HIV-related Policy and National Programming: How to Include the World’s Largest Minority?

Skills Building Workshop Manual for Participants

XIX International AIDS Conference, Washington DC

Facilitators/Editors: Dr. Jill Hanass-Hancock (HEARD), Dr. Emelia Timpo (UNAIDS), Mrs. Muriel Mac-Seing (Handicap International)

Guest Speakers: Charlotte McClain-Nhlapo (USAID) and Jan Beagle (UNAIDS), Medi Sengooba (HRW, Uganda), Sabin Nsabimana (RBC/IHDPC, Rwanda) and Richard Matlhare (NACA, Botswana)

Group Facilitators: Rosangela Berman Bieler (UNICEF), Wendy Porch (CWGHR), Darryl Barrett (AusAID), Phillip Coetzer (QASA)

Venue: Mini Room 1

Time: 23 July 2012, 14:30-18:00
Acknowledgements:

We would like to thank UNAIDS and the IAS for funding the Skills Building Workshop at the XIX International AIDS Conference in Washington as well as RATN and HEARD for funding the development of the workshop manual and material. Further we would like to acknowledge the knowledge development of academics and implementers in this field whose work has contributed to the development of the knowledge displayed in this manual in particular Nora Ellen Groce, Jill Hanass-Hancock, Stephanie Nixon, Hellen Myezwa, Elisse Zack, Wendy Porch, Kelly O'Brien, Catherine Grant, Ann Strode, Leslie Swarts, Emelia Timpo, Rosangela Berman Bieler, Jennifer Jelsma, Rene Brandt, Rebecca Johns, John Meletse, Darryl Barrett and Muriel Mac-Seing.

Contents

Workshop Agenda.................................................................................................................. 3
What is Disability? .................................................................................................................. 5
Disability and HIV an Emerging Issue.................................................................................. 7
  People with Disability and HIV ......................................................................................... 8
  HIV-Related disability ....................................................................................................... 11
  Episodic Disability.............................................................................................................. 14
Guiding Principles for Disability Inclusion in NSPs............................................................. 14
Key Elements of National Strategic Plans as Relevant to Disability .............................. 17
Including Disability in Prevention, Treatment Care and Support.................................... 18
  Accessing HIV-Services for People with Disabilities......................................................... 18
  Rehabilitation and Disability ............................................................................................. 20
  Identifying Disability......................................................................................................... 21
  Addressing Disability through Different Structures.......................................................... 22
Resources and Links.............................................................................................................. 23
References............................................................................................................................. 23
Appendices ........................................................................................................................... 28
  Appendix 1  Disability Inclusive NSP Framework.............................................................. 28
  Appendix 2  UNAIDS Disability and HIV Policy Brief....................................................... 28
  Appendix 3  NSP Disability Inclusive Analysis Toolkit....................................................... 28
Workshop Agenda

The UNAIDS, WHO and OHCHR Policy Brief on Disability and HIV (2009) recognises the interrelationship between HIV and disability, and emphasizes that this issue has not received sufficient attention. It stresses the point that people with disabilities are one of the key populations at higher risk of exposure to HIV. It also emphasizes that people living with HIV may develop impairments and disabilities as a result of the disease and side effects of treatments.

Disability HIV

Despite evidence, only a few countries have included disability in their national responses to HIV. One of the main obstacles is the lack of disability sensitivity and skills of those who influence the development of National Strategic Plans or Frameworks (NSPs).

The workshop will use a disability inclusive NSP framework and examples of good practice to enable stakeholders to address disability within HIV policy and programming. The workshop aims to develop:

- an understanding of the intersection between HIV and disability
- skill to use the disability inclusive NSP framework
- knowledge of good practices on disability inclusion in HIV policy and programming

The workshop will be divided in four sections 1) Understanding of disability 2) Intersection of disability and HIV 3) Structure of NSPs and the integration of disability 4) Good practice examples. It aims at enabling participants to include disability in all main sections of an NSP: the situation analysis, prevention, treatment care and support and monitoring and evaluation.

- Issues regarding the definition of disability
- Vulnerability of people with disabilities to HIV
- Introduction to HIV-related disabilities
- National Strategic Frameworks and legal obligations
- Implications for HIV services
- Implications for rehabilitation services
- Challenges and good practice example
Agenda

14.30-14.40 Welcome and opening remarks Charlotte McClain-Nhlapo (USAID)

14.40-15.15 Film: Stepping into the Unknown (20 min) facilitation Jill Hanass-Hancock (HEARD)

15.15 – 15.30 Presentation: The intersection of Disability and HIV, Emelia Timpo

15.30 – 15.45 Presentation: A disability inclusive NSP framework, Muriel Mac-Seing

15.45 – 16.30 Group-work: Work with NSP framework and selected NSP sections in regards to their inclusion of disability. facilitation Jill Hanass-Hancock
   1. Situation analysis group, suggested group facilitator: Rosangela Berman Bieler
   2. Prevention group, suggested: suggested group facilitator: Phillip Coetzer
   3. Treatment, care and support group, suggested group facilitator: Wendy Porch
   4. Monitoring and evaluation group, suggested group facilitator: Darryl Barret

16.30 – 16.45 Break

16.45 – 17.15 Round table discussion on country examples good practise and dedication to change with Medi Ssengooba (HRW, Uganda), Sabin Nsabimana (RBC/IHDPC, Rwanda) and Richard Matlhare (NACA, Botswana) facilitation Muriel Mac-Seing (Handicap International)

17.15 – 17.45 Gallery work in groups: local, country, regional, global level of action on flip-chart for individual commitment and remarks, facilitation by Emelia Timpo (UNAIDS)

17.45 – 17.50 Summary and next steps

17.50 – 18.00 Closing remarks, Jan Beagle (UNAIDS)
What is Disability?

The World Health Organisation (WHO) and World Bank (2011) reports that 15% of the world’s population are living with various disabilities throughout the world (up to 20% in resource poor settings) and that the number is increasing due to various factors including the rise in chronic diseases \([1, 2]\). This makes them the world’s largest minority. HIV and AIDS is one of the chronic diseases. Data shows that 80% of people with disabilities live in low-income countries, are poor and have limited or no access to basic services, including education and rehabilitation.

However, the term disability means different things to different people of different contexts and cultures, even though there has been a major shift internationally in the understanding of disability in recent decades. The social model, the medical model and the International Classification of Functioning Disability and Health (ICF) are the most commonly used models:

### The Medical Model

The medical model historically focuses on the dysfunction or impairment of the individual. It conceives disability as the outcome of impairment. Focusing on physical differences the model seeks to cure the impairment rather than address the disabling factors in the environment. It sees people with disabilities as people with bodies that are impaired, don’t work and cannot be productive. Often this approach focuses on particular groups such as "the blind" or "the deaf". The medical model has been criticised because it reduces disability to a physical construct when in fact there are many dimensions that contribute to disability.

### The Social Model

The social model of disability asserts that an impairment itself is not an obstacle for a person with disabilities, but is a socially-created problem and demands a political and social response. Disability in this understanding is caused by physical barriers, personal attitudes and other features of the social environment. Inaccessibility to buildings and difficulty using transportation are some of the barriers that limit full social participation of people with disabilities. This model seeks to change the environment in which people with disabilities live, work and play. The model focuses on society and not on curing the person.
The ICF Model

Over the last four decades, a gradual shift in the conceptualisation of health and disability from a medical model towards a combined model of disability has occurred. The WHO or ICF model synthesises the medical and social models of disability and creates a "bio-psycho-social" model, which reflects the complex phenomena of disability [2].

In the ICF framework, disability is understood as a “complex phenomenon that manifests itself at the body, person and social level” [3] and appears on three levels namely body structure/function (impairment), activity level and participation in society. According to this model these three levels are outcomes of interactions between health conditions, the intrinsic features of the individual and extrinsic features of the social and physical environment (see figure 1).

Impairments of body structure or functioning are understood to be problems with the anatomical structure of the body (e.g. a missing limb) or its physical functioning (dementia, deafness, albinism, epilepsy, HIV infection). Depending on environmental (social and physical) and personal factors this condition may or may not lead to activity limitations and/or participation restrictions. Activity limitations are understood as difficulties with executing a task or action (e.g. getting dressed, walking, reading) and participation restrictions are problems relating to involvement in life situations (accessing work or social life).

HIV can be integrated within the ICF model as well. On the one hand, HIV is a health condition that affects the immune system. With appropriate treatment this
might never develop into an activity limitation. However, because of the stigma and discrimination related to HIV, the person might experience participation restrictions without any major activity challenges or impairments. On the other hand, people living with HIV (PLHIV) may also develop impairments/change in body functions (e.g. deafness, blindness, paralysis, HIV-dementia, or mental health issues such as depression) that have the potential to develop into activity limitations (disabilities) and/or lead to participation restrictions.

**Disability and HIV an Emerging Issue**

The United Nations Programme on HIV/AIDS (UNAIDS) recognises that vulnerable populations with limited access to their basic human rights are often at increased risk of exposure to HIV [4-6]. Consequently the UNAIDS strategy 2011-2015 recognizes persons with disabilities as a neglected group in HIV programming that needs to be included [7]. The limited evidence available suggests that people with physical, intellectual or sensory disabilities are as likely, if not more likely, to be at risk of HIV infection. HIV and AIDS also serves to exacerbate existing difficulties facing people with disabilities by, for example, increasing health, welfare and psycho-social needs, providing additional fuel for stigma and discrimination and further limiting economic opportunities [5, 8].

Additionally, there is a growing understanding that people living with HIV are also at risk of developing disabilities on a permanent or episodic basis as a result of their illness [5, 9]. In resource poor settings, very little is understood on this issue, and since the introduction of antiretroviral (ARV) medication, it can be expected that there will be a tremendous impact on health systems. Therefore it is necessary to understand the interrelationship between HIV and disability to inform an adequate and sustainable response.

The field of disability and HIV/AIDS has been growing in the last two decades. Attention to the interrelationship between HIV and disability was first drawn in the resource rich settings since the 1990s with the availability of ARVs [10]. The experience of living with HIV for people who could access these new treatments had shifted from, typically, palliative care to a life of hope combined with uncertainty. Although people were living longer they were experiencing episodic illness and disablement as a result of the secondary effects of HIV (i.e. a broad range of HIV-related conditions that previously had not had time to surface), as well as the side effects of treatment. However, at that time ARVs were not accessible in resource poor settings. In Southern Africa they only became available around 2004. We can therefore predict that similar issues will arise which will be exacerbated by the fact that these countries are resource poor settings. In addition there exists a tremendous gap in knowledge around this area in these settings.
Figure 2: Evolving Understanding of the Interrelationship of Disability and HIV [10]

<table>
<thead>
<tr>
<th>Northern experience of the disabling effects of HIV since availability of ARVs in the 1990s:</th>
<th>Raised attention of the vulnerability of people with disabilities to HIV (2003-2010):</th>
<th>Recognition of the interrelationship of disability and HIV (2010 onwards):</th>
</tr>
</thead>
<tbody>
<tr>
<td>People living with HIV and their experience of disability</td>
<td>People with pre-existing disabilities and their experience of HIV</td>
<td>Exploring synergies and cross-learning, identifying a future research programme</td>
</tr>
</tbody>
</table>

About the same time that treatment became available in resource poor settings the abiding assumption that people with disabilities are at little or no risk for HIV was disproved in the Global Survey on HIV/AIDS and Disability, a seminal World Bank study conducted by Nora Groce in 2004 [8, 10]. As the first of its kind the study, which collected data from organizations working with people with disabilities in 57 countries across four continents, concluded that almost all known risk factors for HIV and AIDS are increased for people with disabilities, yet they were most often forgotten or left out of HIV programming. This was taken up in some resource poor regions. For instance, the Africa Campaign on Disability and HIV\(^1\) raised awareness on the interrelationship between 2007 and 2010 and has inspired a number of studies that have provided more evidence on the vulnerability of people with disabilities towards HIV and AIDS. Yet very little is known about good practices and only very few countries had integrated disability in their National Strategic Plans on HIV and AIDS in Eastern and Southern Africa by 2010 [11].

**People with Disability and HIV**

It has been argued that part of the lack of attention to the vulnerability of people with disabilities to HIV is based on the assumption that they are not at high risk for HIV infection because they are asexual, do not use drugs and are not in danger of sexual exploitation or abuse. However, it is clear that these assumptions are false. People with physical, mental, intellectual or sensory disabilities have recently been recognised as a key population at higher risk of

---

\(^1\) The Africa Campaign was led by the Secretariat of the African Decade for Disabled People (1999-2009) and Handicap International. For more information: [http://www.africacampaign.info/](http://www.africacampaign.info/)
exposure to HIV [8, 12]. The literature argues that people with disabilities are at increased risk of HIV because of the following points [12, 13]:

1. **Poverty**: People with disabilities are often the poorest members of their communities and the World Bank estimates that persons with disabilities may account for 20% of the poorest citizens in the world.

2. **Lack of education**: People with disabilities are often excluded from school because they are not considered in need of education, are assumed to be a distraction in class, or are believed to be incapable of learning. Even when in school, children with disabilities are less likely to receive science and health education and more likely to be excused from sex education courses as one does not want to “wake sleeping dogs”.

3. **Lack of HIV and "safer sex" information resources**: There is a pervasive misconception that people with disabilities are either asexual or oversexed. Although adolescents with disabilities are generally more socially isolated, they have been shown to be as sexually experienced as their able-bodied peers. Reproductive health awareness-raising programmes are known to frequently exclude people with disabilities. Individuals with disabilities are rarely the targets of HIV interventions designed specifically to address their particular prevention needs and are less likely to have access to condoms or other methods.

4. **Elevated risk for violence and rape, and lack of legal protection**: Abuse among women with disabilities ranges from double to quadruple the rate found among women in general. Approximately 80% to 90% of persons with disabilities are victims of some type of abuse at some point in their lives. Adult women with a disability are more likely than non-disabled females to be physically or sexually assaulted by their partners and women with disabilities are more likely to be subjected to serious violence. However, legal protection is still lacking.

5. **Substance abuse**: Drug abuse among select groups of people with disabilities is reported to be significantly higher than the general population. Substance use is associated with elevated sexual risk-taking and may also lead to sharing injecting equipment, resulting in increased vulnerability to HIV.

6. **Vulnerability of disabled orphans**: Children with disabilities who are orphaned have been found to be particularly vulnerable and are less likely to receive the same care and support as their non-disabled orphaned peers.

7. **Precarious access to affordable health care**: Health care providers have been reported to deny people with disabilities access to HIV testing and HIV and AIDS care. Lower priority is often placed on individuals with disabilities when scarce HIV medications and services are being rationed. Furthermore, people with disabilities face barriers to accessing any form of health care services (e.g., because clinics are often without ramps and Braille or sign interpreters), which can result in other sexually transmitted infections being undiagnosed, further increasing risk of HIV infection. In addition health care workers might lack knowledge and capacity to deal with disability issues.
8. Stigma: Stigma has been associated with HIV, as well as with disability. People with disabilities who become HIV positive and PLHIV who experience disability may experience double stigma. A further layer of discrimination may also be experienced by people who are not heterosexual.

The few prevalence studies that are available confirm this claim. For instance the national prevalence study from the Human Science and Research Council (HSRC) in South Africa, released in 2008, revealed that at 14.1% (see fig 3), HIV prevalence among the group of people with disabilities was higher than the national average of 10.6% [14]. In this study, the group of people with disabilities showed higher prevalence rates than other key populations such as men who have sex with men. Studies in other African countries on the deaf population similarly indicate that deaf people are as likely (Kenya), if not twice as likely (Cameroon) to be infected with HIV as the general population [15, 16]. The vulnerability of people with disabilities to HIV and AIDS is in keeping with the general recognition that marginalised, stigmatised communities with limited access to their basic human rights are frequently at higher risk of HIV infection and they feel the impact of HIV and AIDS more significantly. Research shows that people with disabilities have higher levels of illiteracy, unemployment and poverty, and are at risk for sexual abuse and assault, factors generally linked to vulnerability to HIV and to a greater impact of HIV infection.

Fig 3: People with Disabilities at increased risk of exposure to HIV [14]

![Graph showing prevalence rates](image)


Although advocacy efforts have raised the awareness of disability and HIV in the region, people with disabilities are still not fully included in HIV interventions providing prevention, treatment, care, support and impact mitigation. In addition to myths about their behaviour and life experiences, the failure to distinguish between the different needs of people with different impairments (such as the needs of the visually impaired compared with the needs of the physically disabled), the lack of accessibility to health information and services, insufficient training and negative attitudes of health professionals, as well as the social...
isolation of people with disabilities have all had a negative impact on their ability to access HIV-related health care. It is assumed that the lack of knowledge on how to address these issues as well as still unknown barriers to implementation are responsible for the difficulties in addressing the interrelationship between disability and HIV as the vulnerability of people with disabilities to HIV infection persists, increasing the impact of HIV and AIDS on their lives, once infected or affected by HIV and AIDS.

To sum up, although there is a body of research that argues well the point that people with disabilities are particularly vulnerable to HIV and AIDS, there is little knowledge on how to address this issue in the National Strategic Plans and HIV and disability legislation as well as on good practices that can be taken forward for implementation. This indicates that there is a need for evaluation and implementation research as well as a need for capacity building on disability issues in HIV programming and the dissemination and exchange of good practices.

**HIV-Related Disability**

It has been suggested that HIV, AIDS and its treatment may cause long term and episodic disabilities and services need to be prepared for this extra need for rehabilitation particularly in high prevalence areas such as Southern Africa. In their book “AIDS in the 21st century” Barnett and Whiteside [17] describe the different waves of the HIV epidemic (see fig 4) which follow logically in time. The first wave describes the increase in HIV prevalence which is followed by an increase in AIDS cases as the disease progresses within the infected population. Both waves are well described within the biomedical field. However the third wave which focuses on the social and economic impact only became visible at a later stage. This wave describes for instance the impact of AIDS death. It assumes that period of illness and the death of a person has social and economic implications for the family as well as for society as a whole. With the roll out of ART (Antiretroviral treatment) in Southern Africa the “face of AIDS” has changed from an acute into a chronic illness. However life on treatment does not only mean the prescription of a suitable treatment regime but also the risk of developing disabilities. The HIV epidemic second curve has changed. While countries that have had ART available since the 1990s (e.g. Canada) have already responded to this need, countries in Africa still have to establish the scope of the problem and suitable
responses. However given the number of people in need of ART we can predict that Southern Africa will have to address the issue of disability on a large scale within the next decade.

Data from several studies point to rising numbers of health conditions and impairments, which have the potential to develop into disabilities in PLHIV on the body function, activity and participation level. The literature provides evidence in regards to challenges of the respiratory, musculoskeletal, neurocognitive (dementia, neurophathy) and sensory (blindness and hearing impairments) systems, as well as in regards to mental functions, pain and energy levels mobility. On the activity level challenges in regards to self care, domestic activities and work have been described in the literature. Particular in resource poor settings and/or epidemic countries this provides an additional burden to the health care system. Analyzing literature from hyper epidemic countries in regards to secondary conditions and disabilities experienced by PLHIV in the era of ART a review revealed studies in regards to the following health challenges:

1. **Mental health disorders are increased in PLHIV:** Many studies have shown that mental health disorders are frequently experienced by PLHIV. Particularly symptoms of depressions & anxieties, post traumatic stress and alcohol disorder have been described in several studies. Women are more prone to show signs of depressions and anxieties. There is also an indication that mental health symptoms are linked to other challenges including other health conditions (e.g. stroke) or activity limitation (e.g. reduction in mobility, self care and work) [18-23].

2. **Mental functions in regards to memory, language and intelligence:** Studies indicate that people on treatment may develop HIV demencia [24-30]. This loss of intellectual function may affect other areas such as cognitive-motor ability, which included processing speed, verbal learning/memory, language, psychomotor speed, executive function, and fine motor speed (dominant and non-dominant hands).

3. **Sensory and perceptional functions are affected:** PLHIV may also experience symptoms such as “tingling” and/or “numbness” and studies indicate an increased prevalence of neurological disorders (e.g. stroke) or with peripheral neuropathy in PLHIV [31-34]. Other sensory impairments have also been reported in regards to vision, taste and hearing. On a broader level Myezwas and Van As studies indicate an overall high prevalence of sensory function problems on a very high level with 71-83% of their samples experiencing challenges in one of the sensory areas [23, 35]. This area is however much less researched.

4. **Challenges related to the cardiovascular & respiratory functions as well as digestive, metabolic and endocrine system:** PLHIV may report a number of issues which can be related to the function of several system. Studies provide data that indicates challenges in regards to the respiratory system (shortness of breath often related to post TB), hypertension & high blood pressure, digestive challenges, and even diabetes. This area has seen
very little researched in resource poor settings and the scare data is only an indication of issues experienced by PLHIV [36].

5. **Issues related to the genitourinary and reproductive system**: PLHIV have reported issues in regards to renal and sexual functions [37-39]. Again this is an under researched area. Only renal impairments have been explored more rigorously. Sexual and reproductive functions might be affected to a larger extend however research is lacking particularly in resource poor settings.

6. **Impairments of the neuromusculoskeletal movements**: PLHIV have found to experience neuromuscular problem particularly the loss of muscle power as well as fine and cross motor skills. Children living with HIV have also found to experience developmental challenges. For instance Jelsma and Forgesons work indicates that 66% of children living with HIV experience motor developmental delays – much more than children without the infection [40, 41].

7. **Skin problems**: Skin and hair problems have been reported by PLHIV. This seems to be the case for people on treatment as well (5-8%). Skin problems can cause irritation and have been linked to stigma and discrimination [35, 42, 43].

8. **Mobility problems caused by a number of impairments associated to HIV**: One of the main results of HIV-related impairments is related to the reduction of mobility levels. Studies have captured this with different tools but generally indicate that a large portion of PLHIV experience significant challenges with walking, lifting and moving objects. This effects the ability to perform tasks but also the ability to access health and other services and is therefore also relevant to adherence [23, 35, 44].

9. **Self care problems associated to HIV-related disability**: Studies also indicate challenges associated with self care. PLHIV may experience problems while using the toilet, dressing or washing themselves [23, 33, 35, 45].

10. **Domestic activity challenges associated to HIV-related disability**: Studies report on challenges related to domestic activity as well. PLHIV who experience disability might find it challenging to look after others, provide food, clean the house or mend the garden. Often other household members including children have to take over these tasks [23, 35].

11. **Work and related activity limitations**: Studies also indicate challenges related to work and related activities. Mobility changes, pain and fatigue may force people to retire from work. More severe disabilities (e.g. blindness, extreme fatigue) also forced people to lay down informal work or other income generating activities such as gardening or begging. In the absence of a social support system these people may enter a viscous circle of disability and poverty where the one elevates the other [23, 35].
12. **Stigma and Participation Restrictions are increased:** PLHIV experiences of stigma have been well described in the literature. However, very little data is available in regards to stigma of PLHIV who develop disabilities. The Sepo study in Zambia for instance revealed that disability stigma is much more elevated than HIV stigma and that the stigma associated with disability restricts peoples participation and activity in society much more than their HIV status [46]. PLHIV who experience disability might experience stigma when visiting health services, in community activities (e.g. church or community gatherings) and within family and friends. Women with disabilities may also experience rejections from their partners and might have to look after children by themselves [47-51].

**Episodic Disability**

Episodic Disability is a concept that was developed by Kelly O’Brien and colleagues in the context of PLHIV in the Canadian context. It refers to the episodic nature of disability as experienced by PLHIV (see graph underneath) [52, 53]. Research indicated that PLHIV experience disability related to HIV episodically and may feel its impact to different extend on different days and times. This gave thought to the development of the episodic disability framework. This framework accounts for the ups and downs while living with HIV as well as to challenges related to uncertainty particular in regards to the future.

*Figure 5: Episodic Disability Framework O’Brien et.al.[53]*
Guiding Principles for Disability Inclusion in NSPs

Beside countries legislations and obligations, three main documents are particularly relevant to address the interrelationship between disability and HIV:

2. Declaration of the UN High Level Meeting 2011
3. Country National Strategic Plans or Frameworks (NSP) on HIV and AIDS

Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD includes several articles which are relevant to the context of HIV and disability (figure 9).

**Figure 6: Key provisions in the CRPD relevant in the context of disability, HIV and AIDS [11]**

- Article 5 protects the rights of all persons to equality, prohibits discrimination on the basis of disability and guarantees to persons with disabilities equal and effective legal protection against discrimination on all grounds *e.g. include reference to protection of rights of PWDs in NSP*
- Article 8 provides for States to take measures to raise awareness and foster respect for the rights of disabled people, and to combat stereotypes, prejudices and harmful practices relating to persons with disabilities *e.g. include interventions for the rights protection of PWD in the NSP*
- Article 9 promotes accessibility for disabled people, and requires State Parties to take measures to ensure access to the physical environment, transportation, information and communications and to facilities and services *e.g. include provision for adaptations and disability specific services in NSP*
- Article 12 provides disabled people with equal rights to recognition as persons with legal capacity before the law *e.g. provide for the disability assistance in justice system*
- Article 13 requires State Parties to ensure effective access to justice for disabled people
- Article 16 requires State Parties to take measures to protect disabled people from exploitation, violence and abuse *e.g. address sexual abuse of PWD in the NSP*
- Article 22 protects disabled people from unlawful invasions of their right to privacy, including the privacy of personal, health and rehabilitation information *e.g. address confidentiality issues for PWDs*
- Article 24 requires State Parties to recognise the rights of disabled people to education *e.g. provide accessible HIV information and sexuality education*
- Article 25 provides persons with disabilities the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability
- Article 26 provides for State Parties to take appropriate measures to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life *e.g. address HIV related disability and access to rehabilitation for PLHIV*
- Article 27 recognises the rights of disabled people to work on an equal basis with others *e.g. include PWDs in the NAC structures*
- Article 30 requires State Parties to collect appropriate information, including statistical and research data to enable them to formulate and implement policies to give effect to the UN Convention. *e.g. use disability indicators in national surveys*
23. Welcome the adoption of the UN Convention on the Rights of Persons with Disabilities, and recognize the need to take into account the rights of persons with disabilities as set forth in that convention, in particular with regard to health, education, accessibility and information, in the formulation of our global response to HIV and AIDS;

31. Noting with concern that prevention, treatment, care and support programmes have been inadequately targeted or made accessible to persons with disabilities;

60. Commit to ensure that financial resources for prevention are targeted to evidence-based prevention measures that reflect the specific nature of each country’s epidemic by focusing on geographic locations, social networks and populations vulnerable to HIV infection, according to the extent to which they account for new infections in each setting, in order to ensure that resources for HIV prevention are spent as cost-effectively as possible; and ensuring particular attention is paid to women and girls, young people, orphans and vulnerable children, migrants and people affected by humanitarian emergencies, prisoners, indigenous people and people with disabilities, depending on local circumstances;

69. Commit to promote services that integrate prevention, treatment and care of co-occurring conditions, including tuberculosis and hepatitis, improve access to quality, affordable primary health care, comprehensive care and support services, including those which address physical, spiritual, psychosocial, socio-economic, and legal aspects of living with HIV, and palliative care services;

73. Commit by 2015 to address factors that limit treatment uptake and contribute to treatment stock-outs, drug production and delivery delays; inadequate storage of medicines, patient drop-out, including inadequate and inaccessible transportation to clinical sites; lack of accessibility of information, resources and sites, especially to persons with disabilities; sub-optimal management of treatment-related side effects; poor adherence to treatment; out-of-pocket expenses for non-drug components of treatment; loss of income associated with clinic attendance; and inadequate human resources for healthcare;

Other Examples of possible protection and inclusion of disability within legal frameworks

- Constitutions
- Disability Strategies, Plans, Policies and Acts
- Poverty Reduction Strategies
- Employment Equity Acts
- Sexual Abuse Acts
- Other Equity Acts
Key Elements of National Strategic Plans as Relevant to Disability

Another key document for the implementation of disability inclusive HIV services are the National HIV and AIDS Strategic Plans (NSPs). NSPs set out a country’s response to HIV and AIDS, providing programmatic orientation addressing the needs of those infected, affected and vulnerable to HIV and AIDS. As a result, NSPs are a critical determinant in the allocation of national resources towards HIV and AIDS. In many instances the funding, resources and human capacity that will be devoted to the national HIV and AIDS responses will be utilised within the context of the strategies described in the NSP. Where an NSP is silent on an issue, it is possible that the issue will not receive national attention. The general structure of an NSP might look as follows:

Situation Analysis
Structure and General Approach
Guiding Principals
Priority Areas (old) / Strategic Objectives (new)

4.1 Prevention
4.2 Treatment, Care and Support
4.3 Monitoring and Evaluation
4.4 Human Rights

New: Operational Plan

Some countries might also have additional disability sector plans complementing the general NSP. In order to guide HIV programme developers a disability and HIV task group of the Global Contact Group on HIV and Disability (GCGAD) designed a disability inclusive NSP framework. This can guide countries in regards to the inclusion of disability within their framework or plan (appendix 1). The framework provides information to

- Situation analysis and guiding principals
- National frameworks to the response to HIV and AIDS
- Different sections of an NSP (see above)
- step by step guide for the inclusion of disability in NSP and National AIDS Councils as well as
- advise for resource mobilization and funding
Including Disability in Prevention, Treatment Care and Support

Accessing HIV-Services for People with Disabilities
Ideally people with disabilities should be included in mainstream settings. Any intervention, structure or service should be guided by two key principals described in the UN Convention on the Rights of Persons with Disabilities “Universal Design” and “Reasonable Accommodation”.

Universal Design
Universal design is understood as designing “products, environments, programmes and services so that they are usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (CRPD). Building ramps within a school or providing mobile clinics in tents are examples of such universal design.

Reasonable Accommodation
Reasonable accommodation means “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others…” (CRPD). Providing a wheelchair, information in Braille, sign language or simplified HIV-information for people with mental or intellectual disabilities are such adaptations.

Adaptations that require no or little extra resources:
Practically, service providers can improve the accessibility of facilities through using the concept of “universal design” e.g. install crucial services on the ground floor of buildings, using different perception channels in the design of prevention interventions (visual, auditory and touch) and the effective usage of modern technology such as voice recognition, smart phones etc. Additionally training of health care professionals such as VCT counsellors, that already takes place, can include sensitisation around disability issues, address misconceptions about people with disabilities and raise awareness for additional needs.

Adaptations that require resources:
These refer to adaptations within already existing services. Adaptations focus on structural changes to facilities, such as building ramps or providing mobile VCT clinics in tents as opposed to caravans (concept of universal design). Similarly material is made accessible for people with sensory impairments through providing material in large Print, Braille or Braille accessible formats (e.g. word without formatting), broadcasting HIV messages with sign interpreters or subtitles and through including schools and institutions for people with disabilities in awareness campaigns (concept of reasonable accommodation).
Examples Adapting VCT

The HIV Test with People with Intellectual Disabilities

Sheila Hollins and Rebecca Johns booklet “The HIV Test” explains in pictures the HIV test and meaning of results to people with intellectual disabilities. This intervention includes informed consent.

Sign Language at the Clinic level

Zambias Sign Language Poster helps health care providers to remember basic signs around HIV.

Examples of Adapting Treatment and Care

Simplified explanations on HIV infection

GALA’s “Deaf Rights” comic illustrates the different stages of HIV in simple pictures.

Medicine Packaging for the Visually Impaired

Medical Packaging, tablets and tabled containers can include Braille to facilitate accessibility.
## Rehabilitation and Disability

Access to ART has changed the lives of many thousands of people by preventing AIDS defining illnesses and prolonging life expectancy. ARV treatment has led to a dramatic reduction in mortality and morbidity, less intense utilisation of healthcare resources, and an increase in quality of life for many. However, the impact of living with HIV infection over many years intertwined with side effects of ARV have led to an evolving and more complex pattern of health care needs. The Canadian Working Group on HIV and Rehabilitation (CWGAD) identified the following HIV-related health concerns (impairments and disabilities) and how they relate to different rehabilitation streams [54, 55].

<table>
<thead>
<tr>
<th>HIV related health condition</th>
<th>Type of rehabilitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diarrhoea, weight loss, “wasting”</td>
<td>graded rehabilitation</td>
</tr>
<tr>
<td>TB, respiratory secretions</td>
<td>respiratory rehabilitation</td>
</tr>
<tr>
<td>Pain, weakness, muscle imbalance, joint stiffness</td>
<td>musculoskeletal rehabilitation</td>
</tr>
<tr>
<td>Hemiparesis, Hypertonia</td>
<td>neurological rehabilitation</td>
</tr>
<tr>
<td>Visual Impairments</td>
<td>visual rehabilitation</td>
</tr>
<tr>
<td>HIV-dementia</td>
<td>cognitive rehabilitation</td>
</tr>
<tr>
<td>Weakness, tiredness</td>
<td>managing fatigue</td>
</tr>
<tr>
<td>Depressions, anxiety disorders</td>
<td>managing mental health, wellness approach, laugh therapy, lifestyle management</td>
</tr>
<tr>
<td>Loss of mobility and activity levels</td>
<td>vocational / workplace rehabilitation approaches</td>
</tr>
</tbody>
</table>

In resource poor settings providing therapy and rehabilitation for HIV related co-morbidities and disabilities might provide additional challenges for already fragile health care system. These settings will have to develop approaches to HIV-related disability care that take resource constrains and task shifting approaches into consideration. One of the two most important steps to interlink disability to HIV care is 1) Diagnostic of disability 2) Referral and rehabilitative approach.
Identifying Disability

Including HIV related disability in HIV care requires the cooperation of several disciplines such as nursing, physiotherapy, occupational therapy, speech therapy, community workers, home based care, mental health care, psycho social support. One of the first steps in addressing disability is related to identifying impairments and activity limitations through a screening and referral process. Health care professionals might have tools related to side effects of ART, Quality of life etc. but seldom they are provided with tools to identify disability (in the context of HIV). Similar on a national level disability data is often scarce and in the context of HIV not available. Here are a few indicators, screening and diagnostic tools listed that might be useful to different stakeholders for different purposes.

<table>
<thead>
<tr>
<th>Example of simple disability indicator (Washington Group)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Because of a health problem:</strong></td>
</tr>
<tr>
<td>1) Do you have difficulty seeing even if wearing glasses?</td>
</tr>
<tr>
<td>2) Do you have difficulty hearing even if using a hearing aid?</td>
</tr>
<tr>
<td>3) Do you have difficulty walking or climbing stairs?</td>
</tr>
<tr>
<td>4) Do you have difficulty remembering or concentrating?</td>
</tr>
<tr>
<td>5) Do you have difficulty with self-care such as washing all over or dressing?</td>
</tr>
<tr>
<td>6) Using your usual (customary) language, do you have difficulty communicating (for example understanding or being understood by others)?</td>
</tr>
<tr>
<td><strong>Response categories:</strong> No - no difficulty; Yes - some difficulty; Yes - a lot of difficulty; cannot do at all</td>
</tr>
</tbody>
</table>

Other possible tools for screening and diagnostic of disability (and mental health)

- Sheehan disability scale
- Simple disability scale
- ICF-Checklist
- Comprehensive Disability tool
- WHODAS 2.0
- Comprehensive Disability tool
- SRQ 20
- Mental health screening tool
- DSM 5
- Comprehensive mental health diagnostic tool
Addressing Disability through Different Structures

Once diagnosed, clients/patients need to be linked to rehabilitation, when necessary. In resource-poor settings, the structure of rehabilitative services might have to be thought through more innovatively. Here are some examples of three possible ways of structuring rehabilitation service delivery:

1. **Traditional clinical setting** (useful for resourced urban settings where professional therapists are available)

   - Hospital or clinic screening and referral
   - Rehabilitation unit in hospital (e.g., 10 appointments between individual patient and therapist)

2. **Community Based Rehabilitation (CBR)** (urban & rural areas with few specialists)

   - Clinic screening, identification, and referral
   - Local CBR unit with CBR workers from communities
   - Community service (e.g., NGOs) identification and referral

3. **Block therapy approach** (useful in semirural or rural areas, where professional therapists are more scattered and scarce)

   - Hospital or clinic A screening and referral
   - Hospital or clinic B screening and referral
   - 1 week block therapy at one central location with all patients and several therapists
Resources and Links
HEARD Resource Centre:  www.heard.org.za/african-leadership/disability
SOURCE Resources:  http://www.asksource.info
UN Enable:  http://www.un.org/disabilities/default.asp?id=1560

References
5. UNAIDS, Disability and HIV Policy Brief, UNAIDS, Editor. 2009.


Appendices

Appendix 1 Disability Inclusive NSP Framework
Appendix 2 UNAIDS Disability and HIV Policy Brief
Appendix 3 NSP Disability Inclusive Analysis Toolkit
Framework for the Inclusion of Disability in the National Strategic Plans on HIV and AIDS
Framework for the Inclusion of Disability in the National Strategic Plans on HIV and AIDS

Context and Approach

The World Health Organisation (WHO) estimates that 15% of the world’s population, [2, 3] have a disability, making People With Disabilities (PWD) the world’s largest minority [4]. It is estimated that the number of PWDs is increasing “due to population growth, ageing, emergence of chronic diseases and medical advances that preserve and prolong life”[4]. Eighty percent of PWDs live in resource poor settings, where they have difficulties in accessing the most basic services to accommodate their needs [2, 4]. With the signing of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) [1], many countries have now committed to providing services that are accessible to and inclusive of people with disabilities, including services for the prevention, treatment, care and support of HIV and AIDS.

The growing available evidence suggests a strong interrelationship between HIV, AIDS and disability. First, people with physical, intellectual, mental or sensory disabilities are as likely, if not more likely, to be at risk of HIV infection. They have 1) insufficient access to HIV prevention information, (2) are sexually active and therefore might engage in unprotected sex, (3) are at increased risk of sexual violence, in particular women and girls with disabilities and (4) have less access to treatment services [1, 5-7]. This increased risk is reflected in the few HIV-Prevalence Studies that include people with disabilities, which suggest that infection levels are equal to or higher than the national average [8-10], and that girls and women with disabilities are particularly at risk [7].

Second, it has been argued that people living with HIV (PLHIV) experience disability as a result of HIV-related stigma and discrimination that they experience[7].
Third, there is increasing evidence that PLHIV may experience HIV-related disability either as a result of HIV, AIDS or, as a side-effect of HIV-related treatment [11-14]. HIV-related disability can result from a diverse range of HIV-associated conditions affecting the body such as neurological conditions resulting in strokes, cardiovascular system changes that result in heart attacks, musculoskeletal problems related to osteoarthritis and accelerated osteoporosis, changes in sexual function, changes in the digestive system, HIV dementia, mental health problems, as well as problems with vision and hearing.

However, despite the growing evidence on the interrelationship between disability and HIV, PWD have largely been excluded from the national response to HIV and AIDS and existing related frameworks. National Strategic Plans (NSP) often fail to identify the vulnerability of people with disabilities to HIV as well as the reverse relationship of PLHIV to disability [15-17]. Inclusion in this framework allows a human rights-based approach, based on disability rights set out in the CRPD, and its principles of universal design and reasonable accommodation. Additionally, the UNAIDS International Guidelines on HIV/AIDS and Human Rights (UNAIDS, 2006) is a guiding tool for the rights of persons living with HIV/AIDS.

The UN Convention on the Rights of Persons with Disabilities (CRPD) states that State Parties need to “enable persons with disabilities to live independently and participate fully in all aspects of life”. Therefore, “State Parties shall take appropriate measures to ensure persons with disabilities on an equal basis with others, have access to the physical environment, to transportation, to information and communications, including information and communication technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas”. To achieve this goal the convention has two guiding principles: (1) universal design and (2) reasonable accommodation. The UNAIDS (2006) International Guidelines on HIV/AIDS and Human Rights recommend that states adopt a rights-based approach to HIV and AIDS. It provides concrete guidelines to
states on legislative and policy measures to reduce HIV-related stigma and discrimination and to create an enabling legal and regulatory framework that reduces vulnerability to HIV and mitigates the impact of HIV on those affected, in particular amongst vulnerable populations. The rights articulated in these two international documents form the basis for this framework.

1. **Purpose**

This framework is a tool to guide the development and review of NSPs across the globe in terms of their disability-inclusiveness, and to realize the commitments of the CRPD and the International Guidelines on HIV/AIDS and Human Rights in advancing important policy frameworks in the context of HIV and AIDS. The framework, its language and its content, has been developed in alignment with regional and international commitments relating to HIV and to disability. It reflects the structure and format of current NSPs and includes step by step guidelines on integrating disability into plans and programmes at different levels. As such, it may provide guidance, accountability or can be used as a template.

It may guide the development or review of NSPs by governmental entities such as the National AIDS Council (NAC), Ministries of Health, Welfare and Social Services, Justice, Constitutional Development and other related ministries, as well as disability advisors. It can be used in conjunction with the framework for women, girls and gender equality [18]. The framework can also support civil society participation in and mobilisation around NSP development and review by important organisations such as Disabled Peoples Organisations (DPOs). Furthermore, Civil Society Organisations (CSOs) can use the tools and links to hold governments accountable in relation to disability inclusiveness.

2. **Background and Guiding Principles of an NSP** (1/3 page)

An NSP’s background analysis needs to include HIV and disability issues such as:

- Information on incidence and prevalence of HIV amongst people with disabilities (PWD)
• PWD, in particular girls and women with disabilities, as a vulnerable population
• An accurate description of the impact of HIV and AIDS on PWD
• An understanding of the specific vulnerabilities of people with disabilities
• An understanding of the disabling impact of HIV upon those infected
• A quantitative analysis of HIV-related disability found in this particular context

The CRPD (2008) as well as the UNAIDS International Guidelines on HIV/AIDS and Human Rights (2006) emphasise a rights-based approach towards disability or HIV/AIDS. The following key principles should form part of a disability inclusive national framework to address HIV and AIDS:
• Inclusion of PWD in the national response to HIV and AIDS
• Protection of the rights of PWD and the prohibition of unfair discrimination based on HIV and disability
• Provision of accessible HIV-related prevention, treatment, care and support services accommodating the needs of PWD and using the principles of equality, non-discrimination, universal design and reasonable accommodation
• Provision of information and training on the rights of PLHIV and PWD as well as provision of accessible legal services
• Inclusion of disability in mainstream research, monitoring and surveillance of the epidemic

3. National Framework to respond to HIV and AIDS

Each NSP tends to include detailed provisions for the national institutional framework to govern the response to HIV and AIDS. These structures and processes need to involve people with disabilities (PWD). Representatives of people with disabilities should be:
• Included on national multi-sectoral structures set up to guide and oversee the national response to HIV and AIDS (e.g. as a key sector in the National AIDS Councils)
• Involved in the design, implementation, monitoring and evaluation of the national response through various mechanisms
Traditionally, people with disabilities are marginalised. A large number of these persons are among the world's poorest. The national framework needs to provide formal mechanisms to facilitate ongoing dialogue and input from the disability sector. Disabled Peoples Organisations (DPOs) may need capacity building to participate effectively. Support for the development of this infrastructure should be included in the national framework.

4. Priority Areas and Strategies of an NSP

4.1 Human Rights Approach – Equality and Non-Discrimination

NSPs often include protection of the rights of people living with HIV (PLHIV), those affected by HIV and AIDS and vulnerable populations at higher risk of HIV exposure. Rights-protection aims to reduce stigma and discrimination on the basis of HIV and AIDS, ensure that PLHIV have full access to their rights and also to reduce vulnerability to HIV infection amongst vulnerable populations. Rights-based protection in an NSP should include protection on the basis of HIV and disability. In addition, NSPs often mention the special protection of vulnerable populations, which should include people with disabilities (PWD). The NSP needs to provide for various measures to protect and promote equality and non-discrimination on the basis of disability and HIV. Measures may include, amongst others:

- Reviewing laws and policies to protect the rights of people on the basis of disability and HIV
- Developing education programmes that increase understanding and reduce stigma and discrimination against PLHIV, PWD and other vulnerable populations
- Strengthening appropriate and accessible access to justice for PLHIV and PWD (e.g. through the provision of legal support services)
- Strengthening mechanisms to monitor and enforce the rights of PLHIV and PWD, and
- Training health care and other service providers on the rights of PLHIV and PWD

4.2 Health Related Services

All NSPs identify specific priority areas in relation to prevention, treatment, care and support in order to reduce the spread of HIV as well as manage the impact of HIV and AIDS on those infected and affected
by the disease. All prevention and health services should recognise the barriers to access to services and reasonably accommodate the needs of people with disabilities. Prevention, treatment, care and support programmes therefore need to be provided in an accessible and appropriate format through:

- Developing universal designs of services such as the inclusion of ramps in buildings
- Developing specialised formats such as material and packaging in Braille, sign language interpretation and simplified information to compensate for intellectual challenges
- Including the provision of rehabilitative and mental health services for people living with HIV who experience HIV-related disability
- Including measures to address HIV and disability-related stigma and discrimination within health services
- Developing a disability sector plan that provides more detailed and practical guidance on how to implement disability inclusive services
- Providing budget allocation for disability services

4.3 Legal Support Services

NSPs need to include measures to create an enabling framework to protect and promote human rights of people infected and affected by HIV and AIDS and people with disabilities. For example, NSPs may:

- Provide for the inclusion of information and training in regards to the rights of person with disabilities as well as interventions to reduce stigma and discrimination
- Address the provision of access to justice for people with disabilities and those affected by HIV
- Include disability specific support to access justice in the context of HIV and AIDS

4.4 Research, Monitoring and Surveillance

Most NSPs identify research, monitoring and surveillance as a priority area. The participation of people with disabilities in the design, analysis and delivery of monitoring and research is critical. This section of the NSP needs to include disability and ensure the following are included:

- Disability indicators in national surveys, so it is easy to determine HIV-prevalence in people with disabilities as well as risk behaviour and gaps in service delivery
• Disability indicators in the treatment of people living with HIV (e.g. ICF)
• Indicators on the impact of programmes and policies on people with disabilities
• Participation of people with disabilities in the design, analysis and delivery of research
• Demonstration of the long term transformative processes in terms of disability and social norms
• Demonstration of the effectiveness of disability inclusive or specific programmes

5. Resource Mobilisation

Operationalizing the principles described above will only occur if resources are mobilised for a disability inclusive approach. Ideally, this requires budgetary allocations throughout the NSP or its operational plan. Examples of the types of programme activities that should be included in the budget are:

• Adapting prevention messages to meet the special needs of such impairments as blindness, deafness and intellectual disability
• Accommodating the special needs of PWD within National AIDS Council structures (e.g. sign interpreter); and
• Undertaking a baseline study to establish the number of PWD
• Capacity building of NGOs, DPOs and health care providers
• Providing accessible services e.g. sign interpreters
• Providing legal support to PWD
• Providing rehabilitation and mental health services for PLHIV
• Ensuring that language is not a barrier in our outreach to the varied populations served

The activities and related costs might be challenging for countries that have already adopted their new NSP or are in resource constrained settings. Nevertheless countries could work incrementally towards resource mobilisation for a disability inclusive approach through developing:

• An additional disability sector plan or approach that also identifies opportunities for resource mobilisation;
• Partnerships with the disability community through NGOs working with PWD and DPOs (Disabled Peoples
Organisations). This should focus on enabling organisations to submit successful proposals to agencies such as the Global Fund or other international donors. Many of these agencies have developed disability policies in the past years and are therefore obliged to include disability in their development work. Article 32 of the CRPD also requires state parties (also donor countries) to develop “inclusive and accessible” development programs and to provide “technical and economic assistance” as well as “capacity building” in regards to disability; and

- Links with existing state programmes on disability which may be able to reallocate resources to HIV issues.

Finally, countries could also in the interim undertake activities which have limited resource implications. For example, NGO partnerships could focus on the inclusion of these organisations in already existing structures and programmes as well as encourage capacity building for existing structures on the rights of PWD.

6. Step by Step guidelines (or a roadmap to inclusion)

This section provides a road map for the inclusion of disability and attempts to map out goals for countries on different levels of the pathway.

6.1 Initiating Inclusion of Disability (initiation step)

- Signing and ratifying the Convention on the Rights of Persons with Disabilities (CRPD)
- Including disability as a sector within the National AIDS Council structures (minimal costs for accommodating special needs)
- Commissioning baseline research to provide a situation analysis and ideas for feasible next steps (research one-time costs)
- Mobilising partnerships and resources to develop a disability sector plan/strategy
- Networking and sharing good practices across a region (minimal start up costs)

6.2. Domesticating CRPD into law and national frameworks (developing legal and other norms on disability step)

- Domesticating the CRPD into legal frameworks, laws and policies
• Capacity building around disability and HIV
• Developing a disability sector plan and submitting it to funders
• Developing integrated pilot projects on disability and HIV

6.3 Developing feasible approaches (towards integration step)
• Integrating disability into the National Strategic Plan (situation analysis and priority areas)
• Allocating resources to disability in key strategic areas (in budget and/or operational plan)
• Integrating disability indicators into national surveys and prevalence studies

6.4 Monitoring and Implementation of disability inclusive programmes (optimal inclusion step)
• Developing monitoring and evaluation tools
• Annual reporting on statistics in relation to disability and HIV
• Mainstreaming disability into all relevant programmes such as prevention, treatment, care, support and surveillance

7 Resource Websites

UN Enable  http://www.un.org/disabilities/default.asp?id=1560

HEARD Resource Centre http://www.heard.org.za/african-leadership/disability

Source resources http://www.asksource.info


8 Contributing organisations

This framework has been developed by the Global Contact Group on AIDS and Disability (GCGAD) NSP task group in cooperation with UNAIDS. It has been inspired by the Framework for Women, Girls, and Gender Equality [18] and the Health Economics and HIV/AIDS Research Division (HEARD) NSP review [16, 19, 20].
We would like to thank all who contributed to the development of the disability and HIV NSP framework in particular the core drafting team Catherine Grant (HEARD), Dr. Jill Hanass-Hancock (HEARD), Ann Strode (School of Law, The University of KwaZulu-Natal) as well as the NSP task group members Darryl Barret (Barrett Advocacy and Training), Steven B. Estey (AIDS-Free World), Prof. Nora Ellen Groce (University College London), Martine Mangion, Canadian Working Group on HIV and Rehabilitation (CWGHR), Muriel Mac-Seing (Handicap-International), Phillimon Simwaba, Disability, HIV and AIDS Trust (DHAT) and Dr. Emelia Timpo, Joint United Nations Programme on HIV/AIDS (UNAIDS).

9 Appendices


References


DISABILITY AND HIV POLICY BRIEF

Context

An estimated 650 million people, or 10% of the world’s population, have a disability.1 The relationship between HIV and disability has not received due attention, although persons with disabilities are found among all key populations at higher risk of exposure to HIV. People living with HIV may develop impairments as the disease progresses,2 and may be considered to have a disability when social, economic, political or other barriers hinder their full and effective participation in society on an equal basis with others.

This Policy Brief discusses the actions needed to increase the participation of persons with disabilities in the HIV response and ensure they have access to HIV services which are both tailored to their diverse needs and equal to the services available to others in the community. These actions, defined in consultation with a broad range of stakeholders including people living with HIV and persons with disabilities, are in line with the commitments made by States to universal access to HIV prevention, treatment, care and support by 2010,3 the Millennium Development Goal of halting and beginning to reverse the spread of HIV.

HIV and Definitions of Disability under International and National Laws

The Convention on the Rights of Persons with Disabilities states that:

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Article 1)

The Convention does not explicitly refer to HIV or AIDS in the definition of disability. However, States are required to recognize that where persons living with HIV (asymptomatic or symptomatic) have impairments which, in interaction with the environment, results in stigma, discrimination or other barriers to their participation, they can fall under the protection of the Convention.

States parties to the Convention are required to ensure that national legislation complies with this understanding of disability. Some countries have accorded protection to people living with HIV under national disability legislation. Other countries have adopted antidiscrimination laws that either explicitly include discrimination on the basis of HIV status or can be interpreted to do so. Such laws offer a means of redress against HIV-related discrimination in a number of areas, such as employment or education.

---

3 2006 Political Declaration on HIV/AIDS, UN General Assembly Resolution 60/262 Article 20.
by 2015⁴ and the principles and standards of international human rights law, in particular the Convention on the Rights of Persons with Disabilities.⁵

**Persons with Disabilities and Risk of Exposure to HIV**

There are few data on HIV prevalence among persons with disabilities. The few existing studies on the hearing-impaired, or deaf, populations, suggest infection levels equal to or higher than those of the rest of the community.⁶ Persons with disabilities may be at risk of HIV infection for the following reasons.

- **HIV risk behaviours**: due to a number of reasons, including insufficient access to appropriate HIV prevention and support services, many persons with disabilities engage in behaviours which place them at risk of HIV infection, such as unprotected heterosexual or male-to-male sex (including in the context of sex work) and injecting drug use.⁷ Additionally, persons with disabilities who also belong to groups that may be socially marginalized, such as men who have sex with men, people who inject drugs, or prisoners, may face compounded stigma and discrimination.

- **Sexual violence**: a large percentage of persons with disabilities will experience sexual assault or abuse during their lifetime,⁸ with women and girls, persons

---

⁴ Millennium Development Goal 6, UN General Assembly Resolution 55/2, Article 19.


with intellectual impairments and those in specialized institutions, schools or hospitals being at particularly high risk. There is also evidence that in some cultures, persons with disabilities are raped in the belief that this will “cure” an HIV-positive individual.

Access to HIV education, information and prevention services: persons with disabilities may also be turned away from HIV education forums or not be invited by outreach workers, because of assumptions that they are not sexually active, or do not engage in other risk behaviours such as injecting drugs. Even where knowledge of HIV is high among persons with disabilities, this does not always translate into use of HIV testing and counselling services.

In a specific instance, children with disabilities account for one third of the 72 million children out of school in the world, and are excluded from the vital sexual and reproductive health education which is often provided in school settings. Low literacy levels and a lack of HIV prevention information in accessible formats (e.g. Braille) make it all the more difficult for persons with disabilities to acquire the knowledge they need to protect themselves from HIV.

Access to Treatment, Care and Support

Persons with disabilities may not benefit fully from HIV and related sexual and reproductive health services for the following reasons.

- Service providers may lack knowledge about disability issues, or have misinformed or stigmatizing attitudes towards persons with disabilities.
- Services offered at clinics, hospitals and in other locations may be physically inaccessible, lack sign language facilities or fail to provide information in alternative formats such as Braille, audio or plain language.

---


11 Ibid.

12 For example a survey in Malawi found 94% of respondents knew about HIV but only 10% had been tested see Munthali A et al (2004) *Effective HIV/AIDS and Reproductive Health Information to People with Disabilities* University of Malawi Center for Social Research. Those who had never been for a test cited reasons such as thinking they would be okay, not knowing what voluntary counselling and testing was, and not being able to walk or find other transport to the testing site.


16 Action on Disability and Development (2005) *Challenges faced by People with Disabilities Uganda, ADD.*
Confidentiality for persons with disabilities in HIV testing and counselling may be compromised, for example, by the need for a personal assistant or a sign language interpreter to be present in order to access HIV-related services. The decision to use support services rests with the person with a disability and should be respected by the relevant health service provider.

In settings with limited access to antiretroviral therapy and post-exposure prophylaxis, persons with disabilities may be considered a low priority for treatment. Where persons with disabilities are receiving HIV treatment, health professionals may not pay enough attention to potentially negative drug interactions between HIV treatment and the medications that persons with disabilities are taking. Some medications may actually worsen the health status of persons with mental health conditions, including depression.

Parents with disabilities may experience multiple prejudices when they are also HIV-positive, because, for example, family members disapprove of their being sexually active. This means they may not have help planning their children’s future (e.g. by establishing custody or inheritance arrangements) and dealing with their own declining health status.

It has been estimated that 4–5% of children who have lost one or both parents to AIDS also have disabilities. They may require additional help with daily activities or have extra medical, educational or rehabilitation needs, but are often accorded lesser priority in an already overstretched household. Furthermore, children with disabilities who are also HIV-positive are also more likely to experience exclusion and discrimination in all areas, particularly in the field of education.

Rehabilitation for People Living with HIV

The increasing availability of antiretroviral therapy means many people living with HIV live longer. Some of these people experience activity limitations or participation restrictions as a result of progress of the disease or side effects of treatment. This may be on a temporary, episodic or permanent basis.

Health-related rehabilitation is increasingly important in the continuum of HIV care and can slow deterioration of the individual’s condition and enable the person to achieve and maintain independence. This involves assisting those living with HIV in self-care and other day-to-day activities that can minimize the impact of the virus on their health. Rehabilitation professionals play a key role in this process.

---

role in accurately assessing and addressing the complex impairments people living with HIV may experience.\textsuperscript{23}

Vocational rehabilitation, income support and other benefits also help a person with an HIV–related disability to maintain a healthy and productive lifestyle.\textsuperscript{24} Service models for people with disabilities such as community–based rehabilitation, personal assistance schemes and other independent living services are often appropriate or can be adapted for people living with HIV.\textsuperscript{23}

**Policy Position**

The 2006 *Convention on the Rights of Persons with Disabilities* commits State Parties to:

“provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other people, including in the area of sexual and reproductive health and population-based programmes” (Article 25)

and to

“take appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life” (Article 26).

Persons with disabilities have the right to participate in decisions which affect their lives, and should be fully involved in the design, implementation and evaluation of HIV policies and programmes.\textsuperscript{26} This is the best way of ensuring these policies and programmes are responsive to the needs of persons with disabilities.

HIV services themselves must be inclusive of persons with disabilities. Eliminating physical, information and communication, economic and attitudinal barriers not only increases access to HIV programmes, but may assist people in accessing broader health and social services. These services are essential to fulfilling the right of persons with disabilities to the highest attainable standard of physical and mental health.\textsuperscript{27}

**Recommendations**

**Actions for Governments**

- Ratify and incorporate into national law instruments that protect and promote the human rights of persons with disabilities, including the *Convention on the Rights of Persons with Disabilities*.\textsuperscript{28}
- Incorporate the human rights and needs of persons with disabilities into national HIV strategic plans and policies.

---


\textsuperscript{24}Ogden, R., *Policy Issues on Rehabilitation in the Context of HIV Disease: a Background and Position Paper* (the Canadian Working Group on HIV and Rehabilitation, CWGHR), (2000) Toronto, Canada, Cross, S. et al. (2000) Strategies to address the barriers to and gaps in the implementation of HIV/AIDS content in the curricula of under-graduate physical therapy programmes in Canada, University of Toronto, Department of Physical Therapy, Course Requirement Module.


\textsuperscript{26}2006 Convention on the Rights of Persons with Disabilities Article 4(3).


Include HIV as prohibited grounds for discrimination in national legislation.

Prohibit all forms of discrimination against persons with disabilities which may hinder access to:

- social security, health and life insurance, where such benefits are mandated by national law; and
- health services such as sexual or reproductive health education and services, measures for the prevention of mother-to-child transmission, and post-exposure prophylaxis for victims of sexual assault.

Establish age-, gender-, culture- and language-appropriate HIV prevention programmes and provide HIV information in tailored formats for people from different disability groups.

Develop appropriate programmes and mechanisms to prevent sexual assault or abuse of persons with disabilities focusing on those settings which place persons with disabilities at greatest risk e.g. specialized institutions, schools or hospitals.

Provide comprehensive HIV testing, treatment, care and support services which:

- adhere fully to ethical principles such as confidentiality and the need for free and informed consent; and
- include early intervention and referral to rehabilitation and support services for people experiencing activity limitations or participation restrictions as a result of their HIV infection.

Provide persons with disabilities with the same range and quality of affordable HIV, sexual and reproductive health services as the rest of the population by:

- adapting mainstream services for persons with disabilities or if appropriate implementing disability-specific services;
- providing support and reasonable accommodation; 29
- accounting for all persons with disabilities, irrespective of the related impairment, and eliminating all barriers in accessing services; and
- supporting empowerment and capacity-building of people with disabilities to take part in all relevant processes, including decision-making processes.

Ensure the national AIDS monitoring and evaluation system has the necessary resources to evaluate the response to the HIV epidemic within the context of disability, and the HIV needs and rights of persons with disabilities.

Involve persons with disabilities in the planning, implementation and evaluation of HIV programmes.

Include training on the rights of persons with disabilities for professionals working in the area of HIV, by persons with disabilities, including those that are HIV-positive.

Integrate HIV education into training for rehabilitation professionals.

Ensure that persons with disabilities are appropriately supported to train and engage in HIV counselling and care provision.

Provide adequate training and support for personal assistants or people who support persons with disabilities in households affected by HIV.

---

29“Reasonable accommodation” is defined by the Convention on the Rights of Persons with Disabilities as “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”.

---
Actions for Civil Society

- Increase networking and information exchange between HIV and disability service, disability advocacy and human rights organizations.
- Ensure disability services, such as support for independent living, are available to people living with HIV.
- Advocate for persons with disabilities to have full sexual and reproductive rights, and freedom from physical and sexual abuse.
- Advocate for persons with disabilities to be included in the planning, implementation and evaluation of HIV programmes.
- Ensure campaigns to combat stigma and discrimination of persons who are HIV-positive are accessible to persons with disabilities.

Actions for International Agencies in Partnership with Governments and Civil Society

- Ensure HIV policies, guidelines and programmes are designed and implemented to be accessible to all persons with disabilities, and make it mandatory that all HIV programmes incorporate access to information, support and services for persons with disabilities.
- Develop, validate and support the use of impairment-specific and disaggregated indicators in the national AIDS monitoring and evaluation system.
- Promote and fund research on HIV and disability, ensuring that persons with disabilities are included on the research team designing, implementing and analysing the research.

Policy and Practice - an example from South Africa


South Africa first included disabled people in the National AIDS Strategic Plan (NSP) in 2007–2011. The 2000–2005 Plan acknowledged disabled people but was not explicit or clear. What promoted the recognition was a combination of leadership from champions within Government, the strong organization of the disability sector and self-representation in the South African National AIDS Council.

Today, while South Africa’s policy legislation and AIDS programming is highly inclusive of disabled people, the challenge is implementation although real efforts in terms of access and participation are under way. For example, disability issues are included in the South Africa HIV Treatment Guidelines in light of the increasing number of disabled people in need of HIV medical care. The Government has also undergone the process of accreditation of disability organizations to increase access to treatment. Today counsellors with disabilities are placed in voluntary testing centres to counsel both disabled and non-disabled clients and free HIV testing is encouraged at disability meetings. In order to improve access to information and services for deaf people, sign language interpreters are being trained in matters related to HIV in recognition of the real limitations of sign language to communicate key messages effectively. These trained sign interpreters are being assigned to HIV clinics in many urban areas.
In terms of **advocacy and communication**, disabilities and vulnerability to the impact of HIV are part of the broader media campaign in South Africa. The South African National AIDS Council also makes available to disability groups resources for ongoing HIV awareness through seminars, training, dialogue and “Indabas”.

**Monitoring and evaluation** is still a major challenge. The Government of South Africa has set disability-specific targets within the broader AIDS monitoring and evaluation framework for the country. Data collected will be measured against pre-defined targets so that Government will not be in a position to ignore the evidence.

While this all seems like a lot, much still needs to be done.

People living with HIV are not classified as “disabled” people in South Africa. This is in part due to the refusal of disabled people to be seen as “sick”, which is implied by HIV infection. There is common ground when it comes to the stigma and discrimination faced by both groups, and in South Africa both disabled people and people living with HIV can benefit from the Disability Grant, a social security cash transfer. Unfortunately, the high numbers of people claiming the Disability Grant pushed the budgetary envelope to unaffordable heights. Disabled people have since lobbied for a “chronic illness grant” as this grant will distinguish between people with pre-existing disabilities and people who also need chronic medical care. Finally, we all know that HIV infection can cause temporary or permanent loss of function. This implies that the rehabilitation sector must be equipped to address not only pre-existing disabilities but also impairment related to HIV.

I believe firmly that disabled people are part of society. What happens in their communities affects them as well. Weak recognition of disability rights by Government becomes a danger when lack of information contributes to continued HIV risk behaviour among disabled people. A lot has been learned in South Africa over the past 25 years about the impact of the AIDS epidemic on the lives of disabled people. We have learned that we cannot meet the objectives of our National AIDS Strategic Plan without addressing the needs of disabled people. We have learned that there are unintended consequences of disability and/or AIDS policy due to HIV being a changing and evolving virus. We have also learned that it is only through involving disabled people themselves in their diversity that we will be successful in addressing HIV and AIDS in our country.
Inclusion of Disability in NSPs

Analysis Tool

Name of country:

Name of plan:

Year of plan:

Plan Sections:
- Background/ situational analysis
- Guiding principles of plan
- National framework to respond to HIV and AIDS
- Equality and non-discrimination
- HIV-related services (prevention, treatment, care and support)
- Legal support system
- Research, monitoring and surveillance

1.1 Background / Situational Analysis of Plan

<table>
<thead>
<tr>
<th>DOES THE NSP/NPP PROVIDE FOR</th>
<th>YES / NO</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>A situational analysis of HIV and AIDS in the country?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The identification of people with disabilities as a vulnerable population?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prioritisation of the needs of vulnerable populations including people with disabilities?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data on incidence and prevalence of HIV and AIDS amongst people with disabilities?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data on impact of HIV and AIDS on PLHIV, in terms of episodic / permanent disability?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 1.2 Guiding Principles of Plan

<table>
<thead>
<tr>
<th>DOES THE NSP / NPP PROVIDE FOR</th>
<th>YES / NO</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>A human rights based response to HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protection of the rights of PLHIV, vulnerable populations, including people with disabilities?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prohibition against discrimination against vulnerable populations, including PWD?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commitment to inclusivity, consultation and engagement with all stakeholder groups?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Promotion of reasonable accommodation of vulnerable groups, including people with disabilities.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 1.3 National Framework to respond to HIV and AIDS

<table>
<thead>
<tr>
<th>DOES THE NSP / NPP PROVIDE FOR</th>
<th>YES/NO</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>A co-ordinated and participatory national framework for responding to HIV and AIDS?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inclusion of various sectors, including people with disabilities, in the national framework (e.g. NAC)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support for community involvement in the response to HIV and AIDS?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 1.4 Equality and Non-Discrimination

<table>
<thead>
<tr>
<th>DOES THE NSP / NPP PROVIDE FOR</th>
<th>YES/NO</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protection of equality rights of PLHIV?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protection of equality rights of vulnerable populations, including PWD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Promotion of equality of PLHIV?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Promotion of equality of vulnerable</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
1.5 **HIV-Related Services**

<table>
<thead>
<tr>
<th>DOES THE NSP / NPP PROVIDE FOR</th>
<th>YES / NO</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV-related prevention services for PWD? (universal approach and specialized for different groups)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accessible and appropriate services designed to meet the special needs of people with disabilities?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV-related treatment, care and support services for people with disabilities with HIV and AIDS? (Universal)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accessible and appropriate treatment, care and support for PWD with HIV or AIDS? (Accommodation)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special protection of the rights of PWD (e.g. to counseling, voluntary and informed consent, to confidentiality, to equal access) in accessing HIV-related health care services?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening and referral system for HIV related disability and mental health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rehabilitation programs for PLHIV who experience disablement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental health services and wellbeing for PLHIV</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

1. Prevention, care, support and treatment using CRPD guiding concepts of “Universal Design” and “Reasonable Accommodation”

2. E.g. Health care services should recognise and address the vulnerability of people with disabilities, rather than stereotyping disabled people in the response (e.g. promotion of abstinence only in the case of prevention programmes for people with disabilities).

3. This should include services for disabled people who become infected with HIV / develop AIDS, as well as PLHIV who develop an episodic or permanent disability as a result of their illness.

4. With particular reference to the need for special provisions for VCT in the case of people with disabilities.
## 1.6 Legal Support Services

<table>
<thead>
<tr>
<th>DOES THE NSP / NPP PROVIDE FOR</th>
<th>YES / NO</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness, education and training on the rights of people in the context of HIV and AIDS?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inclusion of rights of PLHIV with disabilities, and the rights of vulnerable populations including PWD in awareness, education and training?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Targeting of people with disabilities for such awareness, education and training?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accessible and appropriate awareness, education and training in the case of people with disabilities?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information dissemination, materials and media development on the rights of people in the context of HIV and AIDS?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inclusion of rights of PLHIV with disabilities, and rights of vulnerable populations, including PWD, in information dissemination, materials and media?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Targeting of people with disabilities in information dissemination, materials and media development?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accessible and appropriate information dissemination, materials and media development for the special needs of PWD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Redress in the event of discrimination on the basis of HIV and AIDS?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal services to increase access to justice in the context of HIV and AIDS?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accessible and appropriate legal support services for people with disabilities</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## 1.7 Research, monitoring and surveillance

<table>
<thead>
<tr>
<th>DOES THE NSP / NPP PROVIDE FOR</th>
<th>YES/NO</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research, monitoring and surveillance for all aspects of plan?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inclusion of data collection on people with disabilities as a vulnerable population, and PLHIV with disabilities?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data collection on stigma and discrimination and stereotyping, including against PWD as a group vulnerable to HIV and PLHIV who become disabled as a result of HIV?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inclusion of indicators relevant to PWD or PLHIV who may become disabled?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Establishment of HIV and AIDS focal point persons for monitoring in govt depts., including those dealing with PWD?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support to NGOs and CBOs to conduct research, monitoring and surveillance, including NGOs and CBOs for PWD?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
1. Introduction

National HIV and AIDS Strategic Plans (NSPs) and National HIV and AIDS Prevention Plans (NPPs) set out a country’s response to HIV and AIDS, providing for the needs of those vulnerable to HIV and AIDS as well as those infected and affected by HIV and AIDS. So, in order for HIV and AIDS plans to integrate HIV and disability issues, NSPs and NPPs need to integrate and to address the special needs of people with disabilities as a population vulnerable to HIV and AIDS, as well as the needs of PHLIV who may become disabled (either permanently or on an episodic basis) as a result of HIV and AIDS.

2. Key Human Rights Principle

The UN (2008) Convention on the Rights of Persons with Disabilities sets out the rights of people with disabilities and state responsibilities to ensure that these rights are respected, protected, promoted and fulfilled. The UNAIDS (2006) International Guidelines on HIV/AIDS and Human Rights provide guidance to states in developing a rights-based response to HIV and AIDS. In applying the rights of people with disabilities to the context of a rights-based response to HIV and AIDS, the following key principles should form an integral part of an ideal national response to HIV and AIDS:

- Recognition of people with disabilities as a vulnerable population in need of special protection in the context of HIV and AIDS
- Inclusion of people with disabilities within the national response to HIV and AIDS
- Protection of the rights of people with disabilities to equality and prohibition of unfair discrimination and inequality, in order to reduce their vulnerability to HIV and AIDS and to reduce the impact of HIV and AIDS on their lives, once infected and affected
- Provision of HIV-related prevention, treatment, care and support services accessible and appropriate for people with disabilities, including PLHIV who become disabled due to HIV and AIDS
- Inclusion of people with disabilities in research, monitoring and surveillance relating to HIV and AIDS
- Provision of awareness, information, education and training on the rights of people with disabilities in the context of HIV and AIDS in order to increase awareness of rights, improve access to justice and enforcement, and to change attitudes of discrimination and stigmatisation associated with disability and HIV
- Support for appropriate and accessible support services to increase access to justice for people with disabilities in the context of HIV and AIDS

- Guideline 1 recommends that States establish a co-ordinated, participatory, transparent and accountable national framework for their response to HIV which integrates HIV policy and programme responsibilities across all branches of government.
- Guideline 2 recommends that States support community organisations to become involved in all phases of HIV and AIDS policy design, program implementation and evaluation.
- Guideline 3 recommends that States review and reform public health law and policy to ensure that it addresses HIV, and protects rights in the context of HIV and AIDS.
- Guideline 4 says that states should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV and people with disabilities from discrimination.
- Guideline 5 says that states should take measures to ensure the availability and accessibility of quality goods, services and information for HIV prevention, treatment, care and support.
- Guideline 6 recommends that states implement and fund legal support services that will educate people about their rights, provide free legal services to enforce these rights, develop expertise on HIV-related issues and utilise the courts and other means to protect the rights of individuals.
- Guideline 7 recommends that states should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities.
- Guideline 8 says that States should promote creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatisation associated with HIV and AIDS to understanding and acceptance.
- Guideline 9 recommends that the State encourage the development of private sector codes of conduct translating human rights standards into professional responsibilities and practice.
- Guideline 10 recommends that States ensure monitoring and enforcement mechanisms to guarantee HIV-related human rights, including those of PLHIV, their families and communities.
UN (2008) *Convention on the Rights of Persons with Disabilities*

- Article 5 protects the rights of all persons to equality, prohibits discrimination on the basis of disability and guarantees to persons with disabilities equal and effective legal protection against discrimination on all grounds.
- Article 8 provides for States to take measures to raise awareness regarding and foster respect for the rights of disabled people, and to combat stereotypes, prejudices and harmful practices relating to persons with disabilities.
- Article 9 promotes accessibility for disabled people, and requires States Parties to take measures to ensure access to the physical environment, transportation, information and communications and to facilities and services.
- Article 12 provides disabled people with equal rights to recognition as persons with legal capacity before the law.
- Article 13 requires States Parties to ensure effective access to justice for disabled people.
- Article 15 protects disabled people from cruel, inhuman or degrading treatment or punishment, including being subjected without his or her free consent to medical or scientific experimentation.
- Article 16 requires States Parties to take measures to protect disabled people from exploitation, violence and abuse.
- Article 17 protects the rights of disabled people to physical and mental integrity.
- Article 22 protects disabled people from unlawful invasions of their right to privacy, including the privacy of personal, health and rehabilitation information.
- Article 24 requires States Parties to recognise the rights of disabled people to education.
- Article 25 provides persons with disabilities with the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.
- Article 26 provides for State Parties to take appropriate measures to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life.
- Article 27 recognises the rights of disabled people to work on an equal basis with others.
- Article 28 requires States Parties to recognise the rights of disabled people to an adequate standard of living for themselves and their families.
- Article 29 provides that States Parties guarantee to disabled people political rights to ensure that disabled people can participate in political and public life.
- Article 30 requires States Parties to collect appropriate information, including statistical and research data to enable them to formulate and implement policies to give effect to the UN Convention.
3. Application to NSP / NPP analysis

This Tool aims to establish from a review of NSPs and NPPs within SADC and Eastern Africa whether they:

- Identify disability as a key issue which ought to be responded to within the Plan
- Are based on principles of non-discrimination and reasonable accommodation towards people with disabilities
- Create a national framework for responding to HIV/AIDS which is inclusive, multi-disciplinary and includes representatives from people with disabilities
- Include protection for the rights of people with disabilities in the protection of the rights of PLHIV and vulnerable groups
- Provide for prevention, treatment, care and support services which aim at meeting the needs of people with disabilities, as well as being accessible and appropriate for people with disabilities
- Provide for awareness, education, training and information on rights that includes rights of people with disabilities and is appropriate and accessible to people with disabilities
- Provide for legal support services and enforcement mechanisms that are accessible and appropriate for people with disabilities
- Undertake research, monitoring and surveillance to ensure the effectiveness of interventions targeted at persons with disabilities

3.1 Background / Situational Analysis of Plan

Ideally, where an NSP / NPP includes a background discussion or situational analysis, this should include reference to any statistics regarding the vulnerability of people to HIV and AIDS, as well as any statistics regarding incidence and prevalence of HIV and AIDS amongst people with disabilities as well as the impact of HIV on PLHIV, in terms of disability. The analysis should reflect an accurate understanding of the vulnerability of people with disabilities, rather than being based on stereotyped assumptions regarding the sexuality of people with disabilities.

Key Questions for Analysis:

- Does the NSP / NPP include a situational analysis of HIV and AIDS in the country?
- Does the NSP/NPP identify PWD as a vulnerable group?
- Does the NSP / NPP accurately reflect, rather than stereotype, the vulnerability of people with disabilities to HIV?
- Does the NSP / NPP prioritise the needs of vulnerable groups, including people with disabilities?
- Does this analysis include data relating to the incidence and prevalence of HIV and AIDS amongst people with disabilities?
- Does this analysis include data relating to the impact of HIV and AIDS on PLHIV, in terms of episodic / permanent disability?
3.2 Guiding Principles of Plan

Guiding principles in an NSP or NPP should include principles relevant to vulnerable groups, including disabled people, as well as principles relevant to PLHIV with disabilities.

Key Questions for Analysis:

- Does the NSP / NPP protect the rights of people and prohibit discrimination in the context of HIV and AIDS?
- Does the NSP/NPP protect the rights of vulnerable groups, including people with disabilities?
- Does the NSP/NPP promote the principles of inclusivity, consultation and engagement with all stakeholder groups?
- Does the NSP/NPP promote the concept of reasonable accommodation for persons with disabilities?

3.3 A National Framework to respond to HIV and AIDS

Disabled people should be fully involved in the design, implementation, monitoring and evaluation of the national response to HIV and AIDS through various mechanisms.

Key Questions for Analysis

- Does the NSP / NPP provide for a co-ordinated and participatory national framework for responding to HIV and AIDS?
- Does the NSP list the sectors that ought to be included within the national framework (e.g. NAC or similar forums?)
- Does the NSP list PWD as a sector that ought to be represented within the national framework (e.g. NAC)?
- Does the NSP / NPP support community involvement in the response to HIV and AIDS?
  - E.g. are there formal mechanisms to facilitate ongoing dialogue and input from community organisations, including PWD, for all phases of response (design, implementation, monitoring)?
  - Is there support for community organisations, including those with PWD, to integrate HIV and AIDS into their core activities?
3.4 Equality and Non-Discrimination

NSPs and NPPs often include protection for the rights of PLHIV and those affected by HIV and AIDS, in order to reduce stigma and discrimination on the basis of HIV and AIDS and to ensure PLHIV have full access to their rights. Additionally, NSPs and NPPs also promote equality and non-discrimination for all vulnerable groups, since they recognise that inequality and limited access to rights make people vulnerable to HIV and AIDS. Equality protection in NSPs and NPPs should include protection for people with disabilities as a vulnerable group, as well as protection for the rights of PLHIV with disabilities.

Key Questions for Analysis

- Does the NSP / NPP protect equality rights of PLHIV?
- Does the NSP / NPP protect equality rights of vulnerable groups, including PWD?
- Does the NSP / NPP include measures to promote equality for PLHIV?
- Does the NSP / NPP include measures to promote equality for vulnerable populations including PWD (e.g. reduce poverty, increase access to socio-economic rights)?
- Does the NSP/NPP protect PLHIV from discrimination?
- Does it protect PLHIV on the basis of HIV status or AIDS?
- Does it protect PLHIV on the basis of disability?
- Does it protect vulnerable groups from discrimination?
- Are disabled people included in the list of vulnerable groups?
- Does the NSP/NPP stereotype people with disabilities?
- Does the NSP / NPP provide for redress in the event of discrimination on the basis of HIV and AIDS?
- Are procedures for seeking redress accessible and appropriate for people with disabilities?

3.5 HIV-Related Health Services (Prevention and Care)

NSPs and NPPs should provide for HIV-related prevention, treatment, care and support services in order to reduce the spread of HIV and AIDS, as well as to manage the impact of HIV and AIDS on those infected and affected by the epidemic. All health services should integrate the needs of disabled people in order to ensure that disabled people are able to access health services to prevent HIV infection, and PLHIV with disabilities are able to access health services to assist them to manage the impact of HIV and AIDS on their health and well-being.

Key Questions for Analysis:

- Does the NSP / NPP recognise the needs of disabled people for HIV-related prevention, treatment, care and support?
- Does the NSP / NPP include HIV-related prevention services for people with disabilities?
- Are these prevention services designed to meet the special needs of persons with disabilities?
  - E.g. Is there accessible and appropriate HIV and AIDS information and education for people with disabilities?
- Does the NSP / NPP include HIV-related health care services for people with disabilities?
- Is there accessible and appropriate treatment and care for PWD or PLHIV with disabilities?
- Does the NSP provide any special provisions to protect the rights (e.g. the right to voluntary and informed consent, the right to confidentiality, the right of equal access to services) of people with disabilities in respect of health care services?
- Does the NSP provide for the rehabilitation of HIV-related disability and mental health disorders?
3.6 Legal Support Services

NSPs and NPPs often include measures to create an enabling framework that protect and promote human rights in the context of HIV and AIDS. Provisions in national plans may include information and training to increase awareness of the rights of PLHIV and to reduce stigma and discrimination, support for access to justice for PLHIV and those affected by HIV and AIDS.

- Does the NSP / NPP provide for awareness, education and training on the rights of people in the context of HIV and AIDS, and respect for the rights and dignity of PLHIV and vulnerable populations?
- Does this awareness and education include the rights of vulnerable populations, including PWD, and PLHIV with disabilities?
  - Is the awareness and education accessible and appropriate for people with disabilities?
  - Is the awareness and education targeted at organisations and individuals relevant to people with disabilities?
- Does the NSP / NPP provide for information, materials and media on the rights of people in the context of HIV and AIDS?
- Do the materials include information on the rights of people with disabilities as a group vulnerable to HIV and AIDS, as well as on PLHIV who become disabled by HIV and AIDS?
  - Is the material accessible and appropriate for people with disabilities?
- Does the NSP / NPP provide support for legal services to increase access to justice in the context of HIV and AIDS?
  - Are these support services accessible and appropriate for people with disabilities?

3.5 Research, monitoring and surveillance

NSPs and NPPs generally include provision for research, monitoring and surveillance in order to collect data on HIV and AIDS and to monitor and evaluate national responses to HIV and AIDS for their effectiveness. All aspects of research, monitoring and surveillance within national plans needs to include data collection relevant to people with disabilities.

Key Questions for Analysis

- Does the NSP / NPP conduct research, monitoring and surveillance with regard to all aspects of the plan, including prevention, treatment, care, support, and protection of human rights?
- Does this include data collection on people with disabilities as a vulnerable populations, as well as PLHIV with disabilities?
- Does this include data collection on stigma and discrimination?
- Do performance indicators and benchmarks include indicators relevant to people with disabilities or PLHIV who may become disabled?
- Does the NSP / NPP establish HIV and AIDS focal point persons in relevant government departments, including departments / offices dealing with PWD?
- Does the NSP / NPP provide support to NGOs and CBOs to conduct research, monitoring and surveillance? Does this include NGOs and CBOs for people with disabilities?