HIV & AIDS and Disability

National Conference

10-12 June 2003

Safari Hotel

Windhoek, Namibia

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Contents

Acronyms

ASO
AIDS Service Organisations

CBO
Community Based Organisation

CLaSH
The association for Children with Language, Speech and Hearing impairment of Namibia

DED
Deutsche Entwicklungsdienst

DPO
Disabled Peoples Organisation

DPSA
Disabled People of South Africa

DRC
Disability Resource Centre

DYCN
Disabled Youth Council of Namibia

MBESC
Ministry of Basic Education and Sports and Culture

MIB
Ministry of Information and Broadcasting

MLRR
Ministry of Lands, Resettlement and Rehabilitation

MoHSS
Ministry of Health and Social Services

NANASO
Namibian Network of AIDS Service Providers

NAPPD
Namibian Association of People with Physical Disabilities

NFPDN
National Federation of People with Disabilities in Namibia

NFVI
National Federation of the Visually Impaired

NGO
Non-Governmental Organisation

NNAD
Namibian National Association of the Deaf

OPD
Organisation of People with Disablities

PDC
Parents of Disabled Children

PSO
Personele Samenwerking Ontwikkelingslanden

PWD
People with Disabilities

RACOC
Regional AIDS Coordination Committee

RAISA
Regional AIDS Initiative of Southern Africa

SADC
Southern Africa Development Community

SAFOD
Southern Africa Federation of the Disabled

SWAPO
South West African Peoples Organisation

TRP
The Rainbow Project

UNAIDS
Joint United Nations Programme on HIV/AIDS

VSO
Voluntary Service Overseas

WHO
World Health Organisation

Conference objectives

1 To explore the potential issues for disabled people in regard to HIV & AIDS.

2 To discuss with disabled people about HIV & AIDS and learn from them what their needs are in regard to prevention activities, access to care and availability and access to treatment.

3 To assess what the social and economic impacts of the HIV & AIDS pandemic are for a disabled person and how these can be best addressed.

4 To highlight the lessons learnt and share experiences of disabled people, with a focus on prevention care and treatment of HIV & AIDS.

5 To explore opportunities and strategies for increased sharing of experiences and lessons learnt across the region.

6 To discuss how the National Federation of People with Disabilities in Namibia (NFPDN), Voluntary Service Overseas (VSO), the Government and other agencies can further commit to support and strengthen the response both nationally and regionally to ensure that there is more involvement of disabled people at appropriate levels in the future.

7 To establish a working group to follow-up recommendations of the conference.

Acknowledgements

First of all the conference would never have been a success without the input of all the participants. Therefore our appreciation and congratulations.

We would like to thank the Government of the Kingdom of the Netherlands for sponsoring the national conference on HIV & AIDS and Disability. With their financial assistance through VSO Netherlands, this conference was made possible.

We would like to thank the delegates who travelled from our neighbouring countries such as Zimbabwe and South Africa and the sign language interpreter, Mrs Erica Erasmus, for translating everything over the three days.

And finally, we would like to thank the delegates who presented, NGOs, fellow organisations of disabled people in Namibia, the ministries, the private sector and partners.

Executive summary

Mathieu Janssen
National Federation of People with Disabilities in Namibia (NFPDN)

'If we want to recognise the place of disabled people within the HIV & AIDS pandemic, we first have to recognise their basic human right on sexuality and that they do have a sexual life.'

Disabled people are often seen as human beings without a sexual life and therefore not affected by HIV & AIDS. This is one of the major reasons mainstream HIV & AIDS service providers never directed information towards them or even thought of including them into their programmes. Also within the disability movement not a lot of attention went to HIV & AIDS related issues, due to the fact that so many other things are still not in place for them.

In order to place HIV & AIDS and disability on the agenda, the National Federation of People with Disabilities in Namibia (NFPDN) started to think seriously about the issue at the beginning of 2002. At that stage different signals came in that HIV & AIDS should be placed on the agenda of the NFPDN: a rehabilitation officer from the Ministry of Lands, Resettlement and Rehabilitation from the Otjozondjupa region requested help in organising workshops, a social worker from the Kunene region came up with the idea of organising a conference and NNAD started organising workshops for Deaf people.

The NFPDN started to look at a two-way approach: start with a pilot workshop for disabled people in the Otjozondjupa region, in order to get some baseline data on HIV & AIDS and disability and to look at the general knowledge disabled people had on HIV & AIDS. At the same time the conference should be organised to bring together all stakeholders and to discuss issues surrounding HIV & AIDS and disability.

In most of these initiatives, Voluntary Service Overseas and Regional AIDS Initiative of Southern Africa (VSO-RAISA) volunteers were involved or the driving force, so it was logical to seek out VSO-RAISA as a partner.

'The "S" in AIDS stands for sex!'

The first workshop on HIV & AIDS for disabled people took place in February 2003 in Okakarara and saw 25 people participating, half of them physically disabled, half of them mentally disabled. Within the group of participants the knowledge on HIV & AIDS was very limited, even though every person had heard about it, they didn't reflect the information on themselves. This was partially due to the low level of education: only 2 people were literate and had a basic knowledge of English and partially due to the attitude that sex and prevention against HIV & AIDS has nothing to do with disabled people. However, all mentally disabled women were accompanied by their children, most of them also mentally disabled, showing clearly that they did involve in sexual activities. Overall the workshop was very challenging, especially because the low level of understanding, which made progress very slow and the attitudes towards sexuality, which made practical exercises on how to apply a condom very difficult. In the end the participants learned about HIV & AIDS prevention and how to apply the knowledge for themselves and the organisers got a good idea on the level of understanding and the pitfalls involving workshops for disabled people.

'And then the woman was put in a room with a man, because a blind woman will need a child to take care of her'.

This statement by a participant gives a clear indication on the vulnerability of disabled people within the HIV & AIDS pandemic and the cultural attitudes towards disabled people in general.

Seventy-six participants, mainly from Namibia, but also from South Africa and Zimbabwe, explored issues surrounding HIV & AIDS and disability during a conference organised by the NFPDN and VSO-RAISA between 10-12 June 2003. The conference provided an excellent platform to discuss HIV & AIDS and disability for participants from different organisations: the disability sector, civil society, HIV & AIDS service organisations and relevant ministries.

After the official opening of the conference by the Right Honourable Prime Minister Theo-Ben Gurirab a variety of speakers on different topics sparked lively discussions.

A general overview on both HIV & AIDS and disability was provided by Ben Katamila of NANASO and Alexander Phiri of SAFOD, putting the situation at hand in a broader perspective. Unfortunately the World Health Organisation and the line ministry on disability issues, the Ministry of Lands, Resettlement and Rehabilitation didn't address the participants, although they committed themselves beforehand.

Group discussions on different types of disability and HIV & AIDS brought things down to local level and showed clearly the problems encountered, especially related to disability issues. Discrimination in general, leading to lack of access to all services, education and employment were points made to show the lack of involvement of disabled people within the fight against HIV & AIDS. A specific problem, which became very clear, is the lack of access to information, especially for visually impaired people and Deaf or hard-of-hearing people, since they need specific means of communication like Braille and sign language.

Different aspects were explored in further presentations, ranging from the production of HIV & AIDS materials and the in- or exclusion of disabled people within this process, HIV & AIDS and the workplace, minorities in general, gender issues, education and the different organisations of disabled people.

In general this showed that disabled people are left out. However, it also showed the willingness of mainstream organisations to include disabled people within their programmes. A good example is that after complaints of Deaf or hard-of-hearing people, it was decided to release the Mubasen video with subtitles! The discussions highlighted the need to cooperate between different minority groups. Furthermore, it became very obvious that gender inequality is still a major problem within the disability movement, even though women are far more vulnerable in general and within the HIV & AIDS pandemic specifically. Presentations from two schools for children with learning disabilities on how they tackle the issue of HIV & AIDS gave way to heated debates on how the educational system should deal with HIV & AIDS. No consensus was reached on the correct way, however, it was recognised that the educational system can play a major role in HIV & AIDS prevention.

During the discussions on the way forward it became clear that disabled people see HIV & AIDS not as a topic on itself, but as one part of the bigger problem of marginalisation in general. The main recommendations were to establish a taskforce in the NFPDN to work on a programme on HIV & AIDS and disability with a full-time staff member, to network and cooperate with mainstream HIV & AIDS organisations, to establish base-line data on HIV & AIDS and disability and to evaluate the outcome of the conference and see how it was brought forward.

Conference programme

Day 1

- **National anthem of Namibia & African Union anthem**
- **Official welcoming** Gerson Mutendere, NFPDN
- **Message from Mr Willem Aalmans** Charge d'Affairs Dutch embassy, read by Mathieu Janssen
- **Remarks by Mr Daan Gerretsen** VSO, Namibia
- **Key note speech** Theo-Ben Gurirab, the Right Honourable Prime Minister
- **African perspective on HIV & AIDS and disability** Mr Phiri, Secretary-General SAFOD, Zimbabwe
- **HIV & AIDS in Namibia, a Namibian perspective** Ben Katamila, NANASO
- **Group sessions: 4 groups discussing different topics**

Day 2

Presentations

- **Gender issues and HIV & AIDS** Natasha Tibinyane, Sister Namibia
- **Film presentation *The Story of Lukas*** Mubasen video productions
- **SWAPO women's league presentation** Martha Hendjala
- **HIV & AIDS in the workplace** Delme Cupido, Legal Assistance Centre
- **Being on the outside: minorities and HIV & AIDS** Ian Swartz, The Rainbow Project
- **Lironga Eparu presentation** Emma Tuahepa
- **NFVI presentation** John Uheka
- **NNAD presentation** Martin Tjivera
- **NAPPD presentation** Nixon Munamava
- **DYCN presentation** Manfred Howaeb
- **Learning disabled children with the focus on girls** Ms P Beukes, Eros girls school
- **Audio cassette tapes for the visually impaired** Denise Cosgrove, RACOC Keetmanshoop
- **Mentally disabled children** Mrs Hannelore Feddersen, Dagbreek school

Day 3

- **Group deliberations to outline needs and draft recommendations**
- **Official closing** Honourable Isak Katali, Deputy Minister of Land, Resettlement and Rehabilitation
- **Key recommendations**

Day 1
June 10

National anthem of Namibia

-Namibia land of the brave
-Freedom fight we have won
-Glory to their bravery
-Whose blood waters our freedom
-We give our love and loyalty
-Together in unity
-Contrasting beautiful Namibia
-Namibia our country
-Beloved land of savannahs
-Hold high the banner of liberty

Chorus:
-Namibia our country
-Namibia motherland
-We love thee

African Union anthem

-Let us all unite and celebrate
-The victories for our liberation
-Let us dedicate ourselves to rise together
-To defend our liberty and unity

Chorus:
-O sons and daughters of Africa
-Flesh of the sun and flesh of the sky
-Let us make Africa the tree of life

-Let all of us unite and work together
-To uphold our rights and fight for the cause of freedom
-Let us dedicate ourselves to work together
-To build up strength in unity and peace

Chorus

-Let all of us unite and toil together
-To give the best we have to Africa
-The cradle of mankind and fount of culture
-Our pride and hope at break of dawn

Chorus

Official welcoming

Mr Gerson Mutendere
National Federation of People with Disabilities in Namibia (NFPDN)

Mr Mutendere welcomed the delegates to the national conference on HIV & AIDS and Disability, which is the first of its kind in Namibia. In Namibia little focus has been given to the issues around disabled people and the HIV & AIDS pandemic (and in general). There have been major campaigns addressing HIV & AIDS awareness and prevention and none of these campaigns addressed disabled people and their special needs. He raised a concern that disabled people are seen as a group of people who are not sexually active or not entitled to sex, and therefore not at risk of HIV & AIDS which is a serious misconception and a myth. To tackle this issue the National Federation of People with Disabilities in Namibia (NFPDN) with Voluntary Service Overseas and Regional AIDS Initiative of Southern Africa (VSO-RAISA) took the initiative to create this national platform for deliberations.

Message from Mr Willem Aalmans

Charge d'Affairs Dutch Embassy
Read by Mathieu Janssen

Mr Aalmans, who was attending a human rights conference in the Netherlands, wished all the delegates a very good discussion and above all, an operational outcome via results which can be used to lobby politicians, diplomats and community leaders for the cause. Time has long gone that disabled people are to be treated as victims or pitiful people. As any other groups in society one has to fight for its rights in a more and more complex society. He affirmed his faith in the NFPDN's ability to achieve the objectives of this conference and pledged his Government's continued support and commitment.

Remarks by Mr Daan Gerretsen

Voluntary Service Overseas (VSO), Namibia

Comments on the conference
The preparations for this conference took place more than a year ago and the perseverance of the various organisers have brought this platform about. The many representatives of different organisations gathered is the result of such preparation. As with all conferences, they cannot be organised without the financial support from donor organisations. The full funding for this conference has been received from the Dutch Government through their funding body PSO.

VSO has worked in HIV & AIDS and disability for many years. VSO in Namibia is part of the Regional AIDS Initiative of Southern Africa, RAISA for short, which supports partner organisations in the fight against the HIV & AIDS pandemic. VSO's support to the disability sector is slowly increasing and the possible success of the project proposal for a support programme for the organisations of disabled people submitted to the European Union in Brussels will aid in expanding our support further.

VSO was keen to support the NFPDN in their efforts to put HIV & AIDS on the agenda. So far, the needs of disabled people have not been taken into consideration sufficiently when dealing with HIV & AIDS.

This conference, however, will provide the platform to start tackling some of those needs.

The Government of Namibia's commitment to HIV & AIDS and disability is increasing and the presence of the Right Honourable Prime Minister Theo-Ben Gurirab testifies to this. His presence at the conference shows us the importance and commitment the Government of Namibia is giving to HIV & AIDS and disability issues in the country.

Key note speech

Theo-Ben Gurirab
the Right Honourable Prime Minister

I am truly grateful for this opportunity to join you as we celebrate this day, the National Disability Day. I am equally delighted to address you here today on the occasion of this important conference on disability and HIV & AIDS. I should, in particular, like to thank the Government of the Kingdom of the Netherlands for the financial support in making this important conference possible. The National Disability Day has been marked since the year 2000 and is aimed at raising awareness of the rights and protection of disabled people. More than anything, this day is a celebration of the resilience, triumph and achievements of disabled people as well as the recognition of the tireless struggle disabled people encounter in their everyday lives.

It is also a day for us to celebrate the contributions and role of national and international organisations such as the NFPDN and VSO-RAISA who are showing the way towards a sustainable livelihood.

Ladies and gentlemen the focus of this conference is on HIV & AIDS and disability. We are expected to, among other things, evaluate the participation of the disability sector within the HIV & AIDS programme as a whole.

Disabled people are faced with issues such as greater vulnerability to infection, lack of access to information about the pandemic and the more marginal social and economic position of disabled people in society with respect to employment, housing, health and other services.

In this regard, all sectors of our society must become actively involved in de-stigmatising disability and in eradicating the ignorance that leads to stereotyping and myths around disability. The legal framework in the country provides us with the mechanism and ammunition with which to fight this stigmatisation and to work towards improving the quality of life of disabled people.

In the past, disability was viewed as an illness or a welfare issue. As a result of such warped thinking, disabled people have been left with very little information, if any, about HIV & AIDS, and the protective measures needed to be taken to prevent the spread of the disease or infection.

As this meeting deliberates on strategies for the disability sector within the national HIV & AIDS education and prevention programmes, we need to openly confront and challenge the stereotypes, which undermine our campaign to reduce, manage and ultimately defeat this scourge. This includes the misguided notion that disabled people do not actively indulge in sexual activities. It is this kind of attitude which makes most HIV & AIDS messages exclude disabled people.

A very recent study on the living conditions among disabled people in Namibia showed that disabled people had very little understanding of HIV & AIDS and other related issues. It is, therefore, vital that we address these issues urgently and ensure that all HIV & AIDS awareness and prevention campaigns include material suitable for consumption by disabled people. Disabled people are not a homogenous group. Their needs, thus, are varied. This means that different approaches would be necessary to enable them to access information on an equal basis with their *normal* fellow citizens. For example, a common form of communication that has been used widely in HIV & AIDS education is the spoken word, which is sometimes open to misinterpretation and messages may be forgotten. It is therefore crucial to ensure increased availability of HIV & AIDS information in Braille and sign language to assist the visually and the partially impaired members of our society. Disabled people are the most vulnerable group, and the challenge of developing mechanisms to effectively communicate with them remains a daunting one. However, experts in the field must join hands to break through the barrier.

At this juncture, let me also emphasise that while all women are generally vulnerable due to the gender inequalities in our society, women with disabilities probably carry double the burden, and are particularly more at risk of abuse.

Against above background, I should like to call upon all stakeholders, including the National Social Marketing Association and the Social Marketing Association as well as our development partners and international funding institutions to actively incorporate disability dimensions in their programmes. In recognition of the work we need to do with regard to the needs of disabled people the Government has established a disability advisory unit in the office of the prime minister to further strengthen our efforts in how to deal with issues of disability and to provide advice on the necessary measures we ought to consider.

We have a Policy on Disability in place to promote a more conducive environment for disabled people in order for them to realise their full potential. The Policy is aimed at preventing or reducing physical, intellectual and sensory impairments and other permanent functional limitations. In addition, it supports disabled people to realise their optimal human potential by making various sectors of society such as health, education and training facilities more accessible to them.

A further objective of the National Policy on Disability is to integrate disabled people as fully possible into society through community-based rehabilitation. In that regard Disability Resource Centres (DRCs) have been established to serve as a platform for information exchange and job placement. It is indeed pleasing to note that as part of the resettlement programme of the Government, disabled people are among the target groups.

Furthermore, a bill on the National Council on Disability will be tabled soon in parliament by the Ministry of Lands, Resettlement and Rehabilitation. I believe that this Act will be a suitable mechanism, which will ensure monitoring and evaluation of the National Policy on Disability as well as improvement on delivery of services and the creation of job opportunities to a section of our population that has been neglected for too long a time.

The quest for a better life for disabled people extends beyond Namibia, and is a continual effort as evident in the implementation of the African Decade for Disabled Persons, which was launched in November 1999. The decade aims to, among other things, alleviate poverty among disabled people, raise awareness, and place the needs of disabled people on the social and economic agendas of African Governments and to improve the quality of the lives of disabled people on the African continent.

In addition, our Government has ratified the United Nations Mine Ban Treaty, which bans the manufacturing and use of any personnel landmines.

Incidentally the United Nations General Assembly Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Disabled People will meet in New York next week to deliberate on core issues and emerging trends in development approaches to the advancement of disabled people. All these international initiatives, I hope, will result in a speedy realisation of our common goal of full participation and equality for disabled people. Together with disabled people all across our country, I look forward to recommendations that will add value to the campaign against HIV & AIDS, as it relates to our disabled citizens.

It is now my singular honour and privilege to declare this important conference officially open and to wish you all the best in your deliberations, I thank you.

African perspective on HIV & AIDS and disability

Mr Alexander Phiri
Secretary-General, Southern Africa Federation of the Disabled (SAFOD), Zimbabwe

Currently, there are over 600 million disabled people throughout the world; and of these 180 million are children; 400 million live in developing countries; and 80 million live in Africa. Disability prevalence in a majority of countries in southern Africa can only be estimated, as there has not been a comprehensive disability survey. The few countries that can boast of having carried out surveys to count disabled people have too low an estimate that cannot be relied upon.

There is still a tendency among the development worker and agencies in our countries to think or plan for and not with disabled people. This is in fact one of the major reasons which leads to reverse development or *half baked*.

"They continue to talk about us and not with us"

Thus disabled people find themselves at the receiving end, largely with very little or no choices at all. Therefore it is not surprising that disabled people are the poorest of the poor, the least educated and politically they are the least empowered.

Power about disability and development seems to be in the hands of, among others, the rehabilitation consultant's and/or practitioners, medical doctors, physiotherapists, social workers, other specialists, teachers as well as family members. These people wield a lot of power over disabled people that occasionally disabled people succumb to a state of powerlessness and/or hopelessness.

Organisations of disabled people in southern Africa have managed to reposition disability as a human right rather than a social issue. This enabled some counties to be leaders in terms of disability policy and legislation. Such countries such as South Africa, Zambia, Namibia, Mozambique and Botswana have disabled friendly laws of some kind. Malawi, Swaziland and Lesotho are still working on their disability policies. The situation in Angola is still not clear due to

insufficient communication and/or exchange visits between that country and our regional office in Bulawayo.

There are instances where some of the SADC member states that have enacted disability legislation but who are failing to re-direct towards disability programmes. The Zimbabwe Government finds it difficult to allocate the necessary resources for implementing the country's disability policy. However, it is better to have a policy that is waiting to be implemented than no policy at all. Although having a policy or legislation that is gathering dust on Government shelves could be the same as having no policy at all.

Disability policy development implemented in South Africa appears to be a success story that other SADC member states may wish to benefit from. Disabled people in the region are excluded from the mainstream of society and experience difficulty in accessing fundamental rights. This happens in spite of the ongoing lobby and advocacy work of the disability movement in the SAFOD member countries. This is the situation of disabled people in southern Africa.

Disability and HIV & AIDS

Disabled people should be able to effectively participate in programmes of prevention, monitoring and research that relates to HIV & AIDS. A new approach is needed that will be tailor-made for different groups in society concerning disabled people: the role of the family, the role of churches, the role of education and the role of the state.

This needs contextualised programmes and a new language, which avoids stigmatisation and marginalisation.

Dialogue must be increased about HIV & AIDS in general and disabled people and HIV & AIDS in specific. And this exercise must include disabled people.

Gender inequalities are the underlying cause of high HIV & AIDS infection rates in girls and women and these inequalities further speed the spread of the virus. It is important to develop ways in which men and women can be empowered to change gender relations to protect themselves, their children and communities as a whole.

HIV & AIDS in Namibia: a Namibian perspective

Ben Katamila
Namibian Network of AIDS Service Providers (NANASO)

NANASO, which has been in existence since 1991, is a national welfare umbrella, non-governmental organisation, operating as a non-profit making network, which provides a network service to its member organisations to enable them to strengthen and maximise their potential in order to effectively address the HIV & AIDS pandemic in Namibia.

NANASO accomplishes this through:
-coordination
-facilitation
-communication
-advocacy

NANASO's mission statement is to effectively enhance networking services amongst member organisations on HIV & AIDS and related issues. The organisation seeks to provide a networking service to its members to enable them to strengthen and maximise their potential to effectively address the HIV & AIDS epidemic. Mr Katamila stressed the importance of Organisations of People with Disabilities (OPDs) joining NANASO.

Group sessions: 4 groups discussing different topics

The delegates were separated into 4 groups to discuss the same topic but each with a specific disability in mind. Then the groups shared their findings in a presentation.

topic 1 - Deaf or hard-of-hearing people

This group reaffirmed the general lack of materials for Deaf or hard-of-hearing people. Among their worries was the fact that advertisements on television are not suitable for Deaf or hard-of-hearing people. The Ministry of Information and Broadcasting (MIB) in general and the national broadcaster the Namibian Broadcasting Corporation (NBC) in specific does not cater for them. They saluted NBC television for making an effort by having a translator for the weekly “Talk of the Nation”. However it was made clear that Deaf or hard-of-hearing people would prefer having the news interpreted rather than “Talk of the Nation”.

Training interpreters is not easy because sign language is demanding. It is important to find ways to practice sign language as much as possible. It has become a practice that the interpreters stop using sign language as soon as they complete the course and return to their village. Interpreters have the responsibility to either interpret when the person is being counselled or to counsel the person. When the person’s HIV status is revealed then the question arises on the confidentiality of the interpreter which is an issue of professionalism. They have to protect the patient by keeping the status to themselves. This is not easy and needs specific training.

Deaf or hard-of-hearing people are facing a problem with access to information and have not been informed about where to go for information, etc existing videos need to be updated for Deaf or hard-of-hearing people.

topic 2 - visually impaired people

With its focus on visually impaired people, the progress report on the information available to visually impaired people clearly indicated that the visually impaired community is being shut out. No Braille, no audio, no appropriate video or audio cassettes in local languages. The availability of services and public attitudes cause concern. Information necessary for saving lives needs to be translated into Braille, eg the expiry date on condom packaging as this is life saving information. The visually impaired as well as all disabled people are “disabled but not unable” (to have sex).

topic 3 - learning and mentally disabled people

Different types of learning disabilities must be treated accordingly. There is a lack of tailored information. Information should be simplified, translated into various ethnic languages and distributed. Material should be disseminated through schools and special attention should be given to disability sensitive media presentations.

Open discourse about sex and choices. Free speaking and clearing up of prejudices. Some people believe, and quite wrongly so, that HIV & AIDS can be cured by having sexual intercourse with a child. This is even more alarming for children who are mentally challenged, as they are often misled and forced to have sex, even with family members. Consequently, they run the dangerously high risk of acquiring the disease. This goes hand in hand with cultural perspectives and is supported by the common belief that babies must be born perfect. This turns disability into a taboo. Often disabled people are kept in seclusion. In regard to HIV & AIDS it translates into a double negative stigma. The education of mentally challenged children must incorporate computer training to prepare them to be productive in the technological age.

topic 4 - physically disabled people

Thirteen years after independence, many public premises, including the Namibian cabinet, are inaccessible to physically disabled people. This is a sad reality with which disabled people have to deal with. Access to information is a stumbling block for physically disabled people. They get information mainly through the radio but versatile ways must be introduced to make it interesting, eg drama. People acting as if they are physically disabled on national television is unfair towards disabled people. Disabled actors or disabled people can be used instead.

There are not nearly enough human resources, as there is a lack of qualified professionals and the scarcity of funds to run and maintain the necessary programmes are shortcomings that effect the operations of organisations of disabled people.

Day 2
June 11

Gender issues and HIV & AIDS

Natasha Tibinyane
Sister Namibia

Differently abled women find it difficult to find and keep a man and are consequently willing to compromise their sexual rights. In fact, differently abled women will even endure sexual abuse in the bid of keeping that one person content so as not to contemplate leaving them. In cultural instances such as traditional ceremonies women are treated badly. The case of Caprivi girls who are beaten, paraded and told that they should not run home if their husbands beat them testifies to this effect. The example shows that at times unfair treatment is encouraged by society and the question is simple. Where do these girls turn when their husbands start beating them? We cannot even imagine the dimension the problem must take for disabled women.

The sensitive issue of unfaithful husbands or partners is a common problem. Women may remain faithful to their partners, but in Namibian society where men having multiple sexual partners are glorified, chances are more likely that men will bring the virus within the home. In Sub-Saharan Africa the infection rate amongst married women is a wobbling six times that of single women. It is out of the question that a married woman can even consider asking her husband to use a condom. It is already a problem for women to condomise, as they are not allowed to make decisions on their sexual and reproductive health. So in this regard men are acting like HIV & AIDS transporters; bringing the disease from their workplace in the urban areas to their wives in the rural areas. This is destructive and unfair to faithful women.

Men have time and again exerted their dominance over Namibian women and, more often than not, have used violence as a weapon. Namibia's high incidence rate of violence against women and children weigh as heavily on disabled women and children and is enough to intimidate them. This justified fear of violence could be one of the reasons why they cannot negotiate for safer sex. This issue can be addressed by designing campaigns to counteract the stigma against differently abled women. HIV+ women do not know that they have access to drugs that can save the lives of their unborn babies. The female condom is also not easily and widely available. The misconception that differently abled people are not sexually active is not right but nevertheless very popular.

Sister Namibia has not incorporated differently abled persons but Mrs Tibinyane assured that they have realised this shortcoming and will address it.

Film presentation: The story of Lukas

Mubasen video productions

The Mubasen video production crew screened a video production, which involved the British Council, UNICEF and The Rainbow Project, to the delegates. The story is about Lukas, a 15 year old orphan whose parents died of AIDS. It looks at the life of one orphan that has, with the help of donors managed to get into school. This is not always the case, as most orphaned children don't have access to education, food, shelter and health services. It clearly highlights the issues concerning orphaned, incarcerated children and children infected and affected by HIV & AIDS.

After the presentation, concerns were raised about the film having been unfriendly to people with hearing and visual impairments. As the film had no subtitles it was impossible for Deaf or hard-of-hearing people to follow the story.

Mr Phiri from Mubasen replied that they would add subtitles to the film as well as consider disabled people in their future productions.

SWAPO women's league presentation

Martha Hendjala
South West African Peoples Organisation (SWAPO)

Since the SWAPO party Women's Council Workshop that took place in January 2003, there have been numerous activities on disabled people. HIV & AIDS does not know any boundaries; it cuts across all categories of people including disabled people. Equally, the status of disability does not have boundaries; it can happen to any one of us, being women or men, adults and children.

During the workshops organised by SWAPO party Women's Council for women with disabilities, the need for special attention to HIV & AIDS and disabilities was identified. It was in that workshop that the issues of disabled people and their heterogeneity were highlighted. That disabled people are not homogeneity, therefore special attention should be made in respect of their heterogeneity. It was noted that disabled people, especially the Deaf, are left out of HIV & AIDS campaigns. Those in rural areas and illiterates are the most left out of development efforts including access to information.

HIV & AIDS in the workplace

Delme Cupido
Legal Assistance Centre (LAC)

The Namibian constitution ensures fundamental rights such as respect for human dignity, right to equality and freedom from discrimination etc and there is an internationally recognised strong right to health. There have been cases where employers withheld employment from individuals based on their HIV & AIDS status. An employer may not discriminate against an employee in access to or in continued employment, including training, promotion and access to benefits in an unfair manner.

Discrimination on the basis of HIV & AIDS constitutes discrimination in an "unfair manner". The Namibian Defence Force (NDF) has discriminated in such a manner where applicants were excluded from the NDF solely on the basis of HIV status. The High Court found that such exclusion constitutes discrimination in an "unfair manner" as provided for in the Labour Act. Physical and mental fitness to do the job is the criterion – not HIV status. Why? HIV status alone is not an indication of fitness. HIV & AIDS status is confidential and does not need to be disclosed to the employer, as it does not affect working habits, promotion, transfer etc. In cases where people have made their status public they should get the usual compensation and be protected against victimisation. However small, there is also a risk of acquiring and transmitting HIV in the workplace.

Being on the outside: minorities and HIV & AIDS

Ian Swartz
The Rainbow Project TRP

Disabled people are among the minorities in Namibia. Other minorities include women, homosexuals, bisexuals, prisoners as well as the San and the Ovahimba. People with different religious orientation such as Muslim, Hinduism, etc also fall under this group. Sometime the group can be a majority in numbers, however, due to a host of reasons have less impact in the country. This is why women can also be seen as a minority.

It is interesting that one individual belongs to more than one minority at the same time. For example, disabled women fall into two minorities. If that same person falls pregnant it adds another minority… and if she is HIV+. In fact a society is made up of different minorities. Other minorities are discriminated against more than others. Women, although being a minority, are more in number than the Ovahimba.

As sexuality is natural, universal and exists in all cultures every human being is a sexual being. Each person has a sexual identity and a sexual orientation. Law enforcement agencies are ignorant of human rights issues. Regular uninformed hate speeches by political, religious and community leaders create a climate of intolerance. The way forward for minorities can only be realised with an inclusive approach. This can beat HIV & AIDS. Civil society must collaborate and all need to understand and overcome their own prejudices.

Lironga Eparu presentation

Emma Tuahepa
Lironga Eparu

Emma Tuahepa is one of the first Namibians to go public with her HIV+ status. Even though she is not a disabled person, she has experienced discrimination on the grounds of her status.

The risky behaviour of some men, who even after knowing the consequences continue to have unprotected sex, is an undesired occurrence. It seems that some men are still not afraid of contracting HIV. Even after knowing Emma's HIV+ status men still approach Emma and propose to have unprotected sexual intercourse. Many men don't consider before having unprotected sex and only regret their actions immediately after sex.

The problems faced by Lironga Eparu are, among others, parents using the centres as a dumping place for their infected children as well as the financial burden of burying comrades that died of the disease. The many deaths due to HIV & AIDS have given rise to the problem of burial. Many people are dying and, as the family have abandoned them, it is up to Lironga Eparu to bury them. But the organisation also has its financial concerns and cannot always afford the coffins etc. At times, as was the case during the conference, the financial constraints were considerably tight. Thus some bodies were left in the mortuary until the finances were available.

> ***Even after knowing Emma's HIV+ status men still approach Emma and propose to have unprotected sexual intercourse.***

NFVI presentation

John Uheka
Namibian Federation of the Visually Impaired

The Namibian Federation of the Visually Impaired (NFVI) believes that proper and relevant information should be disseminated to help the marginalised.

The message about HIV & AIDS is not being tailored to reach visually impaired community members. This may count against them when the time comes to make life saving choices. All HIV & AIDS clinics and workshops should be made to facilitate disabled people by using appropriate media and languages.

NNAD presentation

Martin Tjivera
Namibian National Association of the Deaf

The Namibian National Association of the Deaf (NNAD) was founded in 1991 as a welfare organisation under the Ministry of Health and its main partner is the Finnish Association of the Deaf (FAD), Finland. The aims of the organisation are to play an important role in the monitoring of issues concerning Deaf people, to defend the rights of the Deaf, and support their effort to gain equal footing with other citizens on all sectors of Namibian society. They are also involved in promoting and maintaining the welfare of all Deaf Namibians.

Their 8 main activities range from Deaf awareness programmes and Deaf women's programmes to sports and Deaf children's programmes. An integral part of their activities is the organisation training of Community Based Rehabilitation (CBR)/social workers, nurses, police, court and other interested people as sign language interpreters.

NAPPD presentation

Nixon Munamava
Namibian Association of People with Physical Disabilities

Disabled people face a host of problems and needs, which the Namibian Association of People with Physical Disabilities (NAPPD) is trying to address. The organisation believes that the situation of physically disabled people will only change for better when the physically challenged talk and act on their own behalf. Thus their aim is to establish a viable, strong and authentic organisation that will be a united voice of all physically disabled people in Namibia as well as unite, organise and mobilise physically disabled people nationally. They also do activities that strengthen physically disabled people to strive for the promotion of their human rights and upliftment of their general living conditions. These include setting up self-help income generating projects for physically disabled people.

Furthermore the organisation engages in support services to its members. These services include information dissemination on disability; disability prevention and care; registration for members as well as for disability grants and other social grants available for disabled people; referrals to service providers; skills training workshops; and job placements. In time to come the NAPPD will offer computer classes for PWDs to prepare them for the job market where computer literacy has become a prerequisite.

A major issue is the urgent need for a consultant, who will work with the organisation on a daily basis. He or she will be responsible for the general organisational skills development, funding proposals, and training on various leadership skills as well as administration skills. Due to financial constraints the NAPPD suffers in getting them on board.

The organisation believes that the situation of physically disabled people will only change for better when the physically challenged talk and act on their own behalf.

DYCN presentation

Manfred Howaeb
Disabled Youth Council of Namibia

Disabled people have been sidelined in most of the campaigns that fight the spread of HIV & AIDS. Thus the disabled youth in Namibia, who are not reached by the campaigns, find themselves in a desperate situation. They are sexually active but in many cases not sexually educated and consequently are at high risk.

Most HIV & AIDS programmes are conducted at schools, as it is an area that has the majority of young people. Disabled Youth Council of Namibia (DYCN) raised their concerns about the minority of youth who are not in school. Thus the information meant for youth does not even reach the disabled people who rarely attend school. A recent study on living conditions of disabled people showed that 75 per cent of disabled people interviewed had not finished school.

It is true that disabled youth are sexually active and others are sexually abused. They are also at risk like any other member of society. Disabled youth also have a right to information so that they can make informed decisions about their lives. The failure to address this problem could result in there always being a group that is spreading the disease, thus making it ever more difficult to control this disastrous disease. HIV & AIDS related information must be tailored, designed and packaged in order to reach as well as be understood by disabled youth. This is necessary as disabled youth are the future of Namibia.

Learning disabled children with the focus on girls

Ms P Beukes
Eros Girls school

The Eros Girls school is a single sex institution, which caters mainly for learning disabled girls. With the efforts of its 30 lady strong staff, which often go out of their way to provide extra food and uniforms, it provides special education in three streams. Their aim is to encourage women of excellence and to help them towards independence. Due to the management's decision the school does not encourage condoms but advises the students to abstain. Consequently they do not promote or teach the students about condoms. However, they give girls that have become pregnant the opportunity to complete their education once they have given birth. According to Ms Beukes, one girl has died of HIV & AIDS.

Audio cassette tapes for visually impaired people

Denise Cosgrove
Voluntary Service Overseas (VSO), Namibia

During field visits out to the rural areas in the Karas region, the regional HIV & AIDS coordinator observed that many disabled people live there. She also learned that many of those people have no access to education. This greatly affects and limits their life opportunities, information and services they receive, especially with regard to HIV & AIDS. The regional HIV & AIDS coordinator was also informed that there are many people in the region who are without the ability to read their mother tongue, and therefore are also often unable to access mainstream information around HIV & AIDS prevention.

Karas Regional AIDS Coordination Committee (RACOC) is responsible for providing appropriate information, education and communication (IEC) materials to the entire population of the region, and devising new ways of meeting this demand. Thus they decided to address this shortcoming by producing audio cassette tapes containing HIV & AIDS education in the 3 most commonly understood languages in our region - Nama, Afrikaans and English.

The majority of people in the rural areas generally do not have access to CD and video players, and the electricity source to power them. Radio was another possible option, but many rural areas do not have reception to receive many of the available stations. Therefore we chose to produce audio cassette tapes, as they are cheap to reproduce, they can be battery powered and tape players are available to most people in the region.

With funding from the European Union (EU) the production of the tapes began. An English script was translated into Afrikaans and Nama. The Namibian Broadcasting Corporation allowed Karas RACOC free recording time in their Keetmanshoop studio. A company in Windhoek reproduced 100 copies of the tapes and a local artist designed the front cover of the tape.

The tape will be distributed through many of the RACOC partners throughout all areas, especially the rural areas, in the Karas region. This project is currently a pilot project and the tapes will be disseminated initially for the purpose of collecting feedback and improving the tape to fit the needs and abilities of the target audience. When the Karas RACOC are satisfied with the quality of the tape it will be reproduced further and, if successful, funding will be sought in order that other languages may be incorporated onto the tapes.

Mentally disabled children

Mrs Hannelore Feddersen
Dagbreek school

Extracts from Mrs Hannelore Feddersen's speech

The misconception that mentally disabled people are not sexually active and therefore immune to AIDS or other sexually transmitted diseases is still a very common opinion in Namibia and elsewhere in Africa. However, mentally challenged people are sexually active, seeing that this is one of the most basic needs in human life. The Dagbreek school tries to educate the learners about alternative sexual behaviour, like abstinence as understood out of a more Christian view, or masturbation as mentioned in the example of the little girl. Of course this sounds very easy, but it's not, seeing that we can only protect our mentally challenged learners through constant supervision for as long as they are in school. School leaving disabled ladies often become kind of sexual slaves within their community, because they cannot say no, and sometimes they don't understand the wrongness of what is expected from them. When they then become pregnant, they often don't even know who the father is. We also have an HIV & AIDS awareness programme in connection with Childline/Lifeline, and I informed myself about other institutions that take their clients to the clinics for contraceptives and work closely together with the Catholic AIDS Action (CAA) group.

Mentally disabled women and children are extremely exposed to sexual abuse and susceptible to contracting HIV & AIDS because of their inability to protect themselves. This dependency on abled people to help them with their daily needs might be exploited by the abled caretakers in such a way that they think these girls/women are kind of *easy prey* for sexual activities.

There is one group of mentally disabled people who are extremely sexually active. They are, for example, some of the people with Downs syndrome, and on the other hand those who are not active, but don't really understand what it's about. Those are the ones that you can find always fiddling with their own genitals. It doesn't matter to which group a mentally disabled person belongs, he or she still needs to be protected against HIV & AIDS. In both cases the awareness of sexuality can start at a very young age, but at the latest it becomes dominant when reaching adolescence. Mrs Feddersen has experienced such behaviour, eg a ten year old girl in her class who enjoyed masturbating whenever she feels so, even at the breakfast table. Talking to her in a nice and decent way only made it worse, because then she even got the teachers attention for her behaviour. Shouting and punishing was useless, because she was not able to understand her sexual behaviour as a cause for the punishment. Mrs Feddersen approached the situation by telling the girl that she is only allowed to do this on a toilet. Now she runs out of class and to the toilet whenever she feels the urge to masturbate. Obviously this girl belongs in the category of being quite active.

Mentally disabled people often also have difficulties in understanding the *rules* of sexual behaviour and therefore are unable to read the signals when someone's intentions are bad, or to give the right signal when they want to become sexually active. An eighteen year old learner at the school always asked if he could take off a lady's shoes when he felt sexually attracted to her.

At times mentally disabled people cannot judge the real intentions of abled people and therefore trust much too easily. Additionally they experience problems when it comes to insisting on safer sex within a relationship, because they don't have the intellect to understand the consequences. They might experience threats like the withdrawal of basic needs such as food and shelter, if they do not comply with the demands of their partners or caretakers. For these people it is also hard to accept that even very close relatives who love you are not allowed to have sex with you, and so

they easily fall into the trap of being abused by their own relatives or friends.

If a person is not able to judge for themselves, how can he or she understand whether the behaviour he or she is showing, is good or bad. And even worse, if this person cannot be held responsible for his or her actions, how do you explain to him or her the reasons for prevention and safer sex, the consequences of unprotected sex or the need of controlling your behaviour. This is a delicate situation and must be dealt with from case to case.

As they are disabled, they already face discrimination, stigmatisation and isolation. Cultural habits, norms and views only make matters worse as they then alienate disabled people by making them feel like outsiders or intruders into a world they're not supposed to live in. Sometimes disabled children are AIDS orphans and are not wanted. They are given to relatives to take care of and in cases end up as street children.

The question raised was simple: Who likes to take care of a family member that will stay a burden for the rest of his or her life?

Lack of knowledge, their own struggle to survive and inadequate possibilities to seek advice imply that disabled people often are either left isolated by the family and/or the community. Which in the worst case can leave a disabled person being *easy prey* for a rapist, because no-one realises what they feel, need or want, or they are abused by their own family members which might lead to incest and furthermore to more mentally or physically disabled children. In both cases one cannot exclude the possibility of becoming HIV infected.

Dagbreek school has often experienced quite some problems with the learners and their sexuality, but through all the years have learned that it is easiest to play with open cards when it comes to sexuality and sexually transmitted diseases. As long as they are not aware of any sexual activities, it is best not to be forceful. Mentally disabled people sometimes are also unaware of the embarrassing moments that can occur. There was this autistic adolescent who was taught that if you feel the need to masturbate you go to the toilet. Once he was standing in a public place and he noticed a lady going to the toilet. So when she came out, he asked her very kindly: 'Was it a good one?'

Which disabled person can afford the proper treatment, once infected with HIV? Shouldn't we rather consider proper support centres and sheltering homes and workshops, where mentally challenged adults can live under appropriate supervision and care? What if all the enlightenment and advertising fails, because the person in front of you has no clue of what you're talking about?

The combating of HIV & AIDS calls for the community to stop discrimination, prejudice and negligence against disabled people. If each and every citizen could see it as his or her duty to protect and help a mentally disabled person where ever he or she needs it, just as it is his or her duty to obey the traffic rules or behave in a public place, we wouldn't have to bother so seriously about the spreading of HIV & AIDS within the disabled community. Day 3 - June 12

Day 3
June 12

Group deliberations to outline needs and draft recommendations

Summary of group presentations

The delegates went into their respective groups to address the specific needs as well as come up with recommendations. The results were fruitful.

Key recommendations were as follows:

- Disabled people must make themselves visible and should be part of whatever body, conference etc, which is dealing with their issues.
- Different organisations and support groups must be more organised and should network.
- All the different organisations of disabled people (representing different disabilities) should be included (both as planners and as recipients) in HIV & AIDS related programmes.
- Disabled people should be involved in all stages, from planning and design to distribution, of information/awareness campaigns on HIV & AIDS.
- All programmes should include training disabled people.

The Organising Committee (OC) recommended that a designated person in the NFPDN be tasked with developing and coordinating an HIV & AIDS programme that other organisations can lead into and that each Organisation of People with Disabilities (OPD) develop their own needs assessment regarding HIV & AIDS plus an action plan. An HIV & AIDS and disability task force must be developed and nominations for this are forwarded to the NFPDN by the 25th June 2003. The task force should be gender sensitive and balanced. A follow-up by the organising committee with the prime minister should be made within a week of the conference end. The task force will ensure that adequate research and collection of data is obtained.

Summary of needs of disabled people:

- Specially trained personnel and decentralised personnel are necessary.
- The rural as well as the urban areas need to be sensitised. NFPDN must spearhead this move.
- Social workers must be made more aware of disabled people.
- Each OPD must provide training for one of its members.

- Access to resources, eg materials, training and facilities.

- Disabled people must make themselves visible if they want to make some serious changes. Strikes and demonstrations can be used to this effect.

- The needs ranged from basic human rights such as the right to communication, access to the right to representation, legal and voting rights to basic needs like food, clean water, shelter, health, education, income and employment to reproductive rights, families.

Initiatives that may not benefit all people must be addressed nevertheless, eg the Braille on condoms will benefit only the visually impaired community but remains a priority. NNAD must appreciate what is being offered yet still lobby for having the news interpreted instead of the "Talk of the Nation." The rise in sign language interpreters will call for policies, salary laws etc. The need to represent HIV & AIDS information in appropriate ways such as Braille, audio and video cassettes, tactile posters, dramas, and visual materials. Disability friendly literature on HIV & AIDS must be prioritised. Existing materials must be adapted, eg cartoons.

Communication and organisational structures must be established to reach all disabled people. Training for disabled people on sexual negotiation skills and assertiveness. Disabled people must be included as trainers as well as participants.

Access to services, eg counselling and health services as well as lobbying and sensitising Government officials to HIV & AIDS and disability are further needs.

Summary of recommendations to help address these needs:

- Acknowledging that disabled people are sexually active.

- It should be made mandatory for disabled children to have access to equity, equality and quality education.

- HIV & AIDS should be part of an educational curriculum.

- We urge the justice systems to review the legal protection of mentally disabled children from abuse.

- Disability grants should be reviewed to meet the personal needs of mentally disabled children.

- The MIB should lead in broadcasting of appropriate materials.

- MoHSS should review services to make them more disabled/youth friendly.

- Community outreach by MoHSS with schools and rural communities can help to build communication and referral systems.

- Organisations of PWDs to build communication structures and develop national databases.

- Shared responsibility with - parents, Government, traditional leaders, schools, women's groups, churches, and NGOs.

- Task force within all the organisations working with HIV & AIDS and disability must take recommendations forward. Each organisation that works with PWDs must have a representative on this task force.

- Time frames must be attached to all recommendations.

- OPDs need to put forward people who are willing to be trained as HIV councillors, trainers and facilitators.

Official closing

Honourable Isak Katali
Deputy Minister of Lands, Resettlement and Rehabilitation (MLRR)

Let me on the outset appreciate your invitation to come and close this conference and also share a few moments with you. However, it is going to be difficult for me to close something that was opened by a big man. It is therefore that I would like to thank the Right Honourable Prime Minister Theo-Ben Gurirab on your behalf for having availed his time for this conference.

Having followed comment from the media, I want to assure you that this conference has sensitised many people who were ignorant on the fact that disabled people are part of the Namibian nation whose socio and economic well-being is being threatened by the AIDS pandemic. I wholeheartedly congratulate you for ringing this awakening bell. I cannot emphasise more on the Government's commitment to facilitate an inclusive society as it has already been assured to you by my political principal the right honourable prime minister, at the official opening of this gathering.

As you are aware the MLRR is the implementing ministry for access to services by disabled people. However, it is also there to sensitise other line ministries and to ensure the practical access for disabled people to all services available to all Namibians. What I am saying is that we are promoting an inclusive society and we cannot separate services for disabled people and non-disabled people. I must acknowledge that as a ministry we have a challenge of both the financial and human resources to play this role effectively. The most important thing is that we have both the commitment and the willingness to do so.

Coming back to the subject of this conference my ministry has been committed to address the situation of HIV & AIDS and disability as we have been at the beginning process when our Otjozondjupa regional office actively participated in the pilot project at Okakarara. We have designated an official at the level of a chief control officer to be part of the working group that plans and manages the project. Our rehabilitation officer in Windhoek has been part of the organising committee of this conference. I can assure you that the MLRR has already sensitised its rehabilitation officers to make sure that PWDs have access to basic information on the cases of HIV & AIDS and on how to prevent themselves from getting the virus. I am saying basic because they have basic information and knowledge. The most important role that my ministry intends to have, is in line with the current policies pertaining to national programmes on the prevention of the spread of the disease.

Gerson Mutendere, master of ceremonies, I am aware that at such gatherings you eagerly wait to hear the progress on the long awaited establishment of the national council on disability. I am here to confidently tell you that they are on track and in the final stages to consult with our legal drafter. We are working hard to table this bill in the National Assembly sometime this year.

During the course of this week we have witnessed in the media a very touchy scene of a household that has most of its family members as disabled people. I can assure you that an inter sectoral team led by our regional deputy director in the North West region has visited this family and helping different needy areas will be made available.

Let me as a final note ask you to please double your actions in sensitising the ignorant, those of us who have no experience in living with a disability to be able to respond to your needs appropriately. Please note that I said those who have personal experience of living with a disability because I believe that most us, if not all of us have lived with a person with a disability in our lifetime.

The workshop has come up with a set of recommendations as follows.

I now declare this workshop officially closed.

Key recommendations

Conference recommendations:

The organising committee proposed the following key recommendations.

- A designated person in the NFPDN must be tasked with developing and coordinating an HIV & AIDS programme that other organisations lead into.
- Each OPD must develop their own needs assessment regarding HIV & AIDS.
- An HIV & AIDS and disability task force, which will be gender sensitive, be developed and nominations for this be forwarded to NFPDN by the 25th June 2003.
- A follow-up by the organising committee with the prime minister must be done within a week of the conference end.
- The task force must ensure that adequate research and collection of data is obtained.
- The task force will consist of representatives of different organisations and will function as a body from early August.

Key recommendations, which were agreed upon by the delegates are as follows:

- Information on HIV & AIDS must be made accessible to and understandable for all. That means that the mediums must be tailored to reach disabled people. Simplify and translate HIV & AIDS information that is already available in writing. This can only be accomplished by collaborating with the various media and by lobbying with the organisers of HIV & AIDS awareness campaigns.
- Networking between organisations of disabled people is an essential prerequisite. Service providers, organisations on HIV & AIDS and professionals need sensitising to disabilities in order to provide the necessary services to disabled people. Disabled people need to be involved not only in society but in matters relating to their health and well-being. PWD need to be capacitated in order to gain more confidence to address the AIDS issue themselves where possible. CBOs must be encouraged to include mentally challenged and people with psychiatric conditions in their programmes, meetings etc. Encourage support groups to be organised and include parents especially with mentally challenged children.
- Free speech, specifically about sex, must be promoted to erode all the prejudices and stigmas that are associated with HIV & AIDS. This will have an effect as a considerable amount of people believe in myths and other prejudices which are untrue and serve only to spread the virus.
- Additionally, specific areas such as social work training curriculum should include modules on disability awareness. Day care providers should be encouraged to accommodate mentally challenged and all disabled children. Specialist training for personnel in all areas in Namibia should be facilitated. Decentralise specialist teachers and social workers so that all Namibians can access the professionals.

Summary of participant evaluations

- **To explore the potential issues for disabled people in regards to HIV & AIDS**

  Not at all-0% Poorly-0% Okay-7% Well-52% Very Well-41%

  comments:
  -It was very good to have people from different organisations and backgrounds together

- **To discuss with disabled people about HIV & AIDS and learn from them what their needs are in regards to prevention activities, access to care and availability and access to treatment**

  Not at all-0% Poorly-7% Okay-14% Well-58% Very Well-21%

  comments:
  -Not enough inputs from organisations of PWDs
  -Not enough participation of PWDs

- **To assess what the social and economical impact of the HIV & AIDS pandemic are for a disabled person and how this can be best addressed**

  Not at all-4% Poorly-11% Okay-19% Well-36% Very Well-30%

  comments:
  -The focus was not kept enough on HIV & AIDS

- **To highlight lessons learnt and share experiences of disabled people with a focus on access to prevention, care and treatment**

  Not at all-0% Poorly-4% Okay-24% Well-56% Very Well-16%

- **To explore opportunities and strategies for increasing the sharing of experiences and lessons learnt across the region**

  Not at all-0% Poorly-0% Okay-21% Well-46% Very Well-33%

- **To discuss how the NFPDN in Namibia, VSO, the Government and other agencies can further commit to support and strengthen the response nationally and regionally to insure that there is more involvement of disabled people at a proper level in the future**

  Not at all-0% Poorly-12% Okay-13% Well-33% Very Well-43%

- **To establish a working group to follow up recommendations of the conference**

  Not at all-5% Poorly-5% Okay-18% Well-36% Very Well-36%

1. Opinions of the individual sessions

- **Day 1: African perspective on HIV & AIDS and disability** (Mr Alexander Phiri, Secretary-General SAFOD, Zimbabwe)

  Not at all-0% Poorly-0% Okay-12% Well-24% Very Well-64%

- **Day 1: HIV & AIDS in Namibia: a Namibian perspective** (Ben Katamila, NANASO)

  Not at all-0% Poorly-0% Okay-39% Well-43% Very Well-18%

- **Day 1: Group sessions: 4 groups discussing different topics**

  Not at all-0% Poorly-0% Okay-20% Well-40% Very Well-40%

- **Day 2: Presentations from different groups on their organisations with the focus on material development and disability**

  Not at all-0% Poorly-0% Okay-23% Well-45% Very Well-32%

  comments:
  -They should have been more focused on disability and HIV & AIDS

- **Day 2: Presentations from organisations on disabled people and their needs**

  Not at all-0% Poorly-10% Okay-10% Well-50% Very Well-30%

  comments:
  -Still to be explored further

- **Day 3: Summary by convener concentrating on identifying gaps and the improvement of networking**

  Not at all-0% Poorly-0% Okay-6% Well-61% Very Well-33%

  comments:
  -The methodology used to raise recommendations was not good, it caused duplication and waste of time

- **Day 3: Group session on the way forward, reporting back and recommendations**

  Not at all-0% Poorly-0% Okay-10% Well-65% Very Well-25%

2. Other aspects of the workshop

- **Pre-workshop communication and information**

  Not at all-5% Poorly-9% Okay-23% Well-45% Very Well-18%

- **Location**

  Not at all-0% Poorly-8% Okay-17% Well-42% Very Well-33%

- **Accommodation**

  Not at all-0% Poorly-0% Okay-2% Well-8% Very Well-12%

- **Catering**

  Not at all-0% Poorly-8% Okay-8% Well-34% Very Well-50%

- **Transport**

  Not at all-0% Poorly-0% Okay-20% Well-47% Very Well-33%

- **General organisation throughout workshop**

  Not at all-0% Poorly-0% Okay-9% Well-52% Very Well-39%

3. Any further comments

- Conference material was not visually impaired friendly
- It was a good event, it created an opportunity for a good platform
- Consistent attendance from the ministry would have been useful
- This should be the first of many events in this field
- It was very disappointing that WHO and UNAIDS as well as MLRR did not attend

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*Seventy-six participants, mainly from Namibia, but also from South Africa and Zimbabwe, explored issues surrounding HIV & AIDS and disability during a conference organised by the **NFPDN** and **VSO-RAISA** between 10-12 June 2003.*

The conference provided an excellent platform to discuss HIV & AIDS and disability for participants from different organisations: the disability sector, civil society, HIV & AIDS service organisations and relevant ministries.

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