

AIDS action

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DISABILITY and HIV

This special issue of AIDS Action is published jointly with CBR News, the newsletter of AHR TAG'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

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 futures are often out of our 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



J. Danaois, WHO/UNICEF

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

This issue of AIDS Action and CBR News is available on audio-cassette in English and in braille. If you would like these, or future issues on cassette, please write to AHR TAG.

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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 percent 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.

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.'



P. Coleridge/Oxfam

Multiple Stigma

Disabled people often face a life of multiple stigma. For example, a disabled woman faces a double burden because of discrimination against disabled people as well as the burden of gender inequality.

Similarly, a person who is disabled and gay (homosexual) faces double discrimination, sometimes even from other gay people.

Multiple stigma means that disabled



P. Coleridge/Oxfam

people tend to be more socially isolated and vulnerable to abuse. This increases their risks for health problems, including HIV.

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.

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 Pirajá 127/201, Ipanema, 22410-001 Rio de Janeiro RJ, Brazil.

UNDERSTAND



REMEMBER



do you know how to say "SAFER SEX" in sign?

by Nicolas Pichay

The dissemination of information on HIV/AIDS to as many people as possible has become more urgent as the epidemic spreads. But what is the most effective way of doing this where Deaf people are concerned? I am a hearing person and do not presume to speak for the Filipino Deaf community. From my limited experience with the Deaf, I raise the following points by way of starting a dialogue on the matter.

The HIV/AIDS information and counselling packages found to be effective are those which take into consideration the culture of the target group. Although containing similar factual information, good educational materials have been individually designed in as many ways as there are ethnic or psycho-social groupings. In the same way, educational or counselling techniques should be reviewed or modified taking into consideration that being deaf is not just a physical status but also a matter of living in a unique culture.

Take the case of confidential counselling. I attended a lecture on HIV/AIDS intended for deaf people a few months back given by a health organisation. The first thing that the lecturer discussed was their phone counselling service. She was around midway into this section when she realised that the Deaf could not possibly benefit from the confidential nature of phone counselling. By that time, the Deaf in the audience were already laughing at the comic turn of events.

In other countries, the Deaf have access to phones that send and receive text messages. But for us which does not offer the same service, some method must be designed for the Deaf to approximate the feeling of anonymity and intimacy that phone counselling brings.

In terms of culture, an aspect to consider is the use of language. Sign language, the primary mode of communication among the Deaf, is image-driven. To comprehend written language, it has to conform to a set grammar of word orders.

For example, in Filipino, the usual sentence pattern is verb + subject + object. Example: *Tumatawag si Juan sa telepono* (call, Juan, telephone). In English, it is subject + verb + object. Example: Juan is making a phone call.

On the other hand, sign language is painting images in the air. I should think that this mind set is inherent to the Deaf in the same way that formal grammar is inherent in the hearing in their communication process. From my experience, I notice that the Deaf respond to and absorb more information if the material is presented in the most visual way possible. A string of words using formalistic grammar is a burden to read for most deaf people. This aspect should be taken into consideration when designing written materials for them.

Another anecdote. One time, I was assisting a Deaf friend make a phone call to set an appointment with a non-signing teacher who was going to help him get a scholarship. After the date was set, I informed the teacher that this friend would attend the interview without an interpreter. The teacher asked how he was to communicate with this deaf friend without knowledge of sign language. The teacher, like so many people used to talking, completely forgot that the Deaf can also communicate by writing.

Although obvious in hindsight, the Filipino hearing world is often not sensitive to the nuances of communicating to the Deaf. One of the reasons is because presently, there are not enough situations where the deaf and the hearing can interact and learn from each other.

Maybe the search for an effective HIV/AIDS education campaign for the Deaf is the task that everybody has been waiting for. I would like to see it used as a door for educators, scientists and social researchers to immerse themselves in the Deaf world and to see how wonderfully unique this place is. More than that, it would be an opportunity to assure the Deaf that, although they are a minority, this is as much their world as it is for the hearing.

For now, I look forward to seeing HIV/AIDS lectures being given by the Deaf to the Deaf.

Nick Pichay is a lawyer in private practice, but who is an active volunteer in HIV/AIDS prevention work with various Philippine NGOs.



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.



J.Ober/WHO

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).

Learning to love..... a personal story

"I was 13 when I suddenly became paralysed. I had to get used to my disability at the same time as dealing with puberty. I was anxious to know if I could make love and be loved, but I was very nervous about it. People thought that because my body was paralysed, my sexual feelings were also paralysed. Then I met a man who was also a wheelchair user. I knew that he was attracted to me, but I believed that I could not have feelings like non-disabled people.

He has made me believe in myself, always focusing on my abilities and not on my disability. I began to realise that a disabled person has options if they are brave enough to take them. Exploring touch with someone you love is wonderful. When disabled people lose sensation in one part of their body, other parts become more sensitive. When I talked to non-disabled women I realise that what I experience is normal."

Disabled woman from India.

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 from 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



Source: Cooper, D; *Sexuality and Personal Relationships*, 53, January 1996



Learning Disability, Sexuality and HIV/AIDS

In many Asian cultures, sexuality is not openly discussed. The sexuality of persons with disability, whether physical or intellectual, is an even greater taboo. In reality, people with disability are also sexual beings. More disturbing is that they are more vulnerable to sexual exploitation due to power imbalances in their sexual relationships — the non-disabled over the disabled, the men over the women. This also increases their risk of contracting HIV. In dealing with the complicated issues of disability, sexuality, and HIV, counsellors and care-givers often encounter the following barriers:

- Low self esteem of many people with learning disability makes them less motivated to care for themselves. They need to first realise their self-worth before they can be convinced that they are capable of taking care of themselves.
- Many people with learning disability are disempowered in their sexual relationships. In an unequal power relationship, negotiating for safer sex is difficult, if not impossible.
- Private time and space for sex is often not available for persons with learning disability. If sex takes place when and where the opportunity arises, then the situation would not be conducive to the practice of safer sex.
- The learning disability in itself is a challenge, as people with learning disability have lower levels of comprehension.

People with learning disability can benefit greatly from individualised sex education and counselling. The counsellor should have a clear understanding of how, when and where sex takes place. The counsellor must not assume that the sex life of a disabled person is trouble-free just because the person does not talk about his or her sexual relationships.

Sources: MacLeod, J., *More Than One Barrier: Men with Intellectual Disabilities Who Have Sex with Men*; Thompson, D., *HIV and People with Learning Disabilities: Difficult Questions, Time for Answers*; McCarthy, M. and Thompson D., *HIV/AIDS and Safer Sex Work with People with Learning Disabilities*. Offprints of these articles are available from HAIN.

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. 

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 by D Werner, 1996, contains information on common childhood disabilities including polio, cerebral palsy, juvenile arthritis, blindness and deafness. It also provides ideas for rehabilitation at the village level and instructions on how to make low-cost aids. Available in English and Spanish. Special discounts are given to developing countries. Write to The Hesperian Foundation, 1919 Addison St., Suite 304, Berkeley, CA 94704 USA. Email: hesperianfdn@igc.apc.org

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.

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

Family Planning NSW is a member of Family Planning Australia and has a project on HIV/AIDS and Intellectual Disability. 328-336 Liverpool Road, Ashfield 2131, Australia

Articles

People with an intellectual disability: a part of our community, A. McDonagh & S. Stewart.

In Australia, people with an intellectual disability are recognised in the third National HIV/AIDS Strategy as a group at increased risk of HIV infection. The authors write that in dealing with HIV in this population, AIDS organisations must first recognise the sexual rights and experiences of people with an intellectual disability. *National AIDS Bulletin* 11(2):16-17. Offprints are available from HAIN.

Directory

Inventory of HIV/AIDS Information Sources in the Asia Pacific Region a comprehensive listing of information centres/organisations identified as key sources of information and materials with systematised documentation system. Free copies are available from UNAIDS Asia Pacific Inter-country Team, 3/f "B" block, UN ESCAP Bldg., Rajadamnern Nak Ave., Bangkok 10200, Thailand. email: UNAIDS-APICT.unescap@un.org

Organisations listed may contact the publisher for any change in information.

Announcement

We would like to invite you to send us your publications/researches on sexual and reproductive health, HIV/AIDS, and gender to be featured in **AIDS Action Resource List**. When sending, please include the following: cost of the publication if for sale, how to obtain, address.

Due to space limitations, some materials may not be included in the resource list.

For more information on HIV/AIDS, gender issues, and sexual and reproductive health, you may contact:

HIV/AIDS Inquiry Services
AIDS Action Asia-Pacific

9 Cabanatuan Road
Philam Homes 1104, Quezon City,
Philippines

Telephones: (632) 927-67-60 or 929-88-05

Fax: (632) 927-67-60

Email: hain@mnl.sequel.net

Web site: <http://www.hain.org>

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