DISCUSSION PAPER OF

UNAIDS STRATEGY BRIEF FOR INTEGRATING DISABILITY INTO AIDS PROGRAMMING

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LIST OF ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Treatment
CBO	Community Based Organisation
CBR	Community Based Rehabilitation
CPR	Comprehensive Psychiatric Rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Peoples Organisation
FBO	Faith Based Organisations
HEARD	Health Economics and AIDS Research Division
HIV	Human Immunodeficiency Virus
HLM	High Level Meeting
ICD	International Classification of Diseases
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
IDDC	International Disability and Development Consortium
LGBT	Lesbian, Gay, Bisexual and Transgender People
MMC	Medical Male Circumcision
MSM	Men who have sex with Men
NAC	National AIDS Council
NGO	Non-Governmental Organisation
NSP	National Strategic Plan
OHCHR	Office of the High Commissioner of Human Rights
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-To-Child Transmission
QALYs	Quality Adjusted Live Years
SLI	Specific Language Impairment
SRH	Sexual and Reproductive Health
TB	Tuberculosis
WHO	World Health Organisation

EXECUTIVE SUMMARY

The task team and reviewers of the UNAIDS strategy brief welcome efforts from UNAIDS to develop a disability strategy in order to address the intersection of disability and HIV. This is of upmost importance as historically, people with disabilities as well as the disabling effects of HIV have been excluded from the response to HIV and AIDS. In the light of this fact, the review team would like to see a future disability strategy that addresses this gap comprehensively. However, the strategy also needs to set specific aims and goals that are monitored and evaluated over time. The reviewers' comments were summarised in ten strategic recommendations as follows:

1. *Strategy Background:* A UNAIDS disability strategy needs to provide a comprehensive background on the intersection of disability and HIV. Current research findings, including HIV and disability prevalence data, provide evidence on the vulnerability and capacity of people with disabilities as well as evidence in regard to HIV related disability. All need to be included in the background section.

2. *Goals and Objectives:* Such a strategy needs to formulate concrete objectives and goals. These need to include SMART (specific, measurable, attainable, relevant and time-bound) aims and objectives aiming at programme level National Strategic Plans, donors and governments as well as knowledge sharing. National or regional task groups focusing on disability may be a useful mechanism in order to identify and achieve these aims and objectives in cooperation with UNAIDS. Such a task group needs to include people with disabilities and their organisations in meaningful leadership positions.

3. *Benefits:* In developing a disability strategy, UNAIDS will contribute to the achievement of its global objectives such as stopping new infections and keeping people alive. Through including one of the world's biggest minorities in its strategy meaningfully and effectively, it will work towards this goal. A disability strategy should clearly articulate that without including disability, UNAIDS will not be able to achieve its goals in relation to HIV.

4. *Principles:* In adopting a rights-based framework in line with the CRPD, the UNAIDS strategy needs to make clear reference to the principles of universal design and reasonable accommodation outlined in the CRPD as well as the relevant Articles of the convention.

5. *Frameworks:* In order to increase the uptake and implementation of the disability strategy, it is essential that UNAIDS speaks to HIV as well as disability frameworks (e.g. community based rehabilitation (CBR), International Classification of Functioning, Disability and Health (ICF)). In order to better reach out to HIV programming the strategy needs to mainstream disability into global UNAIDS approaches such as the investment framework.

6. *Populations:* A UNAIDS disability strategy can also take cognizance of current discussions around key populations and develop an approach that clarifies how people with disabilities fit into these discussions. This needs to include country discussions around populations informed by evidence around the intersection of disability and HIV.

7. *Strategic Issues 1:* A strategic approach needs to advocate for the inclusion of people with disabilities into all parts of HIV prevention such as behavioural interventions, condom promotion, accessibility to information, medical male circumcision and prevention of mother-to-child transmission. In particular, the inclusion of disability in National Strategic Plans on HIV can be a marker of how well this integration has taken place on a planning level. UNAIDS also needs to identify and appoint regional and/or country persons who can advise countries in regards to the practical integration and implementation of disability into HIV prevention as well as HIV into disability programmes.

8. *Strategic Issues 2:* The UNAIDS strategy needs to advocate for the inclusion of disability, rehabilitation and mental health into national planning around HIV and AIDS. Again, National Strategic Plans on HIV highlight the degree of political commitment towards addressing HIV-related disability. As these are complex issues, a multi-disciplinary approach is needed to develop suitable and cost-effective responses to co-morbidities and disabilities associated with HIV. UNAIDS may need to identify and appoint regional and/or country teams who can advise countries in regards to the integration of disability into HIV treatment, care and support.

9. *Implementation:* The implementation of such a strategy needs to use a twin-track approach: a) mainstreaming disability into HIV programmes and b) mainstreaming HIV into disability programmes. This includes the promotion of disability rights legal frameworks such as the CRPD as well as the inclusion of disability within basic HIV programme activities and all social and programme enablers. The inclusion of people with disabilities and their organisations, Disabled Peoples Organisations (DPOs) is of upmost importance in this process. The operational plans of National Strategic Plans on HIV highlight the budget allocations to disability in the context of HIV and therefore need to be a key reference for UNAIDS. UNAIDS needs to appoint a point person as

well as a task team to be able to implement its strategy and enable cooperation and dissemination of good practises.

10. *Monitoring and Evaluation:* Monitoring and evaluation of this strategy will have to play a key role. The UNAIDS appointed person as well as a task team (ideally regional task teams) need to be able to advise on how best to monitor and evaluate this strategy. This may refer to the inclusion of disability indicators in UNAIDS reporting structure, monitoring and evaluating of UNAIDS staff and activities in regards to disability as well as changes in countries' strategic responses to HIV and AIDS.

The eight approaches listed in the UNAIDS disability strategy brief, can be reviewed with the input from this discussion paper as well as the support of an expert advisory team which includes people with disabilities. Recommendations have been provided throughout this document and in particular in the last chapter.

SECTION ONE: INTRODUCTION

1.1 Background

Over one billion, or about 15% of the world's population, have some form of disability, and 80% of these live in the developing world [1]. There is growing evidence that suggests that people with disabilities are at equal if not increased risk of exposure to HIV [2-5] as they are exposed to all known HIV risk factors such as increased risk of poverty, limited access to education and health care, lack of information and resources, lack of legal protection, increased risk of violence and rape, vulnerability to substance abuse and stigma. In addition, evidence suggests that people living with HIV (PLHIV) or those with AIDS are also at risk of developing permanent or episodic disabilities due to their illness or related treatment [6-9].

With the advent of the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2008, disability issues have received growing recognition in international policy debates, including in the context of HIV. In 2009, UNAIDS, together with the World Health Organisation (WHO) and UN Office of the High Commissioner for Human Rights (OHCHR), issued a policy brief on disability and HIV that recognized people with disabilities as a key group at increased risk of exposure to HIV infection [4].

In 2011, the UN High Level Meeting (HLM) *Political Declaration on HIV/AIDS* included four specific references to disability, underscoring the imperative to do more [10]. The declaration welcomed the adoption of the CRPD and recognized the need to take into account the rights of people with disabilities in the formulation of the global response to HIV and AIDS. It further noted with concern that HIV "prevention, treatment, care and support programmes have not been adequately targeted or made accessible to people with disabilities" [10]. Similarly, it "promotes services that integrate prevention, treatment and care of co-occurring conditions, including tuberculosis and hepatitis, improved 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*"* [10].

This called UNAIDS to action. Consequently in 2012 at the *Skills Building workshop - HIV policy and national programming: How to include the world's largest minority?* at the XIX International AIDS Conference in Washington DC, UNAIDS launched its 'Strategy for Integrating Disability into AIDS Programmes' — a strategy that will complement the tools developed by UNAIDS' partners in order to access National Strategic Plans (NSPs) on HIV in terms of their disability-inclusiveness [11, 12].

As yet, this 'strategy brief' has not been adopted due to concerns surrounding its content, structure and the initial process of its development. Given the latter concern and its commitment to inclusive programming, UNAIDS identified a need for a more wide-ranging and inclusive consultation process involving co-sponsors, the disability sector, civil society and other key stakeholders in order to finalize the strategy. In view of this, the Health Economics and HIV/AIDS Research Division (HEARD) in cooperation with the International Disability and Development Consortium (IDDC) task group on disability and HIV, were approached by UNAIDS to lead part of the consultation process. The following discussion paper provides the outcome of a review process and a first step towards a UNAIDS disability strategy. More consultation is still needed.

1.2 Objectives of the Strategy Review

The main objectives of the review process were:

- To support the UNAIDS Secretariat in developing a comprehensive global outline of the UNAIDS strategy on disability.
- To identify areas for action to ensure the implementation of the UNAIDS strategy on disability.

1.3 Strategy Review Process

The review process was conducted over three key stages. These key stages, which are illustrated in the timeline in Table 1, included developing an assessment tool, identifying a global task team, and an analysis of reviewers' comments.

Table 1: Dates and Procedures followed in the review process

Date	Procedure
01 - 4 Oct 2013	HEARD reviews strategy brief and develops assessment tool.
07 – 15 Oct 2013	HEARD and IDDC identify task team members and other relevant stakeholders to review strategy brief.
16 Oct – 8 Nov 2013	Task team members and other stakeholders review strategy brief.
09 – 29 Nov 2013	HEARD and IDDC compile draft discussion paper
2014 onwards	UNAIDS develops a further consultation process

1.4 Engagement with Civil Society and Disability Experts

The review engaged with civil society and disability experts across the world. In order to do this, a questionnaire was developed in consultation with UNAIDS and members of the IDDC disability and HIV task team. The questionnaire consisted of nineteen questions, which reflected key strategic elements such as:

- Background OR Why is this important?
- Objectives OR How does this help UNAIDS and its partners?
- Benefits OR What are the benefits of this strategy and its outcomes?
- Principles OR How does this fit with developmental needs?
- Strategies OR How do we get to policy and practice?
- Responsibilities OR Who will be responsible for or assist in the implementation?
- Goals OR Where are we now? And where do we want to be?

In order for the disability strategy to coincide with UNAIDS global objectives, the questionnaire was also constructed in line with the UNAIDS investment framework for the global HIV response [3].

1.5 The Global Task team and Reviewers

In order to facilitate the review, a task team consisting of ten experts in the field of disability and HIV were identified to undertake an in-depth review. The members of the task team were selected according to their experience and knowledge within the field of disability and HIV and AIDS, including HIV-related disability. Furthermore, they represented a range of civil society organisations of affected communities of PLHIV and people with disabilities as well as experts from academic institutions in various geographical areas. The IDDC task group on disability and HIV assisted in identifying and recruiting task team members.

In addition, other leading experts from disabled people organisations, international and national non-governmental organisations (NGOs), researchers and other civil society groups were invited to take part in the review process (see Acknowledgements).

This report is a synthesis of the views, comments and recommendations of the task team and reviewers.

SECTION TWO: FINDINGS OF THE REVIEW

2.1 Background

2.1.2 Disability and HIV: An Emerging Global Issue

As indicated earlier over one billion people or 15% of the global population have some form of disability. Of that number, between 110 and 190 million people experience very significant disabilities [1]. Despite these numbers, the definition of disability has different meanings to different people across the globe. In most instances, there has been an historical shift from viewing disability in relation to the medical model (i.e. focus on the individual's impairment) to that of the social model (i.e. the recognition of social barriers created through disability). In the last four decades, disability has also come to be defined in the context of the ICF, which synthesizes the medical and social model [13]. Through the review process, it was evident that the majority of the reviewers understood disability in the context of the social model or the ICF. Furthermore, it was also reported by many of the reviewers that the current definition of disability used in the strategy (i.e. the UN Standard Rules on the Equalisation of Persons with Disabilities) was outdated and should be replaced with the definition from the UN CRPD.

Definition

The United Nations *Convention on the Rights of Persons with Disabilities*, *20069* says "Disability results 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 with others."

In terms of HIV, although countries have become more knowledgeable about the spread of the HIV pandemic and its known at-risk populations (e.g. men who have sex with men (MSM), injectable drug users and sex workers), very little attention has been given to people with disabilities. This is commonly attributed to dominant socio-medical discourse that depicts people with disabilities as asexual, de-gendered and disassociated with other at-risk groups. [14] Despite this, growing prevalence data, although not conclusive as yet [5], indicates that people with disabilities are at equal, if not increased risk to HIV [15] [5] [16] due to various socio-economic and socio-cultural barriers. The most significant barriers have been identified as poor access to healthcare, education including sexuality education [17-19] and judiciary services, lack of accessible information on sexual and reproductive health and HIV and AIDS [20], poverty [21-23] and marginalization, stigma and high rates of sexual abuse and exploitation [4, 24-29]. In addition, due to dominant socio-cultural attitudes that perceive people with disabilities as being asexual or unable to take drugs, they are generally not seen as being at risk of STIs or HIV and therefore, are excluded from HIV and AIDS programming.

Although the current strategy acknowledges these risk factors, it does not provide sufficient links to research evidence outlining these risks, or recent disability and HIV prevalence data [30] [31] [32]. Furthermore, although the current strategy reports on the misperceptions of asexuality, it does not include any evidence to support the fact that all adults and youth are active sexual beings. In addition, it was identified through the review process that the current strategy does not adequately account for the voice and experiences of children and adolescents with disabilities including those who are orphans.

Notwithstanding these risk factors, increasing evidence also suggests that HIV and AIDS and its treatment may also cause episodic or permanent impairment and disabilities [33] [34] [6]. For instance, PLHIV have been found to develop musculo-skeletal, sensory (visual and hearing) and neuro-cognitive (dementia, depression) impairments. Besides these impairments, PLHIV are also subject to similar social barriers as those with disabilities such as stigma and discrimination and poor access to work and education. Furthermore, as outlined by a number of researchers [6-9, 35, 36] with the increased role out of antiretroviral treatment (ART) and the fact that PLHIV are living longer, there is likely to be a significant rise in prevalence of HIV-related disabilities in the next decade. This highlights a key relationship between HIV, the provision of rehabilitation services and its associated costs, which is currently not addressed in the global response to HIV.

Although the current strategy briefly mentions HIV-related disability, it does not go into any depth or provide any research evidence to support these claims. Also, many of the reviewers indicated that the significance of rehabilitation, including community based rehabilitation (CBR) in relation to HIV was absent from the current strategy brief.

Recommendations for UNAIDS strategy:

A UNAIDS disability strategy needs to provide a comprehensive background on the intersection of disability and HIV. Current research findings, including HIV and disability prevalence data, evidence on the vulnerability and capacity of people with disabilities as well as evidence in regards to HIV-related disability need to be included in the background section.

2.2 Outlining the Objectives and Goals

The main objectives of the UNAIDS global strategy is to reach zero new infections, zero AIDS-related deaths and zero discrimination (UNAIDS Strategy 2011-2015). In view of this and the ‘historical neglect’ of people with disabilities from HIV strategies, these objectives will remain unobtainable without including disability. Given this context and the recognition of people with disabilities as a group at increased risk of

exposure to HIV [3], it provides a strong argument for the mainstreaming of disability into HIV policies and programming. In this context, some of the reviewers put forward the notion of a 'twin-track' approach to disability inclusion, which includes general inclusion into mainstream HIV programmes and disability-specific inclusion (e.g. provision of print information in Braille or audio recording for people who are blind or simple language for people with intellectual impairments).

Reviewers commented that although the current disability strategy brief outlines eight strategic approaches towards disability inclusion in the Executive Summary, it does not relate these to the objectives of the UNAIDS global strategy or provide any further indicators, timeframes or an account of who is responsible for achieving each strategy. In order to work with the twin-track approach, however, it is important that the global UNAIDS strategy speaks to and includes disability and that the UNAIDS disability strategy speaks to the general approach of UNAIDS (e.g. investment framework or other).

Besides the importance of a disability strategy being in line with UNAIDS global strategy objectives, many of the reviewers also outlined other objectives that address the intersection between disability and HIV. These goals and objectives can be segregated according to the four levels at which UNAIDS operates. These include international, regional support team level, national and working with donors:

<u>International Level:</u>

- To dedicate specific budget for research and advocacy focusing on HIV and disability inclusion (structural, attitudinal and environmental barriers).
- To support the theoretical and operational trickling down of the UN CRPD from international (macro) to regional (meso) and national (micro) levels.
- To assign a specific person or group (possibly people with disabilities) at UNAIDS headquarter level dedicated to disability inclusion.
- To devise a specific global strategy and action (with a budget) for operationalisation on disability inclusion into HIV programming.
- To regularly monitor and report the progress of disability inclusion into HIV programming through UNGASS (and other UNAIDS mechanisms) and UNAIDS annual reports. This can be done at all levels.
- To own the joint Framework on disability inclusion into NSPs including the provision of training in countries.

<u>Regional support team level:</u>

- To reinforce its regional leadership on HIV and AIDS targeting the three zeros for ALL women, men and children who are at risk to HIV (including people with disabilities).

- To devise plans and budgets for rolling out the strategy on disability inclusion into NSPs to all National AIDS Councils (NACs) (this needs to be part of the annual action plans).
- To dedicate specific budget for research and advocacy focusing on HIV and disability inclusion (e.g. structural, attitudinal and environmental barriers) – This can be done at regional and national levels.
- To mobilize trainers and disability advocates in regard to training on disability inclusion into NSPs and HIV programming.

National level:

- To train all NACs on the strategy of disability inclusion into NSPs.
- To work closely with the NACs to make sure that NSPs are disability-inclusive and allocate a budget for this activity.
- To work very closely with the gender, youth, lesbian, gay, bisexual and transgender (LGBT) community and disability focal persons of national NACs for bridging the gaps between international commitments and national laws/policies for rights and protection in regards to HIV and disability.
- To identify local/national level partners that could support the government in the inclusion of disability in NSP and HIV programming e.g. Disabled People's Organisations (DPOs), disability orientated organisations, associations of disabled PLHIV, and research institutes.
- To support the NACs with their national Monitoring and Evaluation (M&E) and database system that disaggregates data per age, race, sex and disability.

UNAIDS works with donors funding HIV and AIDS programmes:

- Encourage donors to better define "vulnerable populations", "marginalized populations", "hard to reach populations" or "key populations" as in most countries people with disabilities are among those.
- To advocate for disability-related indicators in HIV and AIDS research funding agendas, or call for proposals recognizing the intersection of HIV and disability including HIV-related disability.
- To advocate donors to respect and invest in the application of NSPs and not only their external agendas.
- To remind country donors of their accountability. For instance, if their countries have ratified the UN CRPD or have a development disability inclusion policy (e.g. DFID, 2000; USAID, 1997; AusAID, 2010), they must abide by them and apply them to their foreign development aid. This means they have to include and report on disability in developmental work (Article 32 UN CRPD).

2.2.1 UNAIDS Key Aims and Objectives: Developing a 5-year Plan

In terms of developing a 5-year plan for the disability strategy, the following aims and related objectives were identified:

<u>To Develop A Comprehensive Knowledge Map That Identifies A Global Situational Analysis Of Disability And HIV:</u>

- Enhance M&E mechanisms in UNAIDS that are inclusive of people with disabilities.
- Revise government HIV M&E frameworks to include data on disability.
- Develop accessible feedback mechanisms for key role players (e.g. government, researchers, NGOs, Civil Society Organisation (CSO) etc.) to report data to UNAIDS.
- Inclusion of disability data in all UNAIDS international and country reports.

<u>To increase the visibility and inclusion of disability in all international and national HIV strategies and programmes:</u>

- Develop and implement a plan of inclusion to ensure all UNAIDS programmes (and other UN agencies) at all levels, understand the intersection of disability and HIV including HIV-related disability.
- Intensify advocacy efforts with government and HIV service providers surrounding the inclusion of disability in NSPs and HIV services.
- UNAIDS to develop disability and HIV technical groups (including people with disabilities) at international and regional levels to increase the visibility and voices of people with disabilities and their organisations.

<u>To promote the Global Dissemination of information and Resources Surrounding the intersection of disability and HIV:</u>

- Develop a central resource portal (e.g. website/database) that includes a collation of research, guidelines, frameworks and best practice models on disability and HIV (see HEARD website for example).
- Outputs and outcomes surrounding disability and HIV to be published to assist in planning for the next five years.

Recommendation for UNAIDS strategy:

Such a strategy needs to formulate concrete objectives and goals. These need to include SMART (specific, measurable, attainable, relevant and time-bound) aims and objectives focussed at programme level (NSPs), donors and governments as well as knowledge sharing. National or regional task groups in relation to disability may be a useful mechanism in order to identify and achieve these aims and objectives in cooperation with UNAIDS. Such a task group needs to include people with disabilities and their organisations in meaningful leadership positions.

2.2.2 Responsibilities of Other Key Role Players

Although the current strategy outlines the responsibilities of UNAIDS in the implementation of the strategy, no mention is made of the responsibilities of other key role players. Collaborating with other key role players is essential in order to ensure the successful implementation of the disability strategy. These key role players and their responsibilities, as identified during the review process, are presented in Table 2 below.

Table 2: Key role players and their responsibilities in relation to the UNAIDS Disability Strategy

Role Players	Responsibilities
International Agencies of the UN (e.g. UNICEF, WHO, UNESCO, UNGASS etc.)	• Ensure disability inclusion in all international conventions, programming and reporting, in particular HIV related programmes (e.g. NSPs) • Promote UNAIDS disability strategy amongst UN staff and agencies (i.e. memo sent by UNAIDS Executive Director) • Develop accessible channels with other key role players to allow for the reporting on disability and HIV data.
National and International NGOs (disability and HIV-related e.g. IDDC, Handicap International, CWGHR, DPI, DHAT, TAC etc.)	• Work closely with UNAIDS in the dissemination of the strategy amongst governments and CSOs • Collaborate with DPOs and associations of PLHIV for disability inclusion • Engage with governments for implementation of disability-inclusive national programmes including NSPs • Engage with donors in regard to refining or strengthening their disability inclusion efforts • Strengthen communication between CSOs, government and international agencies • Strengthen capacity of CSOs to advocate for disability rights and inclusion • Work closely with researchers and use their evidence to advocate for evidence-based practise
Government Institutions	• Ensure all national policies and legislation are in line with CRPD in order to promote disability inclusion, including NSPs • Promote inter-collaboration between government departments to ensure disability inclusion • Develop M and E HIV frameworks that include disability
Civil Society Organisations (e.g. DPOs, Faith Based Organisations [FBO], PLHIV support groups)	• Advocate for the inclusion of disability in HIV programming • Encourage open dialogue between disability and HIV groups (including, other at-risk groups e.g. gender, LGBT, youth) • Be part of the M and E process of strategy implementation and access to HIV services for

	people with disabilities.
Donors (e.g. Global Fund, USAID, Pepfar, IAS, DFID etc.)	• Recognise disability as a key 'at-risk' population • Allocate funding for disability mainstreaming • Mainstream disability in funding requirement similar to gender
Research Institutions (e.g. HEARD, UCL, SINTEF, UoT etc.)	• Provide up-to-date research on the intersection between disability and HIV • Disseminate research in accessible formats to other key role players • Collaborate with other disability and HIV programmes in reviewing HIV policies • Provide capacity building on the intersection of disability and HIV • Engage with DPOs, NGOs, government and donors to provide applied research needed by these agencies
Media	• Promote news/stories that enhance the positive image of disabled people • Increase access to sexuality and HIV education for people with various impairments

2.3 Benefits of a UNAIDS Disability Strategy

In developing a disability strategy, UNAIDS will contribute to the achievement of its global objectives such as stopping new infections and keeping people alive [37]. The main benefit would be a response to the HIV and AIDS pandemic that is inclusive and therefore genuinely effective. This will include:

- Reduction of new HIV infections among people with disabilities
- Improvement of ART adherence through addressing secondary conditions, stigma and disability
- Recognition of leadership in an emerging topic, i.e. disability inclusion and accessibility
- UNAIDS' accountability to its own commitment (strategy 2011-2015), disability policy briefs and affirmations such as the importance of addressing the needs of people with disabilities from HIV and AIDS
- Increase in the reach of vulnerable groups or key populations such as people with disabilities accessing HIV prevention, treatment, care and support and rehabilitation services in adapted formats and services.

The disability strategy could also be used to inform the writing of the UNAIDS 2011-2015 strategy documents. It could assist in strengthening inclusive disability development throughout UNAIDS country programmes; in this way, it has the ability to inform inclusive programming. Such a strategy is a demonstration of leadership in the area of disability and HIV, something that is much needed within this emerging sector. In this way, UNAIDS will promote the transition of traditional, and often mutually exclusive roles of disability and HIV into a more interactive framework, and encourage real cross-cutting approaches on a global platform, in both policy and programming.

Reviewers recommended that UNAIDS internalise this strategy by developing its own organisational disability action plan or initiative, with a focus on promoting not only the inclusiveness of programmes/strategies but also outlining a plan for inclusion of people with disability within the organisation. Examples of this could include promoting a 'disability champion' in the senior executive of UNAIDS and accessible offices and programmes.

For this purpose, UNAIDS needs to engage with civil society (including DPOs) and international experts and possibly identify a focal person (ideally a person with a disability) and task team. This focal person or task team would then take the responsibility to 'review' or comment on the progress of UNAIDS, and assist by giving high level input to the agency in relation to some of the complex issues. In addition, reviewers also suggested that UNAIDS could engage with the sector through:

- Activities showing intersections between disability and HIV and AIDS at relevant international events (e.g. World AIDS Conference)
- Ensuring that disability is included in all UNAIDS annual reports, along with a progress report on the implementation of the disability strategy
- Collaborating with other international agencies that are committed to disability-inclusive development, such as WHO, UNESCO, UNICEF and UNDP
- Advocating for a disability component to be included in all governmental and programme reports.

Table 3: UNAIDS Stakeholder Benefits

Main Benefits of the UNAIDS Disability Strategy	Monitoring and Evaluation of the Benefits
An advocacy tool by which to promote the increased inclusion of disability in national HIV legislation/policies/NSPs and programmes/services.	• Disability indicators need to be developed and included in mainstream HIV-programmes – in this way the strategy will be encapsulated in the health sector's regular M and E processes. The involvement of DPOs and associations of PLHIV in this type of programme evaluation is important. • Disability audit/analysis of disability inclusion in new NSPs.
An increase in knowledge and empirical evidence of the intersection between disability and HIV. Increased communication and dialogue between the HIV sector and disability sector at all levels.	• Collection and reporting of disability related data at all levels of programming e.g. statistics on people with disabilities and HIV prevalence, people with disabilities reached with programmes (similar to gender). Furthermore, benefits of increased and improved disability related data include the incorporation/availability of disability statistics within national epidemiological and behavioural data, which would advance evidence informed, disability-inclusive HIV programming.
Decrease in mortality rates and improved quality adjusted life years (QALYS) for PLHIV. Prevention of HIV related impairments and early/adequate treatment of co-morbidities.	• Reporting on co-morbidities and disability types in PLHIV in voluntary counselling and testing and ART programmes. • Reporting on mental health and rehabilitation (possibly QALYS/DALYS) intervention to PLHIV.
Reduction in double or triple discrimination in regard to disability, gender and HIV status.	• Engagement with in-country disability sector and gathering of qualitative data in regard to access, discrimination and stigma.
Programme Impact: Implementation of this strategy will create a new movement of HIV prevention and care for disability as a new target group, which will attract much attention from	• The number of participating stakeholders, especially agencies working in disability and DPOs. • The extent of resource contribution and commitment of these stakeholders to the strategy implementation including finance, personnel and necessary materials.

community and society. This could result in a renewed sense of motivation, resource mobilisation and innovative initiatives towards the HIV and AIDS pandemic. This strategy also opens up dialogue around the barriers to health services and ways to improve access for people with disabilities in HIV spheres. Similarly, the strategy is very important for people with disabilities on the ground, with regard to education and treatment programmes.	• The number and impact of policy, guidelines and other regulations created as a result of the effort of UNAIDS and its stakeholders in the process of the strategy implementation.
Reduction in new HIV infections among people with disabilities. Increase of the availability of disability-inclusive services, including improvements in access to health and sexual and reproductive health services.	• Documentation of lessons learnt and good practices. • An innovative way of measuring accessibility and quality of services would be through national client satisfaction surveys from disabled users led by federations of DPOs at country level.

Recommendations for UNAIDS strategy:

In developing a disability strategy, UNAIDS will contribute to the achievement of its global objectives such as stopping new infections and keeping people alive. Through including one of the world's biggest minorities in its strategy meaningfully and effectively it will work towards this goal. A disability strategy should clearly articulate that without including disability, UNAIDS will not be able to achieve its goals in relation to HIV.

2.4 Principles Underpinning a Rights-based Approach to Disability and HIV

2.4.1 The CRPD as a Guiding Tool

As outlined earlier in section 2.1, there has been an accelerating shift internationally from recognising disability as a solely medical construct to that of a human rights-based framework. In this context, instead of focusing just on an individual's impairment, increased attention has been given to the impact of the social and physical environment in terms of the disability experience. This focus has culminated in the adoption of the UN CRPD, which came into force in 2008. Today, 138 countries have ratified the Convention and 158 countries have signed it [38]. The CRPD contains 50 articles that set out the obligations of states to promote inclusive societies and measures to increase the rights of people with disabilities. Key to the implementation of a disability rights-based framework, are the principles of equalisation of opportunities, empowerment and self-representation. These general principles form the foundation of the CRPD (see Figure 1) and also intersect with the human rights of PLHIV.

Figure 1: CRPD General Principles

General principles of the CRPD (Article 3)

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Coinciding with these general principles are the concepts of universal design and reasonable accommodation. The CRPD defines universal design 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" (Article 2, CRPD, p.4). Reasonable accommodation is defined 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…" (Article 2, CRPD, p.4). Notably, universal design and reasonable accommodation are essential principles in the intersection between disability and HIV, and in the creation of disability-responsive HIV programming.

The current strategy brief clearly acknowledges the importance of a rights-based framework with particular reference to the CRPD. Furthermore, the strategy brief recognises the need for a 'paradigm shift' in all legislation, policies, guidelines and practices in order to reflect the principles of the CRPD. Notwithstanding this focus, reviewers commented that the current strategy brief fails to fully engage with any of the aforementioned principles of the CRPD. In addition, the current strategy brief makes no reference or links to the various Articles in the CRPD. Although the CRPD does not include any direct references to HIV and AIDS, several of its Articles have been found to have particular relevance to the context of HIV and disability as demonstrated in Figure 2 below:

Figure 2: CRPD Articles that relate to HIV and AIDS

- **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 people with disabilities in National Strategic Plans (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 people with disabilities in NSPs.*
- **Article 9** promotes accessibility for disabled people, and requires State Parties to take measures to ensure access to the physical environment, transportation, information and communication and to facilities and services e.*g. include provision for adaptations and disability specific services in NSPs.*
- **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 persons with disabilities.
- **Article 16** requires State Parties to take measures to protect disabled people from exploitation, violence and abuse *e.g. address sexual abuse of people with disabilities in NSPs.*
- **Article 21** requires State Parties to ensure effective measures are put in place to ensure people with disabilities can exercise their right to freedom of expression and opinion, including the freedom to receive and impart information *e.g. provide opportunities for persons with disabilities to participate in the planning of NSPs.*
- **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 persons with disabilities.*
- **Article 24** requires State Parties to recognise the rights of disabled people to *education e.g. provide accessible HIV information and sexuality education to children and adults with disabilities.*
- **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 persons with disabilities to work on an equal basis with others *e.g. include persons with disabilities 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.*

Recommendations for UNAIDS strategy:

In adopting a rights-based framework in line with the CRPD, the UNAIDS strategy needs to make clear reference to the principles of universal design and reasonable accommodation outlined in the CRPD as well as the relevant Articles of the convention.

2.4.2 Additional Principles and Frameworks

Besides the CRPD, there are several other frameworks and strategies that incorporate a rights-based framework. Many of these strategies have been developed by UNAIDS itself or other UN/WHO agencies and have particular relevance to the intersection of disability and HIV. Despite this, the current strategy brief makes no mention of these other strategies and in essence, becomes a 'stand-alone' strategy. This could play a detrimental role in the implementation of the disability strategy brief as UN staff and agencies may fail to see its relevance to other strategies.

Through the review process, the following strategies and frameworks were identified as being of significant value to the current strategy brief:

WHO International Classification of Functioning, Disability and Health (ICF) was developed to demonstrate the complex interactions between features of the biological, psychological, environmental and social factors of disability. In this framework, which is also known as the biopsychosocial model, disability is depicted as the "outcome of the interaction between a person's health condition and the context in which the person finds themselves" [39]. This context includes external environmental factors (e.g. assistive devices, physical accessibility, societal attitudes), and those factors internal to the person (e.g. age, sex, coping skills, personality). As elements of the body, and personal and external environmental factors change, so the outcome also changes.

As HIV is recognised as a health condition, the ICF framework could have a significant role to play in determining the functioning of those with HIV and the impact of the internal (i.e. acceptance of HIV status), and the external environment (i.e. HIV stigma) [8].

UNAIDS Investment Framework 2011 The Investment Framework provides a useful framework in which to accelerate progress in the global response to HIV. In taking a rights-based approach, the framework recognises critical social and programme enablers that are crucial to the success of HIV programmes. Although disability is not included in the framework, the critical enablers have crucial significance to the intersection of disability and HIV, and ultimately, the overall success of the

Investment Framework. In addition, disability needs to be discussed in relation to all basic programme areas: (Key populations; elimination of new HIV infections in children; medical male circumcision [MMC); procurement, distribution and marketing of male and female condoms; treatment, care and support for PLHIV; and HIV exposure reduction though a change in social norms and behaviour).

WHO Global Action Plan on Disability 2014 – 2021: Based upon the CRPD and the ICF, the action plan contributes to achieving health, wellbeing and human rights for people with disabilities. The action plan, which is due to be released in 2014, has a strong focus on 'universal healthcare' and 'disability inclusive health'. It also recognises the importance of access to sexual, reproductive and HIV services.

The action plan also recognises the significance of CBR as an appropriate strategy for providing universal healthcare. In accordance with the CBR guidelines [45], CBR could be an effective strategy in raising the profile of disability in HIV and AIDS programmes. Furthermore, it also supports the social inclusion and equalisation of opportunities for PLHIV who may come to experience disability.

Post-2015 Agenda: Throughout the current strategy brief, no mention is made of the post-2015 health agenda regarding HIV and AIDS. Given that disability was excluded from previous Millennium Development Goal discussions, there have been significant strides by the disability sector for the inclusion of disability in the post-2015 health agenda. As a result, a report on the global consultation for health in the post-2015 agenda highlights people with disabilities as a key population to HIV risk and recognises the importance of universal access to sexual, reproductive and HIV services.

Other significant frameworks and strategies that were mentioned in the review process included:

- Disability Inclusive NSP Framework (GCGAD and UNAIDS, 2011)
- Continuum of Care Framework
- Declaration of UN High Level Meeting (2011)
- UNESCO Sexuality Education Framework
- Outcome documents from UN HLM on Disability, 2013
- National NSPs inclusive of disability, disability acts and other national strategies (e.g. Incheon Strategy for Persons with Disabilities in Asia and the Pacific – Asian countries 'are using this to guide their approach to disability inclusion').

Recommendations for UNAIDS strategy:

In order to increase the uptake and implementation of the disability strategy, it is essential that UNAIDS speaks to HIV as well as disability frameworks (e.g. CBR, ICF). In order to better reach out to HIV programming the strategy needs to mainstream disability into global UNAIDS approaches such as the investment framework.

2.5 Strategies and Strategic Questions

2.5.1 Classifications of Key, Vulnerable and Disabled Populations

Within the field of disability and HIV there is a need to clarify key issues such as classifications of groups of people in so-called key, vulnerable and/or disabled populations. These are semantic questions that have policy as well as financial implications in each country. The UNAIDS strategy brief acknowledges people with disabilities as vulnerable populations and provides a number of reasons. The review, however, revealed a more complex interpretation of these semantic questions.

Firstly, people with disabilities may need to be considered as a 'distinct group', which historically has been left out of the response to HIV and AIDS with little to no access to HIV prevention, treatment and care. People with disabilities also need to be considered as subjects with the capacity to contribute like anybody else, particularly in regard to their own issues. The inclusion of disability needs to address issues such as: Providing access to health and social services; access to education and information; tackling misconceptions; addressing prejudices and stereotypes around disability; addressing sexual violence; overcoming barriers to legal services; and tackling poverty among people with disabilities. This may apply particularly to children and youth with disabilities and their families/caregivers who are more likely to be isolated and lack access to healthcare services and education.

Secondly, evidence reveals that people with disabilities are a vulnerable population, particularly in low and middle income countries because they are exposed to all known HIV risk factors such as lack of knowledge about HIV, lack of access to education including sexuality education, lack of access to healthcare, increased risk of poverty and increased risk of sexual abuse. People with disabilities are also as sexually active as anybody else. They are part of all known "populations at increased risk of HIV" [3, 4]. People with disabilities are particularly vulnerable because of their socio-economic situation and their increased risk of sexual abuse and exploitation. Sub-populations such as women and girls with disabilities may be at particular risk of sexual abuse [24, 27, 28, 40-43], hence "most likely to be exposed to HIV and also transmit HIV to other people" (as per UNAIDS definition of key populations). If this is so they may be considered as a key population and need to be empowered, protected by the social and legal system and enabled to protect themselves (e.g. sexual and reproductive health [SRH], sexuality and HIV education).

Thirdly, in some regions, such as East and Ssouthern Africa, disability and HIV are directly associated. Evidence suggests that the HIV prevalence in people with disabilities, for instance in South Africa, may be higher than those of other at-risk populations such as MSM, drug users etc. Similarly there is some evidence that the HIV prevalence among some sub-groups of people with disabilities (e.g. the deaf) is higher than national HIV averages [31] [44]. If this is the case, people with disabilities (or their sub-groups) may have to be considered a key population. However, in order to make this decision countries need to gather reliable data on people with disabilities (meaning active efforts to include them in population-based surveillance). One also needs to carefully shield people with disabilities from being identified as 'vectors' of HIV. The emphasis should be on the need to include people with disabilities, rather than identifying them solely as a 'high risk' group.

Fourthly, identifying people with disabilities as a key population may also be a strategic necessity. In some countries the response to HIV has narrowed down to key populations, which affects funding. Disability sectors and NACs need to reflect how 'labels' will affect funding in a given country. In some countries being identified as a key population increases the political agency of people with disabilities, particularly in regard to funding opportunities.

It has also been debated whether HIV should be considered a disability. This discussion may be of political relevance or have financial implications as it may relate to stigmatising labels or financial benefits depending on a country's cultural and social context. Labelling PLHIV as 'disabled' can also be perceived as drawing scarce resources away from people with other types of impairments/disabilities. In order to answer this question the definition of disability could be re-visited. Within the CRPD, disability is understood as resulting "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 with others" [45].

Hence HIV *per se* cannot be considered a disability because diseases are generally not considered a disability. Some may consider HIV as an impairment because HIV 'impairs' the immune system and also has the potential to develop into secondary impairments, caused by opportunistic infections or treatment (e.g. TB). Others may simply argue that HIV is a chronic disease and not a disability. It can also be argued that both PLHIV and people with disability experience similar socio-cultural barriers, discrimination and stigma. Within the CRPD a person living with HIV can be considered as disabled if the HIV itself or an additional impairment (e.g. pain, fatigue, emotional functions, blindness, depression) in interaction with attitudinal and/or environmental barriers, hinders the person's participation in society (e.g. loss of job, discrimination). In other words, HIV could be considered as any other chronic or long-lasting disease (diabetes, mental illnesses, leprosy or poliomyelitis). Chronic diseases usually have a high likelihood of leading to disability and are often

associated with stigma. Individual case assessments might be necessary. Countries need to provide clear policy guidelines that discuss this issue. The inclusion of PLHIV and those with disability in this discussion is a necessity.

In addition, some countries such as Canada have investigated the disabling effects of HIV in more detail and developed the episodic model of disability (see background section). This model suggests that the experience of living with HIV can include episodic experiences of disability. With such a model, living with HIV can be considered as a disability even if the disabling effects are not always present.

The label of disability may also be connected to financial benefits as in some countries a disability grant is available. As this is financial support it might skew people's perception of who wants to and who can be considered as a person with a disability. Countries who offer such social security grants need to clarify and carefully consider who qualifies for such a grant, how disability relates to HIV and how policy and practice addresses this issue. Some countries have also deliberated on how to distinguish between a disability and chronic illness grant. Whatever the case, disability grants are country specific issues and do not directly relate to the definition of disability *per se*. UNAIDS needs to encourage countries to debate this issue and provide clear policy guidelines.

Recommendations for UNAIDS strategy:

A UNAIDS disability strategy can also take cognizance of current discussions around key populations and develop an approach that clarifies how people with disabilities fit into these discussions. This needs to include country discussions around populations informed by evidence around the intersection of disability and HIV.

2.5.2 Disability Inclusion in HIV Prevention

The current strategy does not identify specific efforts that will be undertaken to improve disability inclusion in HIV prevention, although it promotes two terms: a) Disability-sensitive programming and b) disability-responsive programming. The former acknowledges the interrelationship between disability and HIV while the latter goes a step further and also provides actions to address the interrelationship. However, the strategy brief does not provide further details and the review team has questioned the usefulness of these terms. It is probably more helpful to use already established terms such as 'universal design' and 'reasonable accommodation' as advocated in the CRPD (Section 2.4).

The review team recommended that a UNAIDS disability strategy needs to clearly advocate for the inclusion of disability in HIV prevention, and provide guidance as to

who can be consulted in regard to planning and implementation (the 'how to'). The appointed people need to understand how disability should be integrated into HIV prevention areas that are being considered strategic by UNAIDS. For instance, the UNAIDS investment framework focuses on basic programme activities such as behaviour change, condom promotion and distribution, Voluntary MMC and prevention of mother-to-child transmission (PMTCT). All these basic activities need to include and be accessible to people with disabilities. The UNAIDS disability strategy also needs to recognise the potential of people with disabilities as part of the solution and therefore, meaningfully engage with them as service providers, peer educators etc. in the response to HIV.

Inclusion and accessibility of behavioural interventions

Firstly, HIV prevention interventions have to be tailored to incorporate and accommodate different types of impairment. This includes characters and examples of people with disabilities in mainstream educational material (e.g. drawings, photographs) as well as the adaptation of information and educational material in accessible formats (specific language impairment (SLI), Braille, tapes, simplified pictures etc.). Generalisation in regard to certain impairment types may be problematic and what is suitable in one context may be a failure in another. For instance, the translation into Braille for persons with visual impairments is only useful if the target population is able to read Braille. In some communities therefore, it might be more useful to use audio recording or the radio. UNAIDS should support the further development of a good practice collection.

Secondly, a UNAIDS driven strategy needs to acknowledge the strength and resourcefulness of people with disabilities themselves. People with disabilities can be peer educators as well as provide crucial services such as voluntary counselling and testing (VCT) to people with disabilities. These approaches are of particular value not only because they ensure dignity and inclusion, but they may also be more feasible and effective. For instance, peer counselling from deaf to deaf has been shown to be promising in various settings, suggesting that this may increase VCT uptake as well as being sustainable in the long term [46-48] (as deaf people do not lose sign language like hearing people who are not exposed to deaf people on a regular basis). UNAIDS could also adopt the disability sector approach i.e. "Nothing about us without us", to ensure that people with disabilities are fully engaged in the response to HIV and AIDS.

Thirdly, a strategy needs to highlight the importance of sexual and reproductive health as well as comprehensive sexuality education and HIV information material for people with disabilities [49]. UNAIDS needs to have access to a task team or something similar that can advise which approaches and tools for comprehensive sexuality education have been developed and evaluated.

Accessibility of prevention interventions such as VCT, MMC, PMTCT

Key mainstream prevention interventions such as VCT, PMTCT and MMC need to include and be accessible to people with disabilities. This means that these services need to be provided with universal design and reasonable accommodation [45]. It also means that healthcare staff should be trained and enabled to deal with disability in the work place. This could include training on disability and HIV, training or exposure to sign language and provision of information material in accessible formats. The employment of people with disabilities as part of the solution needs to be promoted. In order to enable this, UNAIDS could promote disability inclusive reporting (uptake of VCT, ART, MMC, PMTCT and employment in these services) as well as the development/adaptation of a disability audit for facilities/services.

No information is currently available on the access of adolescent girls and women with disabilities to PMTCT programmes. Given that overall access to health services is still limited for women with disabilities in most countries [50] [51] [52], there is a strong likelihood that current efforts and commitments to eradicate vertical transmission miss this very vulnerable group. Given the vulnerability that disability imparts and the fact that 15% of the world's population are people with disabilities (19% among women) [1], awareness of transmission risks and access to PMTCT services is urgently required.

Condom promotion and safer sex

Condom promotion is a key programme activity in the Investment Framework, and this needs to include the promotion of condom use amongst people with disabilities. In some cases, it includes education about condoms, correct use of condoms (e.g. expiry date) and promotion of accessible information on condom packaging (e.g. Braille). This might also include the promotion of adult sexuality education in particular for people with disabilities who experience challenges in regard to sexuality and need assistance or adaptation. In regard to the latter, UNAIDS also needs to discuss the use of sex workers/surrogates by people with disabilities and how to promote safer sexual practice when consulting a sex worker or surrogate.

Additional approaches

Reviewers also suggested that other basic components of prevention should be applied to disability and these included:

- Harm reduction, including a needle and syringe programme; methadone maintenance therapy
- Community involvement/participation
- Enabling environment
- Gender-based approach
- Equality and equity approach to information, services and commodities between people with and without disabilities.

In addition, people with disabilities, and here in particular women and girls, are very vulnerable to sexual abuse and exploitation. UNAIDS also needs to promote strategies that address sexual abuse among people with disabilities such as the survivor and perpetrator. Such strategies could include:

- promotion of comprehensive sexuality education
- promotion of peer education and support groups
- promotion of fast tracking of sexual abuse cases involving people with disabilities and specialised assistance to accommodate disability (e.g. SLI, counsellors for people with intellectual disability) [26, 43].

In general, the use of the term "integrate disability into HIV" should be carefully considered in certain contexts due to the following: (i) The population of people with disabilities is much larger than that of PLHIV; (ii) the programme for disability was developed first, and so far there are more comprehensive programmatic elements of disability; (iii) since disability is already integrated into some other health sectors, somehow/sometime HIV could be integrated into disability. This will include approaches such as the integration of HIV information into sexuality education programmes for children with disabilities

Recommendations for UNAIDS strategy:

A strategic approach needs to advocate for the inclusion of people with disabilities into all parts of HIV prevention, such as behavioural interventions, condom promotion, accessibility of information, medical male circumcision and prevention of mother to child transmission. In particular the inclusion of disability in National Strategic Plans on HIV can be a marker of how well this integration has taken place on a planning level. UNAIDS also needs to identify regional and/or country appointed persons who can advise countries in regards to the practical integration and implementation of disability into HIV-prevention as well as of HIV into disability programmes.

2.5.3 Disability Inclusion in Treatment, Care and Support

The UNAIDS disability brief strategy mentions HIV related disability and mental health as an issue, but is then silent on the issue. It also does not raise the issue of people with disabilities accessing ART and challenges associated with this such as access, double stigma and medication issues.

Reviewers recommended that a disability strategy needs to promote disability inclusion, rehabilitation as well as mental health interventions in the context of HIV treatment, care and support. It also needs to take into account that mental health conditions as well as disability have the potential to affect ART adherence negatively

(see Section 2.3). The interrelationship of HIV with other conditions and disability can be quite complex and goes beyond a strategic document, particularly as this is a young field of research and new evidence is emerging continuously. In order to provide professional advice to countries, UNAIDS should work with or appoint a task team or person (regional) who can advise countries in regard to the following points:

Disability inclusion

Similar to VCT the strategy needs to promote access to ART for people with disabilities. This includes physical access (see disability audit and statistics above) as well as issues around disability and HIV medication. Healthcare staff needs to be trained in order to be able to understand disability related complications. For instance, side effects such as diarrhoea may provide more complications for a person in a wheelchair than a person who can walk quickly to a toilet. In addition, homebased care (HBC) will be important since many people with disabilities live and work at home. Hence disability needs to be included in HBC.

Rehabilitation

There is evidence emerging that HIV, its opportunistic infections and treatment, is related to a number of different, adverse effects, co-morbidities/health conditions and impairments that all have the potential to develop into disability. While some health conditions or treatment side effects can be addressed through a biomedical approach (change in ART, drugs for depression) others are of an episodic or a permanent nature and need rehabilitation interventions. In resource rich settings this may fall within the standard rehabilitation care and in some settings specific approaches have been developed to address rehabilitation in HIV care [53, 54]. In resource poor settings rehabilitation may need to link into disability approaches such as CBR [55, 56]. The Comprehensive Psychiatric Rehabilitation (CPR) matrix may provide some useful guidance in order to understand all aspects of rehabilitation (which include health, education, livelihood, social and physical environment and empowerment) that could be related to HIV treatment, care and support [56]. This will include the integration of the following elements into HIV care:

- Promotion of useful screening and diagnostic tools (links into models such as the ICF and the ICD 10 (International Classification of Diseases)
- Provision of rehabilitation (occupational, speech and physiotherapy, mental health)
- Inclusion of early childhood development
- Provision of assistance devices
- Inclusion of work related rehabilitation
- Promotion of self-help groups or peer groups.

The discussion around rehabilitation could also link more with contemporary processes, such as the WHO Global Action Plan (which is in draft) related to inclusive health, focusing on access to rehabilitation and assistive technology and

data. In either case a disability strategy in the context of HIV needs to acknowledge the need for a multi-disciplinary approach.

Mental Health

The Global Burden of Disease Study 2010 identified depressive disorders as a leading result of years lived with disability [57]. There is increased evidence that mental health, and here in particular depression and anxiety, are associated with living with HIV. The causal relationship is not necessarily clear. Mental health conditions may lead to risky sexual behaviour or HIV may lead to mental health conditions [35, 36, 58]. It is also plausible that depression is aggravated by issues other than HIV such as household shocks, death of a family member or impairment/disability. However, mental health is not well integrated into the response to HIV and this may have negative effects on adherence to treatment and livelihoods [59, 60].

The strong occurrence of mental illness among persons with HIV and AIDS needs to be discussed further in the UNAIDS Strategy Brief since a) stopping new infections is one of the main goals, thus adherence to treatment is of paramount importance and b) mental illness creates disability among PLHIV that could be improved with treatment and rehabilitation. Reviewers suggested that the UNAIDS Strategy should link up with current global movements in global mental health and discuss more the risk factors, adherence, co-morbidity, mother/child health and the need for health staff (especially primary care staff) to be better trained to administer support for PLHIV and mental illness. The Strategy needs to discuss collaboration in this field with other actors/strategies in Global Mental Health to scale-up services for PLHIV and mental illness such as the WHO strategy of Integrating Mental Health into Primary Care (2008), the WHO, Investing in Mental Health: Evidence for Action (2013) and the WHO Mental Health Action Plan, 2013-2020.

There are very few mental health specialists available in resource poor settings, hence there may be a need to consider mental health services within a task shifting model in resource poor settings (See also interventions such as the WHO Mental Health Gap Action Programme [2008] the PRIME [2012), Emerald [2012], COBALT [2014]). Therefore, UNAIDS needs to promote the dissemination of and research on innovative approaches for sustainable and feasible interventions in the area of mental health.

Caregiving

There is literature emerging that argues that the interrelationship between disability and the caregiving burden in the context of HIV is increasing the vicious cycle of disability and poverty [61] [62].

Young carers, women and older people are more likely to carry the load of care in resource poor settings exposing them to additional risks that lead to disability (e.g. learning disability, carework related impairments, mental health). Psycho-social

support and AIDS impact mitigation in the context of HIV need to respond to risk and vulnerability. Furthermore, untreated depression among HIV infected mothers may affect a child's health through lack of caring ability [62].

Research in this area is sparse and much more evidence on the interrelationship is needed.

Structural Issues

The interrelationship of disability and HIV is also driven by structural issues such as inaccessible services (e.g. health, education, social services or transport) and lack of integration of services. UNAIDS needs to identify and promote feasible and sustainable responses to these structural drivers in order to ensure the implementation of CRPD principals. These can include:

- Interventions targeting social protection and poverty reduction
- Adaptations to improve accessibility of services
- Promotion of accessibility of related services (e.g. transport).

2.5.4 Social and Programme Enablers

In order to follow a twin-track approach, UNAIDS needs to mainstream disability into the response to HIV and HIV into the response to disability. UNAIDS may also want to consider how a) a disability strategy speaks to other UN agencies such as the Disability Unit at UNICEF and other WHO groups such as the WHO Disability Group and b) how the strategy can speak to other UNAIDS frameworks such as the Investment Framework. At the moment this discussion is absent from the UNAIDS disability strategy review. However, many issues are raised, as social and programme enablers may benefit from the inclusion of disability in the discussion.

Social enablers

Social enablers such as political commitments and advocacy, legal obligations, community mobilisation, stigma reduction, mass media and local responses to change risk environments all need to include disability.

For instance the UNAIDS disability strategy brief acknowledges that stigma and discrimination block vulnerable people from accessing health services (p.3, 7, 13, 15, 18, 23) as weel as blocking the need to raise and discuss the role of stigma as potential barriers to effective health interventions for people with disabilities. This takes into account that not only HIV but also other health conditions (mental health) and disabilities are affected by stigma and that stigma needs to be addressed in relation to all health conditions. Disability or HIV stigma may also intersect with other characteristics such as race and gender, with the potential to increase stigma. People with disabilities may be key to any stigma reduction efforts or interventions and collaborations with local as well as international DPOs may be a central

approach for UNAIDS. Stigma reduction could include the promotion of specific interventions such as:

- Education on human rights for and with people with disabilities (including peer education, self-help groups and gender issues)
- Sexuality and rights education for and with children and young people with disabilities (including gender issues)
- Disability sensitisation (e.g. through training) of UN staff, donors, governments and NAC representatives
- Promotion of disability sensitisation or anti-stigma intervention for healthcare, education and civil service staff
- Community targeted stigma reduction interventions led by DPOs or NGOs working with disability addressing stigma as well as misconceptions.

Similarly, political commitment and advocacy (country disability responsive human rights framework) is a central point in which DPOs may provide a leading role in order to achieve and monitor the goals set within the CRPD. Currently there is still a lack of implementing CRPD principles into the response to HIV and AIDS [63] and UNAIDS could provide a leading role in advocating for the implementation of legal obligations set in the CRPD (ensuring rights and legal protection). Another avenue is collaboration with the CRPD secretariat in New York, its treaty body, the supporting body - the OHCHR in Geneva, the WHO as well as UNICEF. Reviewers highlighted that these offices can be an extensive source of support on a number of levels for UNAIDS as it works to develop and implement a disability strategy.

One of the most important tools that highlight countries' commitment to include disability within HIV programming are NSPs [63, 64]. UNAIDS needs to promote and use established tools to review NSPs in regard to their inclusion of disability. This includes providing training to governments and NACs on how to include disability within NSPs.

Mass media can be an indicator of a) accessibility and disability inclusion as well as b) societal attitudes and the level of stigmatisation and prejudices. Therefore it is necessary to raise awareness of people working within media in order to provide accessible media campaigns and information as well as address the stigma of disability [65].

Lastly, environmental enablers and risk (sexual abuse and exploitation, sex work) for people with disabilities have not been discussed within the disability strategy brief and a disability strategy needs to point towards an approach on how to address risk and how to provide enabling environments. This may include discussing 'taboo topics' including gender, violence, sexuality and injecting drug use in the context of disability and it may also include discussing disability within mainstream approaches to gender, violence (including gender-based violence) and sex work.

Recommendations for UNAIDS strategy:

The UNAIDS strategy needs to advocate for the inclusion of disability, rehabilitation and mental health into the national planning around HIV and AIDS. Again, National Strategic Plans on HIV highlight the degree of political commitment towards addressing HIV related disability. As these are complex issues a multi-disciplinary approach is needed to develop suitable and cost-effective responses to the co-morbidities and disabilities associated with HIV. UNAIDS may need to identify regional and/or in country appointed persons who can advise countries in regards to the integration of disability into HIV treatment, care and support.

Programme enablers

Similarly programme enablers such as community centred design, delivery and communication as well as research and evaluation need to include disability. A UNAIDS disability strategy could identify a number of responses that would enable a better integration of disability into HIV programming (and vice versa) such as:

- Community-centred design and delivery that includes disability: the importance placed on community-centred design and delivery could be improved upon through providing a leading role to communities of people with disabilities and their families.
- Procurement and distribution (budget allocations to disability). A UNAIDS strategy needs to emphasise the importance of planning and budgeting for disability inclusion. A disability strategy should seek more specific commitment from governments and make it an obligation for governments to include disability in their UNAIDS reports. Disability indicators in all phases of HIV programming such as research, planning, implementation and M and E may be a helpful first step.
- Research and innovation: A UNAIDS disability strategy needs to identify research on disability and HIV as a key area of concern. The strategy needs to identify steps on how to promote this kind of research. It could reach from promoting mandatory inclusion of disability in mainstream research (e.g. HIV prevalence, household surveys and census) to funding of specific targeted disability research, particularly in regard to interventions and economic evaluations.

The current disability strategy brief does include a strong focus on M and E and the need for building UNAIDS staff capacity, but, does not adequately address the capacity building of CBOs or DPOs in the implementation or monitoring of the strategy. Thus it fails to address local level advocacy, transparency and accountability.

Recommendations for UNAIDS disability strategy:

The implementation of such a strategy needs to use a twin-track approach: a) mainstreaming disability into HIV programmes and b) mainstreaming HIV into disability programmes. This includes the promotion of disability rights legal frameworks such as the CRPD as well as the inclusion of disability within basic HIV programme activities and all social and programme enablers. The inclusion of people with disabilities and their organisations, Disabled Peoples Organisations (DPOs) is of upmost importance in this process. The operational plans of National Strategic Plans on HIV highlight the budget allocations to disability in the context of HIV and therefore need to be a key reference for UNAIDS. UNAIDS needs to appoint a point person as well as a task team to be able to implement its strategy and enable cooperation and dissemination of good practises.

2.6 Monitoring and Evaluation of the Strategy Implementation

Reviewers recommended that a UNAIDS strategy should develop a clear action plan for its implementation and M&E. Within the UNAIDS office this could possibly include the following steps:

Phase 1 Developing a global strategy on disability and HIV

1) Respond to the discussion paper on the UNAIDS disability strategy brief and continue with consultation process
2) Identify and budget for an appointed person at UNAIDS as well as a dedicated task team (UNAIDS may also want to link to resource centres that already exist on disability and HIV)
3) Develop a UNAIDS disability strategy and operationalise this with clear outputs and outcomes to be achieved in the next five years.

Phase 2 Piloting and implementing the strategy

4) Consultation and training of UNAIDS staff in collaboration with disability sector
5) Collect information on disability and implementation of the strategy in countries annually. Ideally this could lead to the inclusion of disability as a variable in the UNAIDS annual report template. UNAIDS may wish to pilot its strategy in some countries before they roll it out globally.
6) Promotion of UNAIDS strategy through dissemination activities (press releases, conferences, websites, policy briefs) and during the technical assistance that UNAIDS provides to country governments, NACs and civil society.

Phase 3 Monitoring and Evaluation

7) Monitor and evaluate the implementation of the UNAIDS disability strategy related to activities within UNAIDS itself and specific outputs in countries related to planning (disability inclusion in NSPs and NAC inclusion of people with disabilities), implementation (accessibility of services, accessible educational material, number of people with disabilities accessing services) and M and E (inclusion of disability in national surveys, evaluation of national programmes and specifically targeted programmes).

Possible items for monitoring within UNAIDS

UNAIDS disability strategy

- Development of disability strategy and dissemination in countries
- Amount of financial resources to implement this strategy
- Availability of an action plan/roll out plan (annually)
- Number of appointed persons (regional or in country) within UNAIDS staff and development of established task teams

UNAIDS dissemination and collaboration

- Number of presentations/orientation about the new strategy
- Number of people (who, where, position, organization) who received information about the new strategy
- Number of people assigned in the UNAIDS system on disability (HQ, regional and country mission levels)
- Number of communication material, support to a resource centre etc.

UNAIDS staff

- Number of UNAIDS staff trained on disability and HIV
- Level of understanding of the new strategy among top management of UNAIDS HQ, regional and national levels

UNAIDS monitoring system

- Availability of added questions on disability in the UNGASS report
- Availability of added information on disability inclusion in UNAIDS reports
- Availability of internal memo from Michel Sidibé about this strategy
- Number of countries including disability comprehensively in their NSPs and operational plans
- Number of feedbacks from regional support teams and country missions about this strategy
- Number of new projects on HIV and disability following the launching of this strategy
- Amount of donors' money allocated to disability/accessibility and HIV policy and programming

8) Review of outcomes related to disability and HIV through commissioned systematic reviews/research on the interrelationship between disability and HIV.

In order to allow UNAIDS to provide technical support and to monitor and evaluate the strategy implementation, they may want to assess which tools and channels are the most appropriate. This would include:

- UNAIDS requiring countries to submit reports on disability issues as a condition of approval for their strategy implementation (or piloting)
- UNAIDS supporting countries to develop or suggest a packet of indicators on disability for reporting in regard to programming but also in regard to service assessment
- UNAIDS encouraging countries to integrate the indicators on disability into UNGASS
- Developing an M and E framework to assess the scale-up of integration of disabilities into HIV prevention, treatment, care and support (or vice versa)
- UNAIDS advocating for the mobilisation of resources (funding and technical assistance) for countries to implement data collection through surveys, research or to set up regular monitoring systems of disability.

Note: Dissemination activities need to be accessible in different formats e.g. Braille, audioand simplified versions with pictures. This also applies to the UNAIDS disability strategy itself. In this way UNAIDS can lead by example.

Recommendation for UNAIDS disability strategy:

Monitoring and evaluation of this strategy will have to play a key role. The UNAIDS appointed person as well as a task team (ideally regional task teams) need to be able to advise on how best to monitor and evaluate this strategy. This may refer to the inclusion of disability indicators in UNAIDS reporting structure, monitoring and evaluating of UNAIDS staff and activities in regards to disability as well as changes in countries' strategic responses to HIV and AIDS.

SECTION 3: CONCLUSION AND RECOMMENDATIONS FOR THE WAY FORWARD

This discussion paper is based on the comments of a diverse group of people across the globe with different experiences in regard to the intersection of disability and HIV. It is, therefore, not surprising that experiences and recommendations differed and therefore recommendations from this discussion paper will be very generic. These recommendations are related to the eight strategic approaches as presented in the original UNAIDS disability strategy brief as well as in line with the recommended phases from Section 2.6.

<u>Developing a global strategy and collaboration on disability and HIV</u>

- *Strengthen and promote the evidence for integrating disability into HIV:* For this purpose, a UNAIDS disability strategy and action plan needs to be developed. This strategy needs to be based on evidence and work in collaboration with an expert task team in order to support the update of strategic approaches. Ideally such a strategy should follow a twin-track approach integrating disability into HIV and HIV into disability programmes. The strategy needs to set specific, achievable targets and allocated a sufficient budget.
- *Establish and strengthen strategic partnerships:* The reviewers would like to see UNAIDS identify a point person responsible for developing these partnerships on an international level. The approach needs to include international bodies (WHO, UNICEF, IDDC etc.), civil society, in particular DPOs (DPI, DHAT etc.), governments and NACs as well as researchers or experts in the field of education, health and human rights.
- *Initiate dialogue and collaboration:* For this purpose, the reviewers would welcome UNAIDS establishing a platform of collaboration within its office. In particular, UNAIDS may need to identify regional persons as well as a task team that can provide the technical support and advice on the diverse aspects of the intersection of disability and HIV. It also needs to support the dissemination and accessibility of already available evidence and good practices possibly via already established resource sites.

<u>Piloting and implementing a UNAIDS disability strategy</u>

- *Improve the human rights for people with disabilities*: This approach should be interwoven with the CRPD and its principles of universal design and reasonable accommodation. In addition, it should incorporate specific articles from the CRPD that are relevant to the context of HIV and AIDS. It should also include country reviews in regard to the signature/ratification as well as implementation of the CRPD into the legal framework of these countries. UNAIDS can specifically target the implementation in the context of HIV.

- *Intensify advocacy and communication:* This approach needs to be closely linked to a) dissemination activities, b) monitoring of disability in country reporting, and c) capacity building. In addition UNAIDS itself can play a leadership role by providing all their communication material and events in accessible formats and through employing a number of people with disabilities (or disability experts or family members) within their offices.
- *Build capacity*: This is one of the most important aspects of the strategy. It needs to identify strategic areas of capacity building (e.g. stigma, NSPs and legal obligations, education and health) as well as suitable agencies or organisations that can provide this capacity building as relevant for specific regions and countries. Activities need to focus on capacity within UNAIDS itself, governments and NACs as well as civil society, including DPOs.

<u>Monitoring and evaluation</u>

- *Improve performance-based approach to programme support*: The strategy needs to identify how to collect baseline data on disability. This could include mandatory reporting of disability in national surveys as well as reporting on evidence in relation to specifically targeted research or interventions.

- *Enhance M and E*: A strategy needs to specify how and where disability outputs or outcomes are reported (e.g. at UNGASS, prevalence data, intervention reporting) and how and which 'result based management concepts' are being used to monitor and evaluate countries' progress in regard to HIV and disability.

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