

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.

Disability is more than a medical phenomenon, it is also socially constructed. The CRPD (2008) defines disability as a "result from the intersection between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis"[1].

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.

Within the convention *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” [1]. Building ramps within a school or hospital is such a universal design as it means that people with physical disabilities should have access to such buildings without assistance.

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...” [1]. This means for instance providing a wheelchair or a sign interpreter for people with disabilities would be a form of reasonable accommodation.

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>

UNAIDS: http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf

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

- HEARD NSP analysis tool to download at <http://www.heard.org.za/downloads/inclusion-of-disability-in-nsp-in-southern-and-eastern-africa-analysis-tool.pdf>
- HEARD NSP analysis guide to download at <http://www.heard.org.za/downloads/inclusion-of-disability-in-nsp-in-southern-and-eastern-africa-analysis-guide.pdf>

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