accepted as "natural" and "normal" and "right" by most of the local villagers.

But things were not always this way. A few years ago, when PROJIMO had just begun, many people believed that a person with severe or even moderate disabilities should not and could not have a loving relationship, get married, or have children.

One evening in the spring, some years ago, an old woman watched a group of young couples listening to guitar players at the village square. One young man, who had a clubbed foot and used a cane, stood close to a young woman in a wheelchair. When the musicians started playing a romantic song, the couple gently put their arms around each other. The old woman was shocked. Angrily she pointed to the pair and cried, "Isn't that disgusting! People like that have no right to behave like that! It's not natural! They're cripples!"



People with disabilities and their families must educate the public about their rights.

When PROJIMO first began, unfortunately the villagers were not the only ones who thought that people with disabilities should and could not get married or have loving relationships. Many young people with disabilities half-believed it themselves, and in their personal lives were often depressed, frustrated, or confused. While society told them one thing, their hearts and their bodies told them another. Most believed they could never be attractive to another person in a sexual way. Yet through adolescence, they felt increasingly attracted. Many had serious doubts about their own sexual ability. Some had discovered that they did, in fact, have fully developed feelings and functions. But they had no acceptable way to express them.

Some visiting advisers to PROJIMO were older people with disabilities who had learned to understand their own feelings, and had formed loving relationships. Slowly, the young people at PROJIMO began to accept their own desires, needs, and dreams. More important, they began to discover they were not so alone, not as different from other people, as they had thought. Above all, they discovered that they were attractive to other persons. Soon the romances began.

At first, things sometimes got out of hand. The bottled-up feelings of the young people came flooding out. There were occasional mistakes and abuses. When the young people with disabilities discovered that the rules society had set for them were unfair, often their first response was to break the rules recklessly. But then, faced by the sometimes cruel results of their own hurry, passion, and inexperience, they discovered the need for a few precautions and guidelines determined by the group. They had been hurt often enough themselves not to want to cause additional hurt. And now with the spread of HIV, they are also aware they must have "safer sex" if and when they have sex.

Little by little, the PROJIMO team members have discovered their ability to live fuller lives and have more complete relationships than they had previously believed possible. Also, little by little, the local community has begun to accept this. For the first time, romances have begun to develop openly between villagers with and without disabilities. A new level of awareness and acceptance is slowly being achieved.

Conchita, a person with paraplegia, was sure she could never marry. She came to PROJIMO for rehabilitation and later became one of the workers. She is now happily married to another villager.

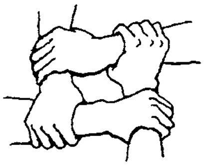
The personal and sexual needs of young persons

Every child has the same basic needs for food, protection, and love. The child who is treated consistently with love, respect, and understanding has a greater chance of becoming a loving, respectful, and understanding adult.

Every child has a need to be touched and held. Small children learn about themselves by exploring and touching different parts of their bodies. A child whose disability makes touching and exploring her body more difficult may have an even greater need than other children to be held and hugged.

Most societies have rules and taboos that attempt to limit and govern sexual behavior. And within most societies, young people (and old) usually find ways of getting around some of those rules, usually more or less secretly. The best answer to sex education is to talk openly and honestly about sexual themes, but also to look for informal and unsupervised ways for adolescents with disabilities to spend time with and share the "secrets" of other adolescents.

But it is also important to make sure that children with disabilities understand how to resist sexual abuse. Adults can take advantage of their power and trust and enter into sexual relations with children, especially children with disabilities. It should be explained to children that these kinds of "secrets" are not acceptable and that they should let others know about what is happening. See ***Helping Children Who Are Blind*** (Chapter 12) or ***Helping Children Who Are Deaf*** (Chapter 13) for ideas on how to prevent sexual abuse and ways to talk with children about this difficult topic.



LOVING RELATIONSHIPS, MARRIAGE, AND FORMING A FAMILY

It is important that people with disabilities and everyone else in the community realize that people with disabilities can build their own families. People with disabilities can participate in close, loving relationships and have children. Except for a few inherited conditions, people with disabilities have no higher risk of having children with disabilities than do people without disabilities.

If an individual or a couple cannot or does not want to have biological children, adoption is often a possibility for people with or without disabilities.

In some societies, nearly everyone is expected and able to marry, including people with disabilities. But in cultures that put great importance on an "ideal" physical appearance, it may be difficult for a person with disabilities to find a partner. The biggest barrier is sometimes the feeling by the person with disabilities that they can never be attractive to anyone. To overcome those feelings, people with disabilities can sometimes advise one another. Those who have overcome their own fears and have formed loving relationships can do much to help others realize that there are many personal qualities that make someone attractive to another person.

Often it takes someone with a disability to see beyond the outside of another person with disabilities to the unique qualities inside. So it often happens that people with disabilities take other people with disabilities as partners—although their disabilities may be quite different. However, as people with disabilities gain greater acceptance and participation in the community, loving relationships and marriage between people with and without disabilities become more common.

Often there are not many chances for young people with disabilities to get to know and become close to other youth. Therefore, such opportunities can and should be sought or arranged. The types of opportunities and how they can be arranged will of course differ from one community to another.

Chances should be provided for young people with disabilities to go to ceremonies, dances, and public events that other young people attend. A community rehabilitation program can arrange games, parties, and other activities to which young people with and without disabilities are invited, and in which they can participate equally.

The need for full integration

It must be remembered that opportunities for a close, loving relationship are only one aspect of leading a full, accepted, and participating life in the community. The more that can be done to bring about greater integration and participation of people with disabilities in the life of the community, the more everyone will learn to look beyond a disability and see the person. When this happens, it opens up many new possibilities.

A community rehabilitation program finds enjoyable ways to bring children with and without disabilities together. Here the village children have been invited to the birthday party of a child with disabilities. They take turns, blindfolded, trying to break a "piñata" (a papier-mache toy filled with candy and nuts). (PROJIMO/Richard Parker)

Family Planning

Young people with disabilities should be given the same information and opportunities as young people without disabilities to avoid unwanted pregnancy and sexually transmitted infections such as HIV. Making such information and methods available may be of special importance for participants in a self-run community rehabilitation program. For different methods of family planning, see ***A Health Handbook for Women with Disabilities,*** Chapter 9, or ***Where Women Have No Doctor,*** Chapter 13 (see p. 654).

The child with cognitive delay and sex

Children with cognitive delay, like others, are increasingly interested in sex as they grow up. In fact, they may take more interest in bodily experiences because opportunities for other activities are more limited.

Because the complex messages that children with cognitive delay get from other people are often confusing or contradictory, these children may develop unacceptable patterns of behavior. Often parents do not know how to handle this. For example, a mother may be afraid to take her child with cognitive delay with her to the market because he tries to touch every girl he sees.

It is important that children with cognitive delay are helped to understand clearly what behavior is acceptable and what is not, and where. To accomplish this, a behavioral approach to learning can be used. The family can consistently reward good behavior and carefully avoid giving the child special attention or in any way rewarding bad behavior. This approach is discussed in Chapter 40. In children with behavior difficulties, if possible, the family should start using a behavior approach to learning long before the child grows up sexually. The younger the better.

A common mistake is to pretend that young people with cognitive delay do not have a need for loving personal relationships. The need exists, and if unanswered, can lead to difficulties both for themselves and for others.

In most communities, it is very difficult for a person with cognitive delay to have a close, loving relationship. In some countries, programs arrange for these people to live together in special homes or to come together for social activities. As a result, some of them form couples, and sometimes marry.

Trying to protect young people with cognitive delay against sexual abuse and unwanted pregnancy, and at the same time respect their rights, can be difficult. Some programs try to solve the problem through sex education, or by providing family planning methods to young people with cognitive delay. Check with your local health worker to see what family planning methods are available and acceptable in your area.

Marriage and family

In countries where people with disabilities have achieved greater acceptance and involvement in the community, an increasing number of people with disabilities, including some with fairly severe disabilities, are getting married and having families of their own.

The ability of a person with disabilities to support a family depends a lot on economics. Thus, an effort to help young people with disabilities learn the skills necessary to work and earn a living or maintain a home is an important part of the preparation for marriage and family.

For more information about sexuality, relationships, and family building for people with disabilities, see *A Health Handbook for Women with Disabilities* (see p. 637).

Sex education

On the average, children with disabilities begin to mature sexually around the same age as children without disabilities. Girls may begin to have monthly bleeding (menstruate) at about age 11 or 12 (or earlier or later). Boys begin to release semen at age 12, 13, or 14 (sometimes earlier or later). Often these new bodily functions take young people by surprise, and may fill them with confusion or even guilt unless they are informed about them.

Because children with disabilities often do not have the same opportunity to mix with other children in an unsupervised way, they can miss out on one of the most common forms of sex education: children's games, jokes, stories, songs, and private discussions. Therefore, older persons should make a point to share basic facts of life with these children in a relaxed, trustful way, inviting questions and answering them honestly.

Equally important, of course, is to make arrangements for children with disabilities to mix with, play with, and join in the secrets of the other children in their community.

The need to accept a range of social relationships

People with disabilities have as much right to sexual relationships as people without disabilities. But opportunities for close relationships may not arise as often or as easily for people with disabilities. Many of the ways that young people traditionally meet may not be available to them.

It is therefore not surprising that some people with disabilities enter into love relationships that are less traditionally accepted—sometimes 2 members of the same sex, or 2 persons from different castes, races, social levels, or other social groups between which relationships are not locally approved.

Before condemning such a relationship, it is important to consider what benefit or harm it is providing for each of the partners. If both partners have entered the relationship willingly and seem happier and more whole because of it, those concerned should perhaps be supportive—even if the relationship is not socially approved. This should be the case whether or not the people have disabilities.

Many groups and organizations of people with disabilities are outspoken in defending the rights of persons to live in ways that are different from the norm, as long as no one is being forced or hurt. They know from personal experience that society is often cruel and unfair in its treatment of those who are different. So they try to take the lead in the re-education of the community toward a more flexible and accepting attitude with regard to human variation. What is important when people have a relationship is not who they are, but that they truly care for and respect each other.

On the other hand, children and young people with disabilities are sometimes in situations where they can more easily be taken advantage of or abused, so precautions need to be taken. It is important to communicate openly with children and young people, with and without disabilities, about their physical desires and needs. Caregivers must explain to young people the idea of "consent," and their right to give or refuse consent for physical contact, and teach them to ask for consent as well. Young people should also know who they can talk to if abuse happens.