

Women's Health Exchange

A Hesperian Foundation publication
for education and training

Issue No. 11, 2006



Breaking barriers in Nigeria Access to health care for women with disabilities

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. FACICP's Health Care Without Barriers Project is specifically focused on including the access needs and participation of

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

— Ekaete Judith Umoh

women with disabilities in the health sector. "The aim of the project," Ekaete writes, "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."

Recently, FACICP began networking with the Society for Family Health (SFH), an organization that provides health education about a wide range of women's health issues. "They (SFH) have 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 is working 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."

For more information,
email: facicp4all@yahoo.com

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Disability and women's health

For most women with disabilities, the disability by itself is not usually a health problem. But women with disabilities often have health problems that go untreated because of physical and social barriers in their communities.

Why do women with disabilities get such poor care?

Finding and getting good health care is hard for a disabled woman. She often has less money than most people in her community and therefore cannot afford health services. Health centers and hospitals are often not accessible, because they are not designed for use by everyone. Also, transportation can be a problem, because even when buses and taxis are available and inexpensive, they often will not take women with disabilities.

In addition, many health books and training manuals do not include information about disabilities, especially about health problems faced by women with disabilities. This means

doctors and other health workers may not understand a woman's disability. Also, health workers often need to be taught that disabled women's health problems are not always just another part of the disability. Women with disabilities can have the same health problems any woman can have.

Attitudes create barriers to care

Sometimes, community attitudes about disability are a bigger problem for disabled women than the limitations in activities she lives with every day. These attitudes and fears create social and physical barriers that prevent many women from getting health care.

Community attitudes also affect how a disabled woman sees herself. She is more likely to have lower self-esteem than other women — thinking that she is of less value than other people. This may mean that she ignores her health problems or feels she does not have the right to health care.

This issue of the *Women's Health Exchange* will help women with disabilities and health workers learn to work together to make health care better and more accessible for everyone. We hope this issue of the *Exchange* will also help doctors, nurses, and other health workers better understand the problems of getting good health care, and be better prepared to serve women with disabilities.



A Health Manual for Women with Disabilities

This new manual, which the Hesperian Foundation will publish in Fall 2006, is being produced with the help of over 40 groups of disabled women in 27 countries. The manual will enable women with disabilities to better care for their health and to work with others for greater inclusion in health care systems and community life. The manual will include information about:

- Basic health care challenges for women with disabilities.
- Sexuality, family planning, sexual and reproductive health, childbirth, and parenting.
- Self-defense, and preventing abuse against women with disabilities.
- Self-esteem and empowerment, including adaptations and aids which can improve accessibility and mobility.
- How caregivers can look after their own physical and emotional health, as well as the needs of the women they care for.

As with all Hesperian publications, this manual will include vital health information, written in simple language and illustrated on every page. It will give examples of how women with disabilities from around the world, with their friends and supporters, have insisted they be included in decisions about their health care and community life. The manual will also show how health workers can provide better health care to women with disabilities.

COMING SOON

For more information,
email: wwd@hesperian.org
or write to Hesperian.
See page 8 for contact
information.

Training guide

Improving health care for women with disabilities

Both disabled women and health workers have important information about how health services work and do not work for women with disabilities. Together they can find ways to improve access and availability of health services, increase knowledge, and change attitudes of health care providers towards disabled women. When they put their points of view together, improvements become possible!



Goals of this training guide

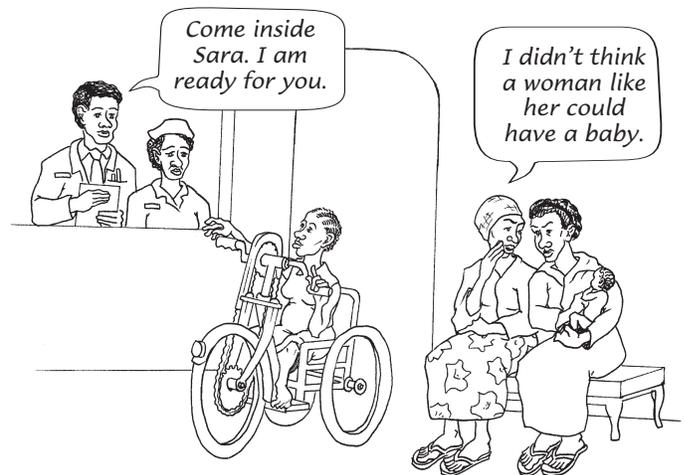
This guide is designed to be used by disabled women and health workers — working together — to improve health care services for women with disabilities. The activities in this guide can be used to:

- raise awareness about the accessibility, availability, and 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.

Women with disabilities change health access in Uganda

The Disabled Women's Network and Resource Organization in Uganda (DWNRO) works to make health professionals become more aware of the needs of women with disabilities. Their main concerns are accessibility, availability, and attitude. For example, when pregnant women with disabilities are treated poorly by hospital personnel, they lose self-confidence and do not go back for prenatal care. They can have problems with the pregnancy later, or with the birth, that could have been prevented with regular check-ups. The DWNRO held regional workshops for doctors and midwives on the lack of access to hospital wards and services, such as postnatal care, weighing scales, exam tables, and adequate communication with deaf and blind women. Some hospitals have made wards more accessible, and a deaf women's group recently trained a group of midwives in sign language. The DWNRO is now working to make women with disabilities aware of these services, so they will demand them.

For more information, email: dwnro-ug@infocom.co.ug



Wrong ideas about disabilities are common. Women need support from health workers to seek the care they need.

STEP I. 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.



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



Maria keeps the peace between her sisters.



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

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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.)



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Role play possibilities

Here are some role plays you can suggest if the group has trouble coming up with an idea of their own:

A woman with cerebral palsy wakes up one day with a fever, chills, and diarrhea. She is the fourth person in her family to get sick like this.

She goes to the local health center where a health worker asks her lots of questions about her disability, but nothing about her sickness.

A deaf woman cannot get anyone at a clinic to understand what she wants.

A woman in a wheelchair cannot get a taxi or bus to take her to a health center.

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, you 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 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.

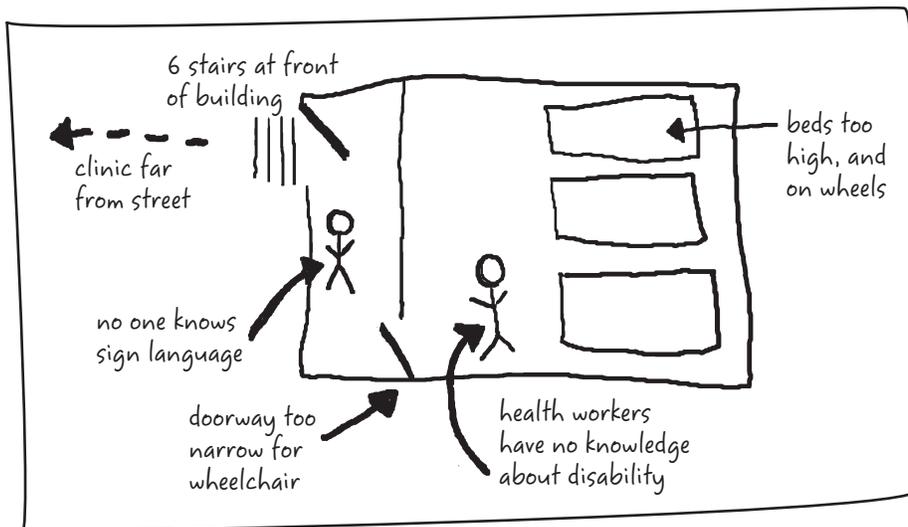


A group will be taken more seriously than an individual. Decide ahead of time who will speak for the group and what that person will say. You may need to get permission ahead of time to make your visit.

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.



Compare the experiences at the different health centers. Did the groups see the same problems?

- stairs at entrance to clinic
- no sign language
- narrow doorways
- no knowledge about disabilities

Training guide

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 or that they would like to change first. Ask them to talk about why the problems they have chosen are important to work on. How can the changes they hope for make a difference in their lives? 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.



STEP 7. An action plan for improvements

Once the group has chosen one or two problems that make it difficult for women with disabilities to get good health care, you 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!

Amina, your brother is a carpenter. He built a good wheelchair ramp at your house. He could show the staff at the hospital how easy it would be to build ramps and handrails there.

I will speak with the other health workers at the health center where I work. I will show them how we can easily make the exam tables and the beds lower and safer.

My uncle is a taxi driver. I will ask him to speak with the other taxi drivers about stopping to give us rides.

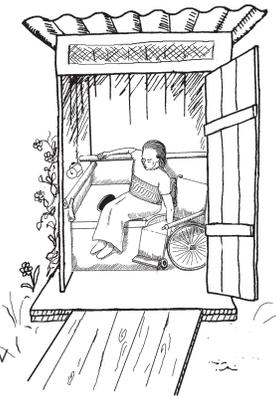
Namita, you know sign language. You could teach it to some of the health workers.



Small steps make big changes

Sometimes the problems in our communities seem too big, and change for the better seems impossible. But even the smallest steps can lead to big changes. Here are some stories from women around the world who have taken small steps to make important changes in their communities.

Alicia lives in Mexico. She is a polio survivor and uses a wheelchair. One day, Alicia went to a local park with several other disabled women, where they found they were unable to use the public toilet because it was not accessible. The next day, Alicia went to the office of the park director and asked him to make the toilet accessible. He was sympathetic but said there was no money to make changes like that. Alicia said she could show him how to do it without spending any money. All he had to do was adjust the door on the toilet so it would open outward instead of inward, and then it would be wide enough for a wheelchair to enter. The change was made, and now the park is accessible to everyone.



Tina lives in the Republic of Georgia. Tina is trained as a cosmetologist and beautician. She has a spinal cord injury caused by an accident several years ago and uses a wheelchair. Three years ago, she led a 6-month training of 15 disabled women on how to apply make-up and remove unwanted hair. All the women were able to get jobs with their new skills. Today, some of the women work in beauty salons in the city, some work in villages, and some work from their homes and have regular clients. The women who work at home also make their own creams and lotions. All the women make enough money so they do not feel they are a burden to their families. Working has brought them into contact with many people, and they feel like equal members of the society and enjoy a busy social life. Two of the women are now married.



Lizzie is from Zimbabwe.

One of her arms was amputated after a car accident when she was 2 years old. Lizzie knew that most disabled women in her community never got health exams. Clinics that were accessible were too far away and too expensive for disabled women. So Lizzie called together a group of women with disabilities. Together, they learned as much as they could about family planning and cancer from Hesperian's book *Where Women Have No Doctor*. The group then persuaded an official from the Ministry of Health to meet with them. The official was so impressed with how much the women had learned, he arranged for the government to provide a free, mobile clinic to provide cancer-screening and family planning services once a month for disabled women in that community.



Rhaua lives in Namibia. She noticed how isolated disabled women are and how non-disabled people keep them at a distance. She wanted disabled women to feel more free to have fun and enjoy themselves in the company of friends and neighbors. So she started talking with non-disabled friends in the community about how to talk and communicate with someone who is disabled, and how to dance with them — especially with blind women and with women in wheelchairs and with crutches. Then Rhaua went to other neighborhoods to work with other women who were disabled. At first, many of the women were reluctant to try dancing. But eventually Rhaua convinced them to give it a try. Before long, she persuaded even more women to have fun and dance.



New from Hesperian

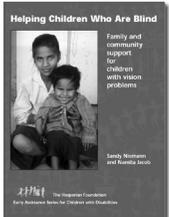
The **Early Assistance Series** books give people closest to a child with a disability — parents, family members, friends, and health workers — an understanding of the disability, and how to help a child learn and grow in the first 5 years of life.



Helping Children Who Are Deaf

by Sandy Niemann, Devorah Greenstein, and Darlena David

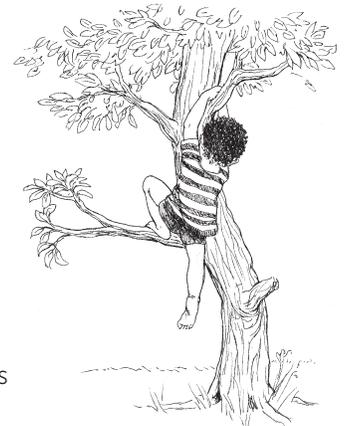
The book explains how deafness affects a child's ability to learn language and develop mentally, and describes how to foster language development through both sign and oral approaches. It also covers how communities can work together to help deaf children. 250 pages.



Helping Children Who Are Blind

by Sandy Niemann and Namita Jacob

The simple and engaging activities in this book show how to help a child with limited eyesight or blindness develop all his or her abilities. Topics include assessing how much a child can see, and teaching common activities like eating, dressing, and personal hygiene. 200 pages.



To order books or download sample chapters, please see our website www.hesperian.org, or contact us at the address below.

Resources for women with disabilities

Many organizations support or fund health care and empowerment for women with disabilities. Check with these groups for a contact in your area.

The Southern Africa Federation of the Disabled (SAFOD), P.O. Box 2247, 19 Lobengula Street, Bulawayo, ZIMBABWE • tel: +(263-9) 69356 • fax: +(263-9) 74398
email: info@safod.org • website: www.safod.org

National Council for the Welfare of Disabled Persons (NCWDP), Ground floor, SRA Building, North Avenue, Diliman, Quezon City, PHILIPPINES • tel: +(632) 926-1760
fax: +(632) 929-8879 • email: council@ncwdp.gov.ph • website: www.ncwdp.gov.ph

ABILIS, Lönnrotinkatu 9 D 14, 120 Helsinki, FINLAND • tel: +(358-9) 685 00782
fax: +(358-9) 685 00790 • email: abilis@abilis.fi • website: www.abilis.fi
ABILIS gives small grants to projects initiated by disabled persons.

Handicap International, Waterman House, 101-107 Chertsey Road, Woking, Surrey GU21 5BW, UNITED KINGDOM • tel: +(44-870) 774 3737
email: hi-uk@hi-uk.org • website: www.handicap-international.org.uk • Handicap International provides technical assistance and support to local disability groups.

The Global Fund for Women (GFW), 1375 Sutter Street, Suite 400, San Francisco, CA 94109, USA • tel: +(1-415) 202-7640 • fax: +(1-415) 202-8604
website: www.globalfundforwomen.org/3grant/ • GFW offers grants to projects that support human rights for women.

Mobility International USA (MIUSA), P.O. Box 10767, Eugene, Oregon 97440, USA
tel: +(1-541) 343-1284 • fax: +(1-541) 343-6812 • email: info@miusa.org
website: www.miusa.org • MIUSA's website includes a database of international disability organizations.

Disability World, a bi-monthly online journal of international disability news.
website: www.disabilityworld.org

Healthlink Worldwide, 56-64 Leonard Street, London EC2A 4JX, UNITED KINGDOM
tel: +(44 20) 7549 0240 • fax: +(44 20) 7549 0241 • email: info@healthlink.org.uk
website: www.healthlink.org.uk/pubs/intnews/html
Healthlink publishes **Disability Dialogue**, an international rehabilitation and disability journal. The website has links to regional disability newsletters and organizations.

You can also refer to Hesperian Foundation's **Where Women Have No Doctor**, Chapter 9, "Women and Disabilities," and Chapter 27, "Mental Health," for more information about health care and support for women with disabilities.

The **Women's Health Exchange** is a publication of the Hesperian Foundation.

The Hesperian Foundation is a non-profit organization committed to improving the health of people in poor communities throughout the world by providing tools and resources for informed self-care. We believe that people can and must take the lead in their own health care.

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