Disability and HIV

This special issue of AIDS Action is published jointly with CBR News, the newsletter of AHRTAG’s disability programme. Together we hope to raise awareness of disabled people’s sexual health needs and to explore how social attitudes to both disability and HIV make people less able to live productive and fulfilled lives.

Many disabled people and people with HIV now have much experience in challenging this discrimination. People are working together to improve their knowledge, challenge barriers they face from others and show other people creative solutions, such as the Brazilian group who describe their project on page 3.

Being disabled can make a person more vulnerable to HIV infection. Disabled people, and their carers and families, need information on sexuality, sexual health and HIV which is appropriate and enables them to take action.

Sadly, information is often not relevant to disabled people’s needs or is not available at all. For example, disabled young people may go to separate schools where the teachers feel unable to discuss HIV and sexual health. On page 4 we talk about why this information is necessary and how it can be provided.

Social attitudes and distorted media images make it hard to accept that disabled people have the same needs, desires and problems as able-bodied people. People make assumptions about our lives. Our res are often out of control. We need to know how to protect ourselves against HIV/AIDS like anyone else, with life skills to help us cope with situations that put us at risk of HIV and training and jobs to improve our economic situation.

A group for disabled young people, Uganda
Disability and impairment

An impairment occurs when part of the body is unable to work fully. This may lead to difficulties in moving, seeing, hearing and learning (sometimes called a mental handicap). Many problems caused by impairments can be overcome by using appropriate aids and equipment, acquiring new skills through education and training, and support from family and community. Disability occurs where an impaired person's activities are restricted or they are less able to fulfil their potential as human beings because of the barriers caused by society. These can be either through the way that we live, for example by making transport or housing inaccessible, or because other people's prejudices and fears make them discriminate against disabled people. Community-based rehabilitation (CBR) means enabling people with impairments to fulfil their potential within their own community.

HIV-related illnesses can lead to temporary impairment, such as being unable to walk. They can also lead to permanent impairment, such as difficulty in seeing because of eye conditions. People with HIV, even when they are healthy, are also discriminated against which makes it more difficult to find jobs or feel accepted by their community. This treatment by others can 'disable' them.

No accurate statistics exist but a commonly used estimate is that ten per cent of the world's population is disabled. What is certain is that all societies fail to take full account of the needs and rights of disabled people.

![Image of woman in wheelchair]

Learning from each other

‘Barriers set up by other people and by society are often more of a difficulty than the disability itself’, says one disabled woman.

AIDS Action highlights some key challenges.

Anyone – disabled or not – can become infected with HIV if he or she is exposed to the virus. However, although there are no figures for how many disabled people have HIV, they may be much more vulnerable to infection because of their circumstances. For example, it is often assumed that disabled people do not have sexual feelings or cannot be sexually active, and therefore do not need to know about safer sex.

Abuses of power

Disabled people are often unable to negotiate what they want with other people and may be sexually abused or exploited, as described below by a physiotherapist in Malawi. ‘A woman attending the CBR centre for repairs to her wheelchair told me that some men in her village thought that they were helping her by having sex with her. At first she did not understand what was happening and then she tried to say no. Now she tries to avoid this group of men. The women in the village resent her for the sexual attention and do not support her. The village headman ignores the abuse because his son is one of the offending group. No man will consider her as a marriage partner because of what has happened. ‘Another woman, who has a learning difficulty, came to the centre with her mother. The anxious mother explained that her daughter had recently given birth to a premature baby in a pit latrine. The woman did not understand what was happening and the baby did not survive. She would not talk about what happened, but her mother suspects rape and feels powerless to protect her daughter.’

Response to risk

Whether involved in disability or AIDS work, organisations need to consider the needs of disabled people who are worried about or have HIV or other sexual health concerns. These needs include:

Appropriate access

HIV, sexual and reproductive health services need to be accessible to disabled people. A deaf person, for example, may need an interpreter to talk to a doctor or a counsellor. People who are paralysed may need special information about sexual
activity or childbearing. Often people using wheelchairs cannot easily reach health or community centres. Young disabled people may find it hard to get access to confidential information because their parents or carers are always with them. People with learning difficulties (mental handicaps) are rarely offered sex education because they are wrongly assumed to be like children who lack sexual desires.

**Supportive environments**

Disabled people are often excluded from community activities, education, training or employment and may even be rejected by their own family or society. Yet disabled people should have the same opportunities as others to experience emotional or sexual relationships and become parents without being pressured or abused. Public education is needed to change people's negative attitudes towards disability and enable disabled people to become more involved in their local communities.

**Working together**

Disabled people and people living with HIV can learn from each other by working together to improve access to information and services and through lobbying for equality and rights. Disabled people's organisations can provide support and information about impairments to people with HIV. HIV workers often have experience in talking about sexuality and can work with staff in disability organisations who may be nervous about addressing such a difficult issue.

The AIDS and Disability Action Project in Canada has built links between AIDS and disability groups. Sharing common experiences helps to encourage more positive social attitudes and also to challenge ignorance about disability in AIDS organisations and prejudice against homosexuality by some disabled people.

---

**Left:** Information and counselling on HIV and sexual health needs to be accessible to disabled people, for example through sign language or braille.

**Right:** Disabled people have the right to lead fulfilling lives in their own community – this includes needs related to sexual and reproductive health and sexuality.

---

**Signs in a time of AIDS**

Deaf people face many barriers in communication and it is difficult to find HIV information and projects that respect and are adapted to our language. By language we mean not only Brazilian sign language but also how our methods of communication reflect our community's culture and how we relate to each other and to hearing people. We have to adapt ourselves to a hearing world which is often unwilling to understand and accept differences.

Our project, *Signs in a Time of AIDS*, began because several deaf people discovered they were HIV positive and wanted to know more about HIV. In 1994 some hearing people began information sessions in sign language, but deaf people were not involved in decision-making. So we contacted an HIV prevention NGO which was already working with other community groups. Now we have weekly discussion meetings run by deaf people who trained as peer educators to work in the deaf community. As well as using sign language, visual aids and models such as photographs, posters, sex toys – even fruit – are very helpful. It was essential for deaf people to be involved in organising the project. Hearing people rarely understand the deaf community. For example, deaf people are curious to explore the world of sensations. Sex and drugs are an important part of this, and yet these activities are disapproved of and labelled as 'promiscuous' by hearing people. There are very few schools for deaf people in Brazil and they do not teach about sexuality or drug use. We feel that teachers in these schools are frightened of these issues.

The project has already had some successes. For example, some deaf school teachers attended a recent National Meeting of People Living with HIV. In 1997 we will produce a video in Brazilian sign language which will be distributed throughout Brazil and other Portuguese-speaking countries.

**Grupo Sinais no Tempo de AIDS, NOSS, Rua Visconde de Piraia 127/201, Ipanema, 22410-001 Rio de Janeiro RJ, Brazil.**

---

**Handicap International (HI),** a French disability organisation, ran a small rehabilitation centre in Burundi for children who had developmental problems, such as being slow to walk or respond to stimulus. However, the staff noticed that some children did not fit the usual pattern of impairments, and constantly cried. They were initially classified as having learning difficulties but it became clear that the children had HIV and this was causing developmental problems. HI have decided to work with disability and HIV organisations to produce information on appropriate community-based rehabilitation for children who have disabilities because of HIV/AIDS.

*Aline Robert, Handicap International, 14 Ave Berthelot, 69361 Lyon, Cedex 07, France.*
Talking about sex and disability

Most of us have concerns about sex and want to talk to someone, but this is often difficult for disabled people.

Carers, families and health workers often focus on disabled people’s physical needs and ignore sexual and emotional health. It can be especially difficult for a person with impaired speech or a learning difficulty to talk about their concerns.

A good listener and counsellor is someone who can make people feel relaxed and ‘safe’, use clear, simple language, avoid being judgmental, and have a good basic knowledge of sex, contraception, HIV and sexually transmitted diseases (STDs). Disabled people themselves, and also health workers, teachers and carers, have an important role to play in discussing these issues.

Growing up Parents and health workers do not always accept that sexual feelings are a normal part of growing up for young disabled people just as they are for non-disabled people. Sexual feelings will not go away even if they are ignored. Avoiding discussion of sexual issues and ‘protecting’ children (especially girls) from sexual knowledge is not helpful. They may be more vulnerable to abuse if they do not understand what is happening and do not feel able to talk to anyone about it.

Young disabled people may have new worries in adolescence. They may be unprepared for leaving home and working, mixing with others or forming relationships and feel great anxiety about their future.

Life changes People who become disabled as adults (for example, through illness, including HIV, or injury) may feel low self-esteem and a sense of failure because they are unable to continue working or having a sexual relationship. Many men in particular say that they are concerned about their sex life.

Women may face additional problems. A woman may worry about whether her husband will stay with her or whether she can have children. Disabled women, and also HIV-positive women, can have children yet they are often under pressure not to. They often have little access to reproductive health information and are forced to be sterilised or have abortions without their consent.

Counselling and support People with different impairments need different types of information, counselling or practical support. For example, a person with physical or sensory difficulties will need a different approach from one with learning difficulties. However, the following guidelines are helpful:

- Provide information and services on avoiding unwanted pregnancies, STD and HIV prevention and sexual abuse.
- Acknowledge anxieties and do not pretend that they are unimportant.
- If disabled people feel that they are unattractive, help them to identify features they like about themselves and to feel more comfortable about their impairment by wearing suitable clothing or making aids and appliances look attractive.
- Identify places where they can meet people, including others with similar impairments.
- Help people overcome feelings of shyness and insecurity or difficulties in talking to their partner by discussing sensitive issues in role plays.

Do not assume that you know what the problem is. Listen carefully to what people say and try to find practical and supportive ways to help them. It is difficult for a non-disabled person to understand the feelings of disabled people. It may be helpful to involve other disabled people to explore feelings more fully, give appropriate information and to provide a positive role model.

These ideas are explored at greater length in Challenging disability, a guide for frontline social workers in Africa, Modules 7 and 8, by Helen Jackson, ILO Southern Africa Regional Office, 1992.

Although now out of print, AHRTAG can send copies of the relevant pages free to readers in developing countries (one copy per request).
What is HIV?
HIV stands for Human Immunodeficiency Virus. HIV only infects humans. It attacks the body's immune system, which protects the body against illness.

Soon after being infected, some people may suffer flu-like symptoms for a few weeks. Otherwise there are no signs of early HIV infection. However, the virus remains in the body and can be passed on to other people. Once infected, a person is infected for life and there is no cure. No traditional or Western medicine has been proven to kill the virus. Some people remain healthy for many years, depending on access to treatments, nutrition and lifestyle.

What is AIDS?
AIDS stands for Acquired Immune Deficiency Syndrome. Getting (acquiring) HIV infection leads to a weakened (deficient) immune system. This makes a person with HIV vulnerable to a group of illnesses (syndrome) that a healthy person without the virus would be unlikely to be affected by (opportunistic infections). These illnesses include rare cancers and eye, skin and nervous system conditions as well as tuberculosis, coughs and diarrhoea.

How is HIV transmitted?
HIV is found in an infected person's blood (including menstrual blood), breast milk, semen and vaginal fluids.

- During unprotected sexual intercourse, HIV can pass from someone's infected blood, semen or vaginal fluids directly into another person's bloodstream, through the mucous membranes lining the inside of the vagina, penis or rectum.
- HIV can be transmitted by HIV-infected blood transfusions or contaminated injecting equipment or cutting instruments.
- HIV can be passed to a baby during pregnancy, delivery and breastfeeding. About a third of all babies born to mothers with HIV become infected themselves.

What is unsafe or high risk behaviour?
This is doing something that involves a high risk of infection for you or someone else. Most people do not know who has HIV and who does not, including themselves, so the following activities are high-risk:

- having penetrative vaginal or anal sex (where the penis enters the vagina or anus) without using a condom. Men can infect both male and female partners through unprotected anal sex
- using unsterilised needles and syringes, or cutting instruments, on yourself or someone else, that are likely to be contaminated by another person's blood
- receiving an infected blood transfusion.

Is disability linked to HIV?
Disabled people are just as much at risk of HIV infection as anyone else if they have unprotected sex or share contaminated injecting equipment. However, they may be more vulnerable because of sexual abuse or lack of information.

What is safer sex?
Safer sex is any sexual activity which does not involve semen, vaginal fluids and blood entering another person's body or coming into contact with broken skin, such as:

- non-penetrative sex — stimulating your own or your partner's genitals (masturbation), thigh sex, massage or kissing
- using a condom for vaginal or anal sexual intercourse.
- Oral sex (mouth contact with male or female genitals) is less risky than unprotected vaginal or anal sex.
- No sex (abstinence) is safe.

What is an HIV test?
An HIV test detects antibodies to HIV in the blood. These are produced by the immune system in response to infection with the virus. If there are no antibodies, the person is antibody negative (seronegative or HIV negative). The test result may be negative if the person has been infected only recently, because it can take up to three months from the time of infection for the antibodies to develop. This is called the 'window period'. Anyone who might have become infected in the last three months should take a second test three months after the first test.

A person should always have counselling before and after an HIV test. HIV tests should never be carried out without the person's informed consent.

How is HIV not transmitted?
The virus can live only inside a living human body and survives for just a few hours outside the body.

- HIV cannot be transmitted through saliva, tears, vomit, faeces and urine, although very small amounts of the virus have been found in these fluids. HIV has not been found in sweat.
- HIV cannot pass through unbroken skin and is not spread through casual contact such as touching someone with HIV, or something they have used; sharing eating or drinking utensils; or using the same toilet seats or washing water.
- HIV is not transmitted by mosquitoes or other blood-sucking insects. Most insects do not pass blood from one person to another when they bite humans. The malaria parasite enters the bloodstream in mosquito saliva, not blood.
Keeping safe, feeling healthy

Life skills education for young people with learning disabilities can help them to develop skills and self-confidence.

All too often young disabled people are treated with pity or misplaced sympathy, or, even worse, their needs are ignored altogether. This is especially true for people with learning difficulties. Adults normally make the decisions which affect these young people's relationships, sexuality and bodies.

It can be difficult to discuss sex with people with learning difficulties. Parents may want to 'protect' their children and feel that they are not interested in sex because they develop differently to other young people of the same age. For example, they may find it difficult to understand that films or advertisements are not the same as people's everyday lives. They need support in learning about appropriate behaviour in public, with their friends or families, or in private by themselves.

They need to develop their confidence and self-esteem, as well as their skills to negotiate sex if they want it or to say no if they don't. Some people think that sex education encourages young people to experiment with sex, but in fact research shows that they make wiser decisions about sex if they have information and can practise the skills to put their choices into action.

Learning to live

In the Netherlands a sex education project for young people with learning difficulties focuses on three themes:

- **myself as a person** — photos and drawings showing different stages of physical development and how to look after your body
- **myself in relation to others** — different types of relationship and lifestyle
- **myself in relation to society** — understanding private and public behaviour including sexual feelings and actions.

Using photos and drawings helps teachers and parents to discuss many different aspects of sexuality. The aim is to promote self-esteem and a positive self-image and express thoughts and feelings about sex. Games or very simple role plays are used to practise communication and assertiveness skills.

These games and activities are very challenging for both adults and teachers, but as a young person with a learning difficulty said after doing this course, 'Talking about sex is fun. Now I can ask my teacher all kinds of questions. I am in love now and I know what to do.'

With thanks to Doortje Braeken, Rutgers Foundation, Netherlands.

---

**Different aspects of life skills education for people with learning difficulties**

- **Feelings and emotions**
  - Understanding and expressing feelings, such as fear, happiness, sadness, responding to others' moods

- **How I look and how others see me**
  - Clothes I like and dislike, choosing colours and hairstyles I like

- **Understanding my body**
  - Personal hygiene, sex and development, pregnancy, parenthood, delaying sex

- **Developing self-confidence**
  - Using and enjoying my senses, practicing speaking up for myself and being assertive about my decisions

- **Keeping and feeling safe and healthy**
  - Touches that I like and dislike, words which make me feel good or bad

- **Relationships with others**
  - My family and my home, friendships, differences between strangers and friends, caring for other people

Source: Cooper, D: Sexuality, Bulletin on sexuality and personal relationships, 32, January 1996
Check your attitudes

This activity aims to encourage people to think more deeply about their attitudes towards different people's sexuality.

It is often difficult to talk about sexuality and relationships. We have our own beliefs about what is 'right' and 'wrong' and may feel awkward discussing this in public. This activity uses pictures of different people to encourage discussion about common assumptions and to explore whether these are true or not. It allows us to discuss our beliefs without having to disclose personal experiences.

Before you start

The pictures you use should reflect the local situation and stimulate discussion about common attitudes, for example that disabled people are not sexually active. Think about what attitudes exist locally and what people in your group may feel able to discuss. Draw different pictures, or cut photographs from newspapers. Here are some examples of pictures and questions but you will need to choose ones which are appropriate for your situation.

- Explain that the activity aims to help us think more about how we see other people and to question our own assumptions.
- Invite people to look at each picture and answer the following questions:
  - What work do you think that this person does?
  - Is this person married?
  - Where does this person meet other people socially?
  - Do you think that this person has children?
  - Would they like to have children?
  - Do you think that this person has sex? If so, with whom?
  - What concerns might they have about sex or relationships?
  - Who does this person talk to when they are worried about their relationships or sexual health?
- Once people have talked about these issues, the facilitator should encourage discussion about whether people are like these pictures in real life. How do assumptions made about people affect their daily lives? How can we challenge attitudes which limit people’s opportunities to have fulfilled lives?

With thanks to Tracy O'Reilly.
AHRTAG wants to hear from you...

If you work on disability and AIDS write to us and share your experiences. We would like to hear more about projects similar to the ones featured in this special issue. If you found this issue on disability and HIV useful and would like to continue to receive CBR News or AIDS Action, please write to AHRTAG.

Future issues of AIDS Action


If you would like to contribute to these issues - or any others - please send articles to AHRTAG.

RESOURCES ON DISABILITY

Community-based rehabilitation, CBR, for and with people with disabilities describes what CBR is and gives ideas for sustainable CBR programmes. Single copies are available free from the Vocational Rehabilitation Branch, ILO, 4 Route de Morillons, CH-1211 Geneva 27, Switzerland.

Disabled village children: a guide for community health workers. Rehabilitation workers and families has information on disability and how to set up CBR programmes using simple language and illustrations. Single copies are available for £7 plus postage and packing in English, French and Spanish from TALC, PO Box 49, St Alburns, Herts AL1 5TX, UK. Other languages including Arabic, Hindi, Portuguese, Swahili and Urdu available from Hearsway Foundation, Box 1692, Palo Alto, CA 94302, USA.

Essential CBR information resources is a list of nearly 120 key free or low-cost publications and articles on CBR. Available free to developing countries (£5/US$10 elsewhere) from AHRTAG.

Everything you ever wanted to know about safer sex book is an illustrated booklet on sex, contraception and HIV prevention for people with learning difficulties. Available for £4 (book) and £7 (tape) from People First, 207-215 King's Cross Road, London WC1X 9DB, UK.

RESOURCES ON HIV AND AIDS

Essential AIDS information resources lists 125 key free or low cost resources on HIV and AIDS for developing countries. Available free to developing countries (£5/US$10 elsewhere) from AHRTAG.

Strategies for Hope is a series of booklets describing successful case studies and practical strategies on HIV care and prevention projects. Available from TALC. (Booklets cost £1.95 and £2.50 - contact TALC for price details.) AHRTAG and its partners can put readers in touch with local HIV prevention and care organisations.

NEW PUBLICATION

Starting the discussion: steps to making sex safer provides ideas for training activities to enable people to participate in discussion about HIV prevention and making sex safer.

This guide is based on an earlier series of booklets Let's teach about AIDS. Available free to developing countries (£7/US$14 elsewhere including postage) from AHRTAG.

ORGANISATIONS

Disabled People's International (DPI) is the world-wide co-ordinating body for disability organisations run by disabled people with the goal of achieving equal rights. DPI, 101-7 Evergreen Place, Winnipeg, Manitoba R3L 2T3, Canada.

Disability Awareness in Action is an international information network supporting disabled people's human rights. Disability Awareness in Action, 11 Belgrave Road, London SW1V 1RB, UK.

AIDS Action is published quarterly in seven editions in English, French, Portuguese and Spanish. It has a worldwide circulation of 165,000. The original edition of AIDS Action is produced and distributed by AHRTAG.

SUBSCRIPTION DETAILS

If you would like to be put on the mailing list to receive AIDS Action or CBR News, please write with details about your work to:

AHRTAG
Farrington Point, 29-35 Farrington Road
London EC1M 3JB, UK.

Telephone +44 171 242 0606
Fax +44 171 242 0041

E-mail ahrtag@gn.apc.org
http://www.poptel.org.uk/ahrtag/

Annual subscription charges
Free Readers in developing countries and students from developing countries
£6 Other students
£12/US$24 Individuals elsewhere
£24/US$48 Institutions elsewhere

REPRODUCING ARTICLES

AHRTAG encourages the reproduction of articles for non-profit making and educational uses. Please clearly credit AIDS Action/CBR News/AHRTAG and, if possible, send us a copy of the reproduced article.

AHRTAG is committed to strengthening primary health care and community-based rehabilitation in the South by maximising the use and impact of information, providing training and resources and actively supporting the capacity building of partner organisations.

Registered charity no. 274260
Printed by Russell Press

ISBN 0953-0096/0963-5556