

CHAPTER 2

Organizing for disability-friendly health care



We can make our voices heard by advocating for our rights and ensuring that disability issues become a priority.



Women with disabilities have a right to be healthy and to have access to good care. But few health centers, clinics, and hospitals are designed to be used by women with disabilities. Also, they may be too expensive, or too far away, and you may not have a way to get there, pay for the medicines or for treatment, or be able to communicate with the health workers.

In this chapter we tell the story of one woman, Delphine, and how she worked with other women in her community to solve a health problem she had. Delphine and her friends discovered that a lasting solution to her problem involved looking beyond Delphine's situation. The health problems of a woman with a disability, like most health problems of all women, are almost never her problems alone—her health problems are a community issue.

Like Delphine and her friends, you and other disabled women you know can work together to have access to good health care, to identify the root causes of the problems in your community, and work to change them.

Delphine's story

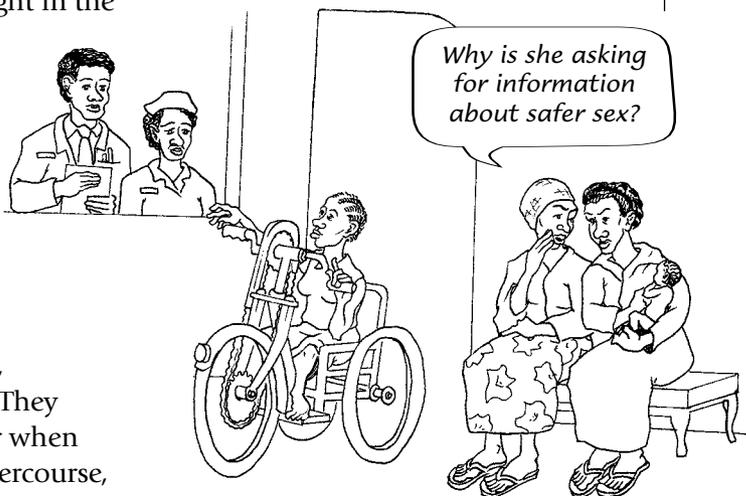
Delphine has cerebral palsy. She uses a wheelchair to get around. She has a boyfriend who does not want anyone in the community to know he is having a sexual relationship with a woman with a disability. He is a "midnight husband," who comes to see her only when it is dark at night, and leaves before it gets light in the morning.

One day Delphine realizes she has an unusual discharge from her vagina. She tries local remedies to cure it, but nothing helps. The discharge starts to get worse, and she also gets a pain in her belly. Finally, Delphine goes to a clinic. They do not want to believe her when she says she has sexual intercourse, and she does not want to give them the name of her boyfriend because she fears he will not see her any more.

At the clinic they insist her disability must have caused her problem and try stretching her arms and legs, which makes her muscle spasms worse, and they try giving her medicines to relax her muscles. The medicines do nothing to help the pain in her belly, which gets worse and worse. She also starts sweating and gets a high fever, and has pain when she passes urine.

Delphine remembers a friend telling her about a group of disabled women who meet together and she goes to them to tell them her problem. They have recently been studying a book someone gave them called *Where Women Have No Doctor* and they read about how infections can be passed from one person to another during sex.

Two of the women in the group volunteer to go with Delphine to the clinic again. Together they are able to convince the doctor that she has had sex. So the doctor does the proper tests and discovers Delphine has a serious sexually transmitted infection in her womb caused by gonorrhea and chlamydia (see Chapter 8). He gives her the proper medicine. He also tells her that her boyfriend will also need to take the medicine, and that he should use condoms when they have sex so he does not pass an infection to her again.

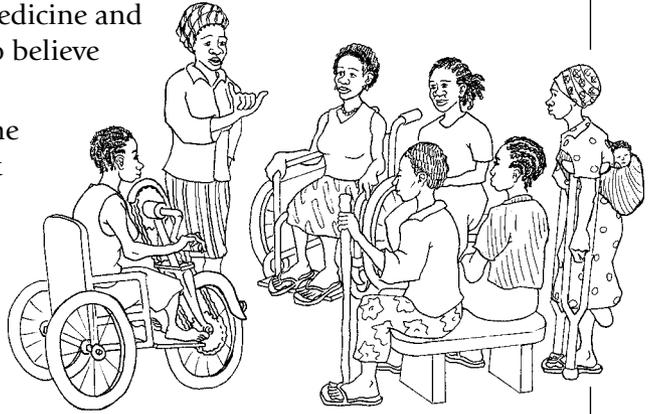


LOOKING FOR THE ROOT CAUSES OF PROBLEMS

After Delphine had taken the medicine and was feeling better, she wanted to believe her health problem was over.

But after reading the book, she knew this was not true. The next time her boyfriend came to see her, she would get infected again if he did not also take the medicine and use condoms.

Delphine discussed the problem with the other disabled women in the group, and together they decided to play a game called "But why..." to help everyone identify all the conditions that created the problem.



WHY did Delphine get sick from gonorrhea and chlamydia?

Because she was infected by her boyfriend.



BUT WHY did the health workers at the clinic stretch my arms and legs instead of treating my discharge?

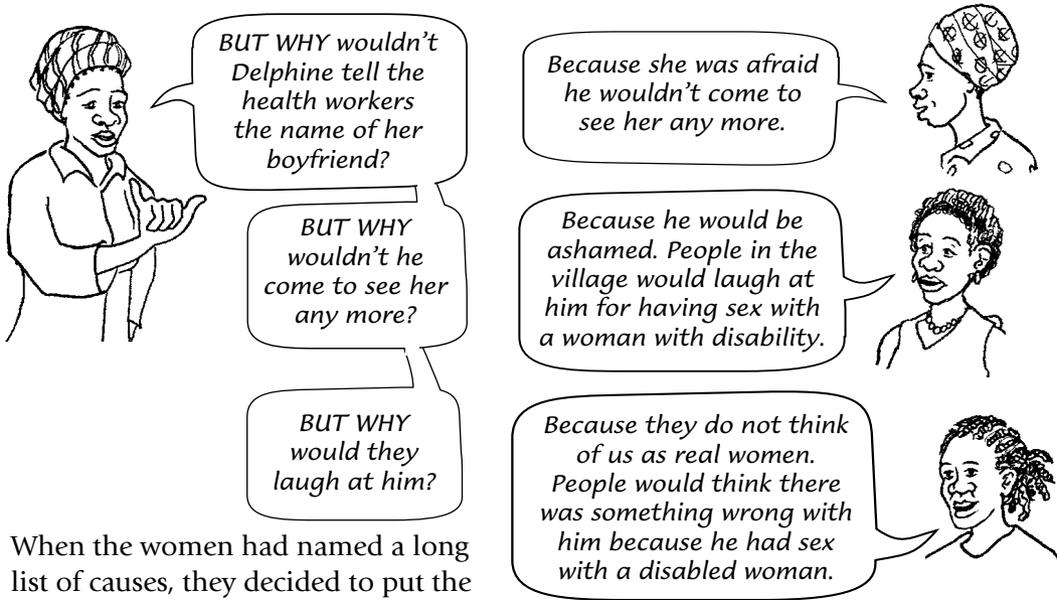
Because they believed your disability was the health problem. They did not believe it was possible for you to have sex.



BUT WHY did they not believe it was possible for me to have sex?

Because many health workers do not see a person with a disability as a normal person with normal feelings. They do not understand that disability is not a barrier to sex.





When the women had named a long list of causes, they decided to put the causes in groups.

This way it was easier to see the different kinds of conditions that cause health problems and the different areas in which solutions had to be found.

<u>PHYSICAL CAUSES</u>	<u>WRONG IDEAS ABOUT DISABILITIES</u>	<u>GENERAL SOCIAL CAUSES</u>
<ul style="list-style-type: none"> • Gonorrhoea germs • Chlamydia germs • Women's bodies are more susceptible to STIs than men's bodies, especially if there are cuts or sores in the vagina or on the cervix. • Poor nutrition and many pregnancies can make women weak and less able to fight disease. 	<ul style="list-style-type: none"> • Disabled women are not seen as "real" women. • Disabled women can't have sex. • Doctors believe most health problems disabled women have are caused by disability. 	<ul style="list-style-type: none"> • Men often have other sex partners. • Men won't use condoms because it's "unmanly" and spoils sexual pleasure. • Lack of education about STIs. • Female condoms are expensive and not easy to get. • Men are ashamed of disabled partners.

Health care is a human right for all

Good health care prevents problems that make disabilities worse. Good health care also prevents health problems caused by disabilities. Treating a modest problem, at the right time—such as treating a pressure sore caused by sitting or lying in one position too long—stops it from turning into a life-threatening crisis.

We must promote good health with good nutrition, physical activity, reproductive health care, and prevention and treatment of health problems. We must also change the conditions of our lives so we have power over our own health.



In Thailand we pay less than US\$1 for medical care in state hospitals.



Health care must be made available to all disabled women, regardless of social status. Good health care includes free or low-cost health services, insurance or access to funds to pay for health care, and public transportation that is easy to use. This is especially important for women who are isolated or poor.

I know this lump might be dangerous. But what shall I do? The medicines are too expensive and the clinic is very far. Besides, everyone will probably laugh at me.

Poverty and health

Economic and trade policies worldwide have created more poverty, fewer resources for health care, and greater social differences between people. These inequities have made it harder for women to get health care for themselves and their families. User fees for health care are another barrier to health services. Other financial barriers, such as the cost of medicines and transportation, can make health care unaffordable.



It is very hard for women with disabilities to get health care. In most countries in Africa, for example, only 1 out of every 100 people with disabilities has access to the health services he or she needs. Added to the lack of services and facilities is the cost, distance, physical barriers, and harmful attitudes. Even when a woman has some money, the health services available are rarely appropriate for the health needs of women with disabilities, especially their reproductive health needs.

What good is it to go for a checkup? Even if the checkup is free, the medicines won't be. My family can't afford to buy another medicine for me.



Breaking barriers in Nigeria

Ekaete Judith Umoh is from the oil-rich Niger Delta region of Nigeria and is a polio survivor. Today, she is sometimes called “Mama Mainstream,” because of her insistence that all health care programs include girls and women with disabilities at every step of program planning and services. “She who wears the shoe knows where it hurts the most,” Ekaete says. “We are women and entitled to whatever services are provided for other women in the society.”

In 2000, Ekaete founded the Family-Centered Initiative for Challenged Persons (FACICP), a non-governmental organization that works to ensure that the rights and needs of disabled people, especially women and girls, are respected in all health care and development programs. Ekaete describes FACICP’s Health Care Without Barriers Project: “The aim of the project is to make reproductive health care services, including information on HIV/AIDS, accessible to women with disabilities. We are in the process of translating simple reproductive health information into Braille for blind women, and we now hold monthly meetings to discuss sexuality education, especially as it relates to pregnancy, parenting, and disability.”

We are women and entitled to whatever services are provided for other women in the society.



FACICP also works in partnership with the Society for Family Health (SFH), an organization that provides health education about a wide range of women’s health issues. “SFH agreed to invite us to any training program or workshop they conduct to further raise awareness of the health needs of women with disabilities,” Ekaete

told us. FACICP works with SFH to make sure workshops are held in places with access for wheelchairs and that sign language interpretation is provided, so deaf women can fully participate. With SFH training, disabled women can become family health educators in their communities.

Ekaete and her colleagues are also challenging governments, multilateral organizations, and civil society to begin using a “disability lens” in all their development work. They have proposed, for example, that World Bank-funded projects include people with disabilities in training, technical assistance, consultations, project funding, and distribution of material resources. This will ensure that the health rights and needs of people with disabilities are always in focus and not forgotten. As Ekaete reminds us, “People with disabilities are everywhere, entitled to the same rights and privileges enjoyed by the citizens of any community.”

Making health services easier to use

Together disabled women and health workers can make health services better serve women with disabilities. They can find ways to make it easier for women with disabilities to get into a health center, to use the equipment, to increase knowledge about disabilities, and to improve the attitudes of health workers towards disabled women. Most of these changes are not difficult or expensive to do.

These changes will also help many others, such as older people who do not move as easily as when they were young, or anyone who has had an accident and is temporarily disabled with a broken leg or arm.

Ideas to make health services more disability-friendly

- Offer weekly or monthly home visits to people who live far from health centers.
- Offer free health services for women with disabilities.
- Make equipment easy to use.
- Provide public or private transportation to the health center. Transport must be easy to use for people who use wheelchairs, crutches, or have difficulty walking.

For more information about access, see *To learn more*, beginning on page 376.

BARRIERS TO HEALTH CARE

- For a woman using a wheelchair or crutches, most health centers and hospitals are difficult to get to. They are often far away and there is no transport a woman with a disability can easily use to get there.
- Equipment and supplies such as lower beds or good quality catheters, are often not available.
- The hours the health center is open may not be convenient.
- There may be few women doctors even though many women feel embarrassed to go to a male doctor.
- Health workers do not know how to communicate with someone who is deaf, and there are no health information materials for women who are blind.
- Health care workers, including nurses and doctors, may not be very well trained, or may not know much about disability. They may have wrong ideas about disability and may not listen to you.
- Health services can be expensive and you may have to bribe someone before you can meet with a health worker (corruption).

Most health workers do not listen to us because they think we're useless. If we're lucky enough to be examined, they just do the test quietly. And if we ask questions, they just shout at us.



SUGGESTIONS TO MAKE CLINICS AND HOSPITALS EASIER TO USE

Clinics or hospitals must:

- be nearby and there must be transport available to reach them.
- be easy to use for people who use wheelchairs or crutches, or have difficulty walking.
- have ramps or lifts as well as stairs.
- have toilets that disabled women can use.

Clinics and hospitals must also have trained staff members who can communicate effectively with people who are deaf or blind, or who have cerebral palsy, and who can make sure that women who have learning difficulties understand what is happening in the clinic.

Clinics and hospitals can:

- train everyone about disability.
- include women with disabilities as health workers and staff members in clinics and hospitals.
- put handrails or ropes around the building so that people who are blind or do not see well can find their way inside safely.
- organize activities about health and women with disabilities.
- provide monthly or regular counseling sessions for women with disabilities.
- make it easy for women with disabilities to combine as many appointments in different departments as necessary during the same day they go to the clinic or hospital. Some health centers allow village health workers to make these appointments for women with disabilities.
- make information on how to use health services easy to obtain and understand.
- provide health information in different languages.
- provide blind women with health information in Braille or on audio cassettes.
- encourage health workers to use simple, clear language and pictures to illustrate what they are saying to women who have trouble learning or understanding.
- train health workers to communicate with women who have problems with speaking clearly.
- train staff members in sign language so they can give health information to deaf women.

A written list of your health problems may help you so you do not forget!



A clinic will be easier for deaf women to use if even one health worker knows the sign language used among deaf people who live in that community. If there are no formal sign language classes close to the clinic, perhaps a clinic worker can learn sign language from the national deaf association, or learn sign language from a deaf person who lives nearby. They can also use a local sign language dictionary if one is available. Even without using formal sign language, health workers can use gestures to communicate. Deaf women themselves will be the best people to tell health workers the type of communication that works best for them.

See pages 369 to 371 for some health-related sign-language suggestions.

Community health workers can provide care

In many countries, the skills needed to care for disabled women are considered special and provided only by doctors. Yet many of these services could be provided at lower cost by trained community health workers, teachers, and rehabilitation workers.

Bringing services to disabled children

Field workers from the Hospital and Rehabilitation Centre for Disabled Children in Kavre, Nepal support disabled children throughout Nepal. These trained field workers provide disabled children with treatment for their pressure sores, and provide physical therapy and exercises to strengthen affected muscles and prevent contractures. Field workers also provide aids so the children can move about in their communities more easily.

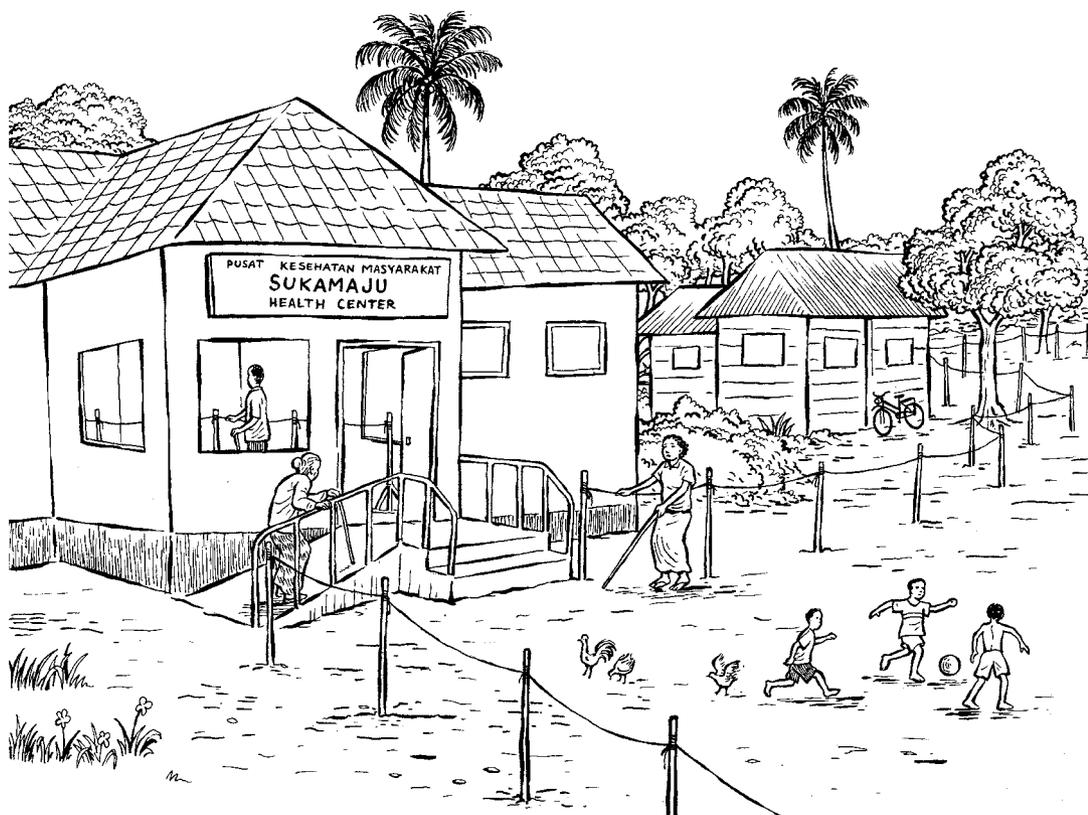
For more information about community-based support for people with disabilities, see *Disabled Village Children*.

Low-cost ideas to make health center and hospital buildings easier to use

Buildings can be designed to welcome all people or to keep some people out. It is amazing what a few good pathways, ramps, handrails, staircases with shorter steps, lifts (elevators), larger toilets, or floors that are not slippery can do to make it easier for people to get in and use any building.

Handrails (or ropes)

Handrails or ropes along pathways leading to a building and along the walls inside will help people who are blind, or who have balance problems or difficulty walking, to get in and find their way around.



Roped pathways and smooth road surfaces with textured edges make areas around health centers easy to use. Textured edges can help women who are blind or do not see well.

Doors

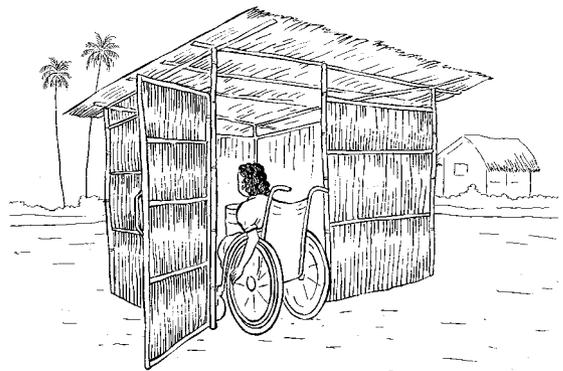
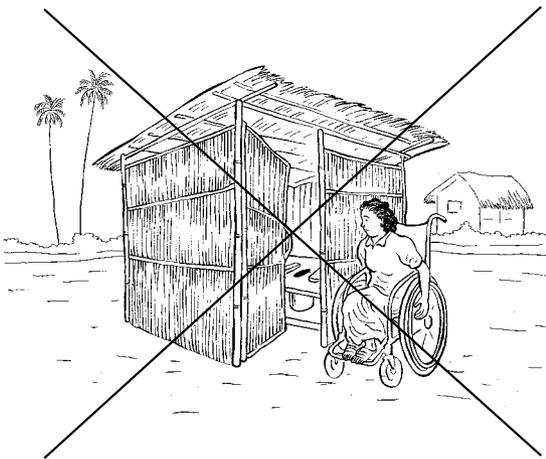
A door handle is easier to use than a round door knob. People who cannot easily move their hands can often press down on a handle. Most people who use wheelchairs also find handles easier. And anyone who is carrying something will always find a door handle easier to open.

You can change a door knob into an easy-to-turn door handle by welding a metal plate onto the door knob. Put the handle low enough for easy reach by someone of small stature or someone who uses a wheelchair.

If a door is hard to open, you can use oil, grease, or candle wax on the hinges. Then the door will swing more easily.

Also, doors sometimes do not leave space to move a wheelchair into a room. If the space is small, such as in a toilet, try to make sure the door opens out into the bigger space or room. When a door swings into the smaller room, it can make it hard for someone to move in and out of the room or space. Sometimes, doors can be made to slide if space is limited.

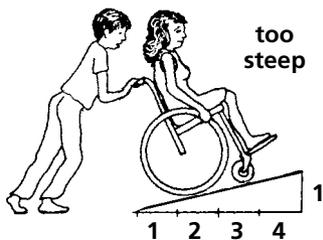
The doorway itself should be wide enough for a person in a wheelchair to pass through. It should leave enough space for her wheelchair and her hands on the wheels.



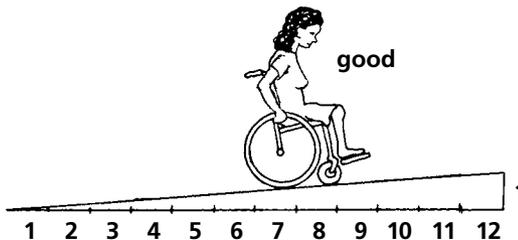
Often you can change the hinges on a door so it opens the other way.

Build ramps

Ramps make it easier for many people to get in and out of buildings and public places such as health centers, schools, and libraries. Ramps not only help wheelchair users, they also help people who have a hard time walking and people with temporary injuries.



This ramp is 4 times as long as it is high. It is too steep for most people to use, except for short distances.



Ramps can be between 8 to 12 times as long as they are high. This ramp is 12 times as long as it is high. This slope is easier for people who use wheelchairs.

Toilets



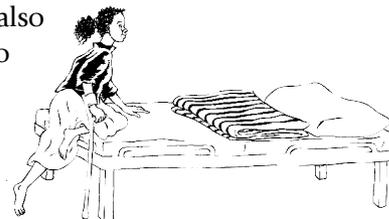
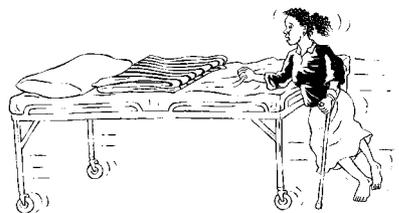
If you use a wheelchair, toilets should have enough space for you to move around and transfer from your chair onto the toilet seat. It is easiest for you to get onto the seat if the toilet is at the same height or a little lower than your wheelchair seat. If there is not a seat (in a squatting toilet or latrine), or if the seat is too low, you can make a simple box seat with hand-holds and an opening. You can also put a bar or a hand-hold on the wall so you do not fall (see page 123.)

Hospital beds

Many people, not just people with disabilities, complain that hospital beds are difficult to get onto. These beds are usually higher off the ground or floor than the beds people sleep in at home. It is easier for health workers to take care of sick people if they do not have to bend down to reach them in a lower bed.

But when people are sick or disabled, getting onto a high bed can be very difficult. And because the beds usually also have wheels, it can be dangerous, because the bed can start to roll away from the person who is trying to get onto it.

If some beds in a health center have no wheels and are low to the ground, everyone could choose the bed that works best for them.



To the health worker:

LEARNING ABOUT DISABILITY

Doctors and other health workers are usually trained to treat only people without disabilities. They often learn very little about disability in their education. Their only contact with disabled people may be in trying to 'cure' their disability.

Health workers need to learn more about disabilities. They have to learn how a specific disability may affect aspects of a woman's life, such as getting pregnant or growing older.

One good way for health workers to learn more about disability is to include women with disabilities in training programs. Health workers will gain confidence by learning from the experiences of women with disabilities, and they will learn how to best teach health workers to make their care disability-friendly.

I'm so glad you suggested that I examine your chest. The reason you have been getting out of breath is because you have asthma. It has nothing to do with your disability.



Listen to what a woman with disability tells you about her health. Later you can ask her whether or not she feels her disability affects her health problem.

Health workers learn from women with disabilities

The health ministry in Uganda surveyed and talked with midwives and traditional birth attendants across the country to find out what information they needed to do their jobs better. Several of them said they needed more information about how to help women with disabilities.

Now, the health ministry in Uganda is beginning to organize training sessions to share more information about disabled women's health. Women with disabilities help lead the training sessions. By sharing their experiences with health workers, women with disabilities can answer questions about good ways to treat disabled women. And, health workers and disabled women are able to learn from each other.



Next week, the Blind Women's Association will speak to us.

Wonderful! I need to know how to help a woman who is blind get information about family planning.

When a woman with a disability comes to see you for a health problem, remember she is a woman, just like any other woman. First, ask her why she has come to see you and how you can help her. Do not assume it is because of her disability.

Encourage her to ask questions. That way, she can explain her problems. Respect her opinions. After all, she understands her health problems better than anyone else and can make good decisions about her treatment.

Help her relax and give her time to express her unspoken questions. This will help her not to be afraid. Sometimes a woman with a disability may not have the confidence to ask questions about what is really worrying her. Or she may not have enough privacy. But you can help reduce the fears of women with disabilities, help them become more confident, and get the information and care they need.

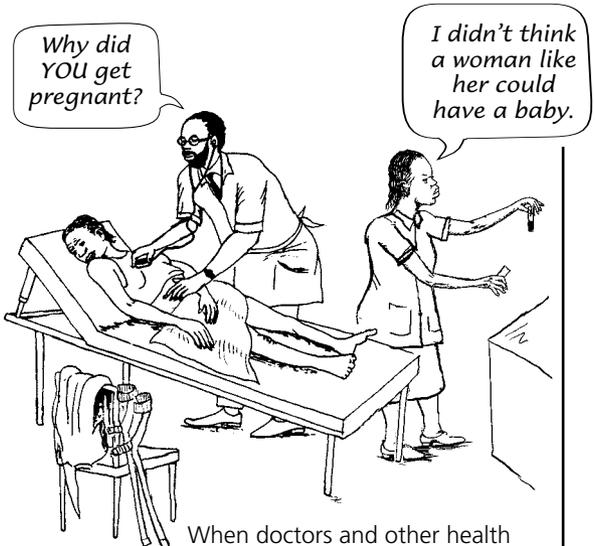
Ask people with disabilities how they would like you to do things. And when they ask questions, you do not have to have all of the answers. It is fine to admit you do not know something, and then offer to find the information they need.



In my ideal clinic the health worker would say: "Is there something about your disability you think I should know? Tell me about how your disability affects your health care."

Respect

Anyone who is concerned about the health of a woman with a disability should know how to care for her in a sensitive way. Anyone who provides her health care must always treat her with dignity and respect. Unfortunately, people sometimes need to be reminded of this. The woman should be encouraged to talk about what she thinks is causing the problem and how she would like to solve it. This way a health worker will learn to understand different disabilities. Working together reduces conflicts and confrontations, and brings the best results!



When doctors and other health workers know little about disability, their attitudes can humiliate a woman with a disability.

HELPING WOMEN WITH PARTICULAR DISABILITIES

A woman who is blind or has difficulty seeing

- Unless it is an emergency, do not touch the woman before telling her who you are.
- Do not think she cannot see you at all.
- Speak in your normal voice.
- If she has a stick, do not take it away from her at any time.
- Say good-bye before walking away or leaving.

Explain to me where I am and guide me to a chair or exam table. Do not leave me in the middle of a room.



A woman who is deaf or has difficulty hearing



Look at me and not at my sign language interpreter or at the family member who interprets my home signs.

- Make sure you have her attention before speaking. If she is not facing you, touch her gently on the shoulder.
- Do not shout or exaggerate your speech.
- Look directly at her, and do not cover your mouth with anything.
- Ask her what is the best way of communicating.

A woman who has difficulty moving

- Do not assume she is mentally slow.
- If possible, sit so that you are at eye level with her.
- Do not move any crutches, sticks, walkers, or wheelchairs without the woman's permission or without arranging for their return.
- If she is a wheelchair user, do not lean on or touch her wheelchair without her permission.

Speak directly with me and not to my family member or caregiver.



Do not pretend you understand me if you do not.

A woman who does not speak clearly

- Even though her speech may be slow or difficult to understand, this does not mean she has any difficulties learning or understanding.
- Ask her to repeat anything you do not understand.

- Ask questions she can answer by "yes" or "no."
- Let her take as much time as she needs to explain her problem. Be patient.

A woman who has trouble learning or understanding

- Use simple words and short sentences.
- Be polite and patient, and do not treat her like a child.

Give me one piece of information at a time and repeat it if necessary.



Working for change

Here are some suggestions you can use to work together with health workers to improve health care services. These activities can be used to:

- raise awareness about accessibility, availability, and the attitudes that make it hard for disabled women to find and get good health care.
- identify actions that can improve health care for disabled women.

Meeting in a group to share personal experiences of health care barriers can build each woman's confidence.

STEP 1. Everyone has something to offer

To help everyone feel comfortable, and to show how each person has a contribution to make, you can ask each woman to tell about something she does well or that she is proud of. (No one has to talk about herself if she does not want to.)

For instance:



Kranti is a good cook.



Maria keeps the peace between her sisters.



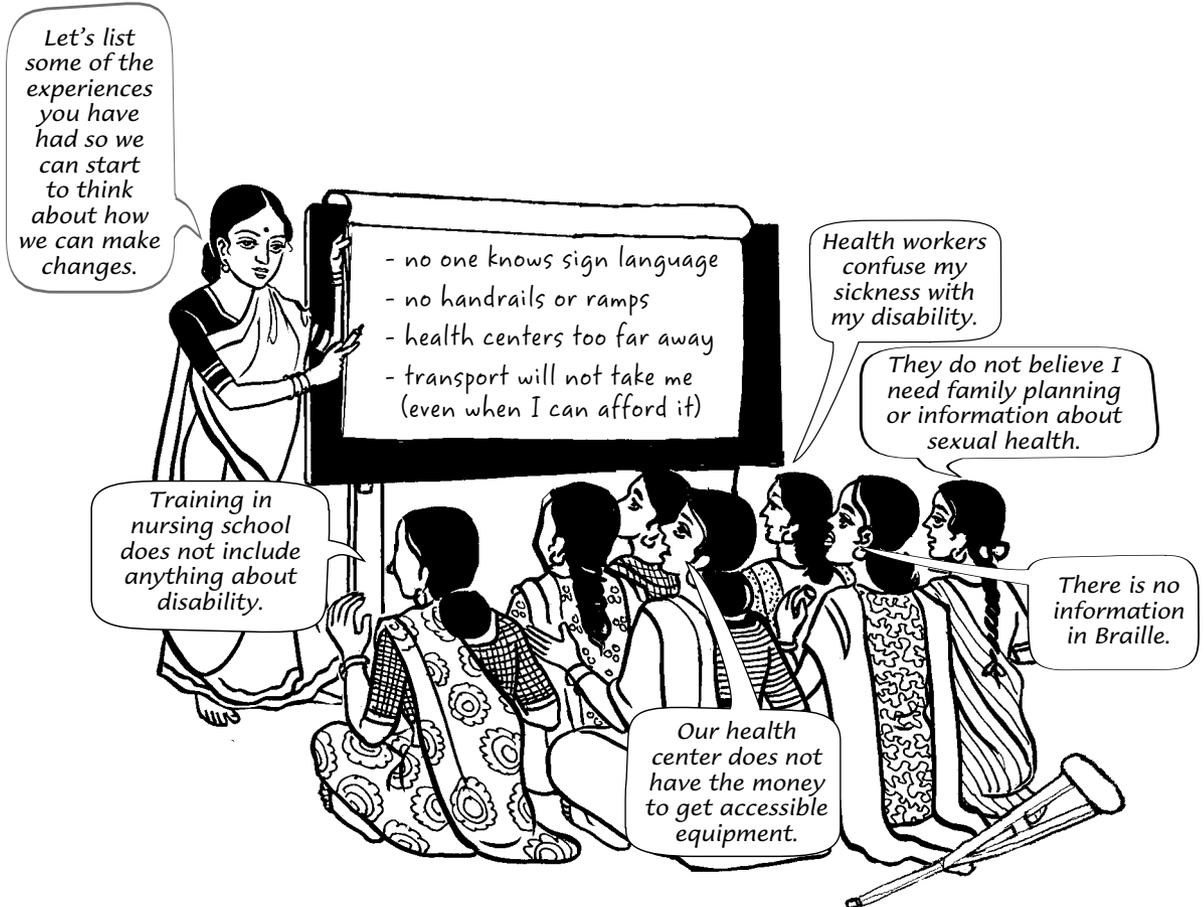
Rania is a skilled midwife and has delivered hundreds of babies.



Adetoun is a good storyteller. The children in her family and neighborhood love to listen to her.

STEP 2. Share experiences about health care access

Ask each person to tell about something she has seen or experienced that has prevented a woman with a disability from getting good health care. Make a list, in no particular order, of the difficulties the women describe.



STEP 3. Role plays to learn about barriers to good health care

Use role plays to deepen everyone's understanding of the difficulties they have listed. Divide the group into several teams that include both health workers and women with disabilities. Ask each team to spend a few minutes preparing a role play about a disabled woman who has trouble getting good health care. Encourage everyone to participate.



People can switch roles— a health worker acting as a disabled woman, and a disabled woman acting as a health worker.

Role plays

One of the best ways to help people understand real-life problems or situations is by acting them out. When followed by an organized group discussion, a role play can help a group look at attitudes, customs, and patterns of behavior, and how they affect women's health. Role playing is useful for developing awareness and exploring alternative solutions to social problems.

Role playing should be fun—but it should be taken seriously. Actions and characters may be exaggerated at times, but they should basically be true to the way things and people really are. Role playing can be done with little or no practice ahead of time, and no memorizing of parts.



(For more information about role plays and other educational theater, see *Helping Health Workers Learn*, Chapters 14 and 27.)

Role play possibilities

Here are some role plays you can suggest if the group has trouble coming up with ideas of its own:



After each role play, ask the “actors” to return to the group. Invite the group to ask each other questions about the role plays that will help deepen their understanding of the problems disabled women have in getting good health care.

STEP 4. Visit a health center

After the group has identified some general barriers to good health care access, they can visit local health centers to take a closer look at things that can cause problems for a woman with a disability. Divide the group into 2, if there are enough people, with at least one health worker in each group, and visit one or more health



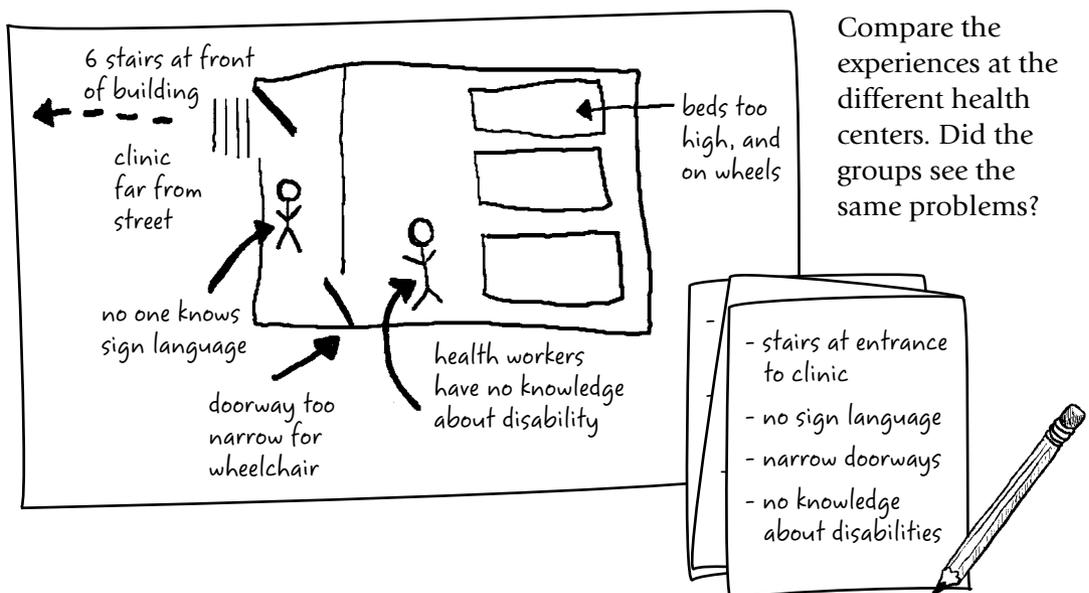
A group will be taken more seriously than an individual. Decide ahead of time who will speak for the group and what that person will say. You may need to get permission ahead of time to make your visit.

centers. (If possible, do not send a group to visit a health center where the health workers in that group work.) Ask 1 or 2 women in the group to write down or make note of any problems and obstacles they find. Also ask them to note anything they find that is helpful for women with disabilities.

The trip to the health center can also be used as an example of how women can help each other and work together to use each other's strengths to overcome problems. For example, wheelchair riders can guide blind women, and blind women can support women who need help with walking.

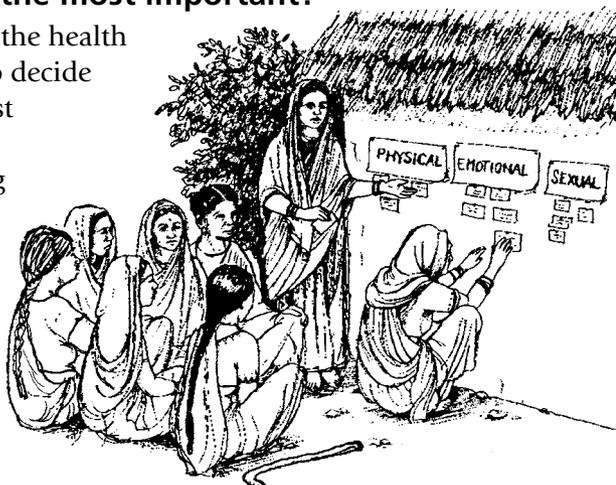
STEP 5. What did you find at the health center?

When you return from the visits, have each group describe the problems they found and things that were helpful to women with disabilities. Also ask each group to describe how they were treated by the director of the health center and the staff. You can make a list or draw a map of the problems they found.



STEP 6. Which problems are the most important?

Discuss the problems seen during the health center visits and ask the women to decide which ones they think are the most important to change, or that they would like to change first. Making improvements to health care services can take planning and time. Your group may want to study the list to see which things you can change quickly, and which may take longer to change. Ask them to talk about why the problems they have chosen are important to work on, and what their hopes and wishes are for the change they may bring if these problems are improved.



STEP 7. An action plan for improvements

Once the group has chosen 1 or 2 problems that make it difficult for women with disabilities to get good health care, they can work on a plan to solve these problems. Ask the group to discuss different ways they can solve each problem, and ask them to think about other people who can help them make these improvements. Work out the steps that will be needed to make these improvements and decide who will be responsible for which step. Then, take action!

