

UNAIDS STRATEGY DEVELOPMENT



UNAIDS STRATEGY REVIEW:

Focus Group Synthesis HIV and Disability

Organizer: David Chipanta, Jill Hanass-Hancock, Joe Amon

Date: 21 July 2020

UNAIDS STRATEGY REVIEW: Focus Group Synthesis

Submitted to strategyteam@unaids.org

Would you accept for UNAIDS to make your report publicly available: Yes

SECTION 1: Information about the focus group

Individuals leading discussion: Jill Hanass-Hancock and Joe Amon

Date of discussion: 21 July 2020

Theme to be discussed: Disability

Participants

Name	Country	Region	Organisation
Misheck Shadreck Mithi	Malawi	ESA	Maximum Inclusion and Development for All
Betty Kwaggala	Uganda	ESA	Mekerere University
Lui Theoplus	Uganda	ESA	Independent
Jacques Lloyd	South Africa	ESA	Director ARRC / South African National Department of Health
Eric Carlson	Switzerland	EU	International Labor Organisation (ILO), head office
Katia Edmundo	Brazil	LAC	Executive Director of the Brazilian NGO CEDAPS
Maribel Ortega	Mexico City	LAC	Executive Director of AVE de Mexico, Blind woman. CBO working in HIV and disabilities
Ninel Díaz	Mexico City	LAC	AVE de Mexico, CBO working in HIV
Thushara Senanayake	Sri Lanka	AP	Saviya Foundation of Sri Lanka. Works on disability and HIV
Cathy Ketepa	Papua New Guinea	AP	Friends Frangipani National Sex Worker Network
Foluke Idowu	Nigeria	WCA	Independent Living for People with Disabilities (ILPD)
Musa Muaazu Musa	Nigeria	WCA	Disability Right Advocacy Centre(DRAC)
Alzouma Maiga Idriss	Niamey Niger	WCA	Fédération Ouest-Africaine des Associations de Personnes Handicapées (FOAPH)
Souley Moussa	Niamey Niger	WCA	Coordonnateur Régional Afrique de l'Ouest du Programme de Renforcement des Capacités pour l'Inclusion des Personnes Handicapées
Ba Moctar	Bamako Mali	WCA	Fédération Ouest-Africaine des Associations de Personnes Handicapées (FOAPH)
Yatma Fall	Dakar Senegal	WCA	Fédération des personnes handicapées du Sénégal
Sheriffo Jammeh	Banjul The Gambia	WCA	Gambian Association for the Physical Disabled (GAPD) - Brikama Branch

Maimuna Secka	Banjul The Gambia	WCA	Gambian Association for the Physical Disabled (GAPD) - Treasury
Lamin Fatty	Banjul The Gambia	WCA	Gambian Association for the Physical Disabled (GAPD) – member KM
ILP Abadan	Nigeria	WCA	Independent
Mamadou Sissoko	Bamako Mali	WCA	Fédération Ouest-Africaine des Associations de Personnes Handicapées (FOAPH)
Jebel Ceesay	Banjul The Gambia	WCA	Gambian Association for the Physical Disabled (GAPD) member
Sirra Ndow	Banjul The Gambia	WCA	UNAIDS, Gambia
Olymatoux Cox	Banjul The Gambia	WCA	UNAIDS, Gambia
Ansumana Sanno	Banjul The Gambia	WCA	Gambian Association for the Physical Disabled (GAPD) - Secretary General
Brigitte Zug-Castillo	Switzerland	EU	International Labor Organisation (ILO) HIV and AIDS
Helen Badini	Dakar Senegal	WCA	UNAIDS, Western and Central Africa (WCA)
Konstantin Voytsekhovich	Regional office	Eastern EU and CA	UNAIDS, Eastern Europe and central Asia
Stela Sacaliuc	Regional office	Asia Pacific	UNAIDS, Asia
David Chipanta	Switzerland	EU	UNAIDS, head office
Sophie Metral	Switzerland	EU	UNAIDS, head office
Lydia Karingithi	Kenya	ESA	UNAIDS, Kenya
Elizabetta Borzini	South Africa	ESA	UNAIDS, Eastern and Southern Africa (ESA)
Mianko Ramarosan	Switzerland	EU	UNAIDS, head office
Garcia De Leon Moreno	Switzerland	EU	UNAIDS, head office
Jane Batte	Switzerland	EU	UNAIDS, head office
Joseph Amon	USA	Amerika	Drexel University
Jill Hanass-Hancock	South Africa	ESA	South African Medical Research Council

Introducing the theme

People with disabilities comprise 15% or one billion of the world's population. Despite their increased vulnerability to HIV people with disabilities are rarely prioritized in health care and HIV interventions. In addition, people with disabilities are among all vulnerable populations including the poor, people who inject drugs, sex workers, lesbian, gay and bisexual, transgender people, men who have sex with men, children out-of-school, people experiencing violence, women and girls, adolescents and migrants. Yet seldom HIV programmes ensure that people with disabilities are included and targeted.

The group discussion started with a short presentation from David Chipanta outlining recent and future UNAIDS strategic developments. This included the following points:

- 1) Outcome of disability inclusion audit of current UNAIDS strategy review
 - a) A disability audit was conducted to appraise the UNAIDS 2016-21 strategy and UNAIDS' inclusion of disability using the UN Disability Inclusion Strategy Accountability Framework https://www.un.org/en/content/disabilitystrategy/assets/documentation/UN_Disability_Inclusion_Strategy_Entity_Technical_Notes.pdf
 - b) The audit revealed that although the previous strategy mentioned disability it had many gaps in terms of disability inclusion and concluded that this needs to be improved in the next strategy and entire UNAIDS work.
- 2) The COVID-19 pandemic exposes the fragility of the global political, financial and health architecture

and the inter-connectedness of health and social and economic vulnerabilities.

- a) It has highlighted the need for continuity of HIV-related services to ensure positive health outcomes of people living with HIV who may acquire COVID-19 and it has magnified the very same vulnerabilities in societies and sub-populations.
 - b) It has also shown how the lessons learned from responding to the AIDS pandemic can be put to practice and respond with speed to a devastating new pandemic.
 - c) It has shown again that people with disabilities are left behind and experience more health disparities than any other group
- 3) With less than 10 years to reach the goal of ending AIDS as a public health threat by 2030, the Programme Coordinating Board (PCB) tasked UNAIDS to review the UNAIDS 2016-2021 Strategy: On the Fast Track to end AIDS, taking stock of the significant gains already made and assess areas not on track to reach the targets, especially for the most vulnerable in society.

The AIDS strategy beyond 2021 will:

- present a roadmap and pathways to guide our collective efforts to overcome challenges and ensure effective country-led AIDS responses
- present with new global targets and resource needs estimates for 2025
- address how HIV responses continue to meet the needs of people living with and affected by HIV, while at the same time respond to the current COVID-19 pandemic and any future emerging challenges.
- needs to become fully disability inclusive and informed by people with disabilities

SECTION 2: People-centered response to HIV – key emerging messages

The discussion started with an analysis of recent data on HIV and disability and of the incorporation of disability into National HIV Strategic Plans (see: Ward E, Hanass-Hancock J, Amon JJ. Left behind: persons with disabilities in HIV prevalence research and national strategic plans in East and Southern Africa. Disability and Rehabilitation. 2020 May 13:1-0). The Power Point is attached to this document.

Thereafter participants divided into three groups and discussed why people with disabilities are vulnerable to HIV infection, what barriers they face to access to prevention, care and treatment and how they can be effectively reached. The main messages coming out from this discussion are here listed.

REACHING THE PERSON	
How do we see the current situation?	<ol style="list-style-type: none">1. Globally 15% of the population has one or more disability<ul style="list-style-type: none">• People with disabilities are a part of all key and vulnerable populations• Ending AIDS without inclusion of people with disabilities is impossible2. People with disabilities are exposed to all known HIV risk factors (e.g. out of school, poverty, lack of employment & dependency, stigma and discrimination, alcohol and drug abuse, transactional sex, sexual violence, multiple partners)3. Women with disabilities are at greater risk of exposure to HIV<ul style="list-style-type: none">• Exposure to transactional sex• Increased risk of violence (e.g. 2-4x more likely re: IPV)4. Persons with disabilities are a heterogeneous group, and what works for one group may not work for another.5. With many people with HIV living longer and into old age due to widespread availability of ARVs, disability arising out of old age and chronicity of HIV will be prominent among people living with HIV, and may impede enjoyment of a quality of life of people living with HIV.

<p>What concerns us?</p>	<ol style="list-style-type: none"> 1. People with disabilities face barriers to health services (including HIV services) as a result of attitudinal, financial, physical, communication factors 2. HIV prevention and treatment services are not adapted to the needs of the diverse persons with disabilities. For example, persons not able to see, who are living with HIV may not differentiate the types of ARVs, deaf person will not be able to access counseling without sign language interpretation and person with intellectual disabilities need simplified information 3. Young people with disabilities are less likely to access comprehensive sexuality education and HIV information than their peers and have lower HIV knowledge 4. People living with HIV experience episodic, temporary and permanent disability 5. Few studies have been published on HIV prevalence among people with disabilities and what works to reduce risk of HIV among this population 6. HIV prevalence was higher among persons with disabilities than national population estimates in many studies (2x and higher). Women with disabilities at higher risk than their peers without disabilities and men. 7. HIV prevalence studies recruiting community samples do not include disability indicators and the few disability specific studies rarely disaggregate by type of disability. 8. The UNAIDS 2016-2021 strategy mentioned disability no more than 3 times. And measure of disability inclusion in the National AIDS Strategies have stagnated
<p>What gives us hope?</p>	<p>Engaging the disability community which wants to support greater attention to this issue.</p> <p>Educated individuals with disabilities taking leadership in creating awareness and rolling out of peer educational behavior change programs</p> <p>Utilizing the emerging evidence from the disability focused research arising from Western and Southern Africa</p> <p>Supporting emerging women with disabilities as leader in low- and middle-income countries</p>
<p>What constrains our ability to achieve our goals?</p>	<p>Lack of disability data in many countries and lack of disaggregated HIV data in all countries.</p> <p>Lack of resources for HIV and Disability Projects</p> <p>Lack of support and leadership development for people with disabilities to represent themselves in the process of designing and implementation HIV programmes</p>

THE STRUCTURES THAT RESPOND TO HIV

<p>How do we see the current situation?</p>	<ol style="list-style-type: none"> 1) Health services do not have universal design and reasonable accommodation – hence are not accessible to all people with disabilities (physical access, attitudinal, communication approaches) 2) Health care staff may hold negative attitudes or misconceptions about people with disabilities and their sexuality 3) Information about HIV-prevention and treatment is still not accessible to people with sensory or intellectual disabilities 4) Many strategies lack disability inclusion, but even if an NSP achieves good disability inclusion in all its areas disability inclusion might lack operationalization in terms of allocation of funding and monitoring and evaluation (example SA NSP) 5) Lack of implementation of a three-track approach (reference UNAIDS reference report on Disability and HIV https://www.unaids.org/en/resources/documents/2017/jc2905_disability-and-hiv) 6) Lack of coordination on disability with other UN agencies (mainstream disability) 7) Not enough collaboration between civil society, disabled people’s organization, researchers and implementers 8) Beyond occasional mentioning of disability in strategic documents there is very minimal guidance and programmatic focus on how to ensure participation, inclusion and accessibility of services for people with disabilities 9) Limited leadership development of people with disabilities in particular women with disabilities
<p>What concerns us?</p>	<ol style="list-style-type: none"> 1) Need to train and empower organizations on disability inclusive HIV programming 2) Need to train health care workers including people with disabilities on the intersection of disability and HIV 3) Need to gain support for HIV and Disability specific programmes in other regions of the world to scale-up lessons learned from examples of good practice such as the West and Central Africa Global Funded HIV and Disability programme 4) Limited focus on development of peer led educational and awareness programmes

<p>What gives us hope?</p>	<ol style="list-style-type: none"> 1) Involving young people and women with disabilities (e.g. UNFPA regional strategy on SRHR and disability) 2) Learning from good practices that involve people with disabilities in the design of strategic plans (South African NSP and Western African HIV programming) 3) Utilising peer support and leadership of people with disabilities (ensure self representation of women and youth with disabilities)
<p>What constrains our ability to achieve our goals?</p>	<p>Need high-level leadership to raise visibility of HIV and disability.</p> <p>Lack of HIV and disability funded projects</p> <p>Lack of skilled and trained peer educators within the disability sector and strategic information to inform resource mobilization</p>

CONTEXTUAL ENVIRONMENT	
How do we see the current situation?	Factors that create vulnerability for PWDs to HIV and barriers to prevention and care are multi-sectoral: education, work, political rights, lack of financial support (voting, lack of accountability/justice for abuses) and participation in society, yet all are under-addressed.
What concerns us?	<ol style="list-style-type: none"> 1) Lack of attention to this issue broadly. Need for more inclusion – nothing about us without us. 2) Negative socio-cultural norms and misconceptions about disability (e.g people with disabilities as asexual, or harmful practices such as virgin rape), disability stigma and discrimination 3) General inaccessibility of environments (Challenges for health workers to reach remote areas and transport challenges for people with disabilities to visit health services) and poverty among people with disabilities and their families 4) Lack of funding allocation to disability (in mainstream and HIV programmes) generally and specifically to disability-led community-based organizations. 5) Lack of training and sensitization of health care staff around disability (hence they lack knowledge on how to accommodate and include people with disabilities) 6) Basic sanitation and inappropriate physical environment of HIV service
What gives us hope?	<p>Including disability as an important issue in the new UNAIDS strategy development discussion.</p> <p>People with disabilities taking action to stand up for their rights</p>
What constrains our ability to achieve our goals?	<p>Big changes need to occur – health structures need to become more accessible, health personnel more adept, sexual violence against women and girls with disabilities needs to be addressed.</p> <p>Funding on HIV and Disability Project need to be accelerated.</p> <p>Mainstreaming alone have not been sufficient to address the needs of persons with disability (hence three track approach is needed)</p> <p>Limited leadership development of people with disabilities</p> <p>Addressing disability in global emergency and epidemic situations like the COVID-19</p>

SECTION 3: RECOMMENDATIONS World Café

In the following plenary participants discussed action points. The main messages coming out of this discussion are listed below.

What are the key recommendations back to UNAIDS in terms of the strategy specifically?	
CONTINUE	<p><i>What is working that we must continue to do?</i></p> <p><i>Very little is being done in many countries but there are some positive examples. For instance</i></p> <ol style="list-style-type: none"> 1) Utilizing and fostering collaboration between civil society, disabled peoples organization, researchers and implementers (e.g. example Humanity and Inclusion in West Africa who used research and advocacy to impact HIV programming http://www.hiproweb.org/uploads/tx_hidrtdocs/DisabilityAndHIV_LL_07.pdf) 2) Training and empowering organizations on disability inclusive HIV programming (HEARD and Humanity and Inclusion have trained participants on disability inclusive programming) 3) Training health care workers on the intersection of disability and HIV (https://www.tandfonline.com/doi/abs/10.3109/09638288.2014.991455) 4) Utilizing peer support and leadership of people with disabilities (ensure self representation of women with disabilities) https://www.miusa.org/sites/default/files/documents/resource/VSO%202010%20bestpractices_inclusion_hiv aids-1.pdf 5) Training of leaders with disabilities 6) Appraising new draft NSPs with disability inclusion audit (example in UNFPA strategy https://esaro.unfpa.org/sites/default/files/pub-pdf/Regional%20Stratategic%20Guidance%20on%20SRHR%20for%20YPWD%20ESA.pdf) 7) Ensuring self-representation of people with disabilities on all HIV programming levels and in all sectors (including women, key populations, health care, prevention, treatment ...) 8) Reaching young people with disabilities (e.g comprehensive sexuality education, e.g. https://link.springer.com/article/10.1007/s11195-018-9525-0) 9) Mandatory inclusion of disability and M&E in all funding proposals

<p>STOP</p>	<p><i>What must we stop doing, that if we don't stop will ensure failure?</i></p> <p><i>Stop overlooking persons with disabilities. Ensure they are represented with attention to the diversity of types of disabilities.</i></p> <p><i>Stop treating people with disabilities as a separate group and include them in all HIV programmes (have an indicator to monitor inclusion)</i></p> <p><i>Stop funding programmes that do not include people with disabilities (make inclusion mandatory)</i></p> <p><i>Stop treating people with disabilities as second class citizens (Advocate for humane treatment of persons with disabilities e.g. no imprisonment because of a disability)</i></p>
<p>START</p>	<p><i>What are we not doing that we have to start doing?</i></p> <ol style="list-style-type: none"> 1. <i>KNOW YOUR EPIDEMIC - Support greater research on HIV and persons with disabilities and require countries to include measures and report on disabilities in population studies. Appraise new draft NSPs with disability inclusion audit (example in UNFPA strategy https://esaro.unfpa.org/sites/default/files/pub-pdf/Regional%20Stratategic%20Guidance%20on%20SRHR%20for%20YPWD%20ESA.pdf)</i> 2. <i>LEAVE NO ONE BEHIND – Ensure attention to PWDs is in national strategic plans, mainstreamed in all programs and specific targeted interventions are developed.</i> 3. <i>CHAMPION THE RIGHTS OF PERSONS WITH DISABILITIES – Work with UNAIDS Joint Partners/Co-sponsors to increase attention to persons with disabilities.</i> 4. <i>Broadly apply Three-track approach (reference UNAIDS reference report on Disability and HIV https://www.unaids.org/en/resources/documents/2017/jc2905_disability-and-hiv)</i> 5. <i>Proactively seek out and formally employ qualified persons with disabilities from disability advocacy circles in UNAIDS institutions.</i> 6. <i>Generate evidence on associated epidemics such as TB and GBV among persons with disabilities</i>
<p>What is the one key recommendation you want to reiterate for strong consideration?</p>	<p>Ending AIDS without including people leaving with a disability is impossible. Services need to be accessible to all people with disabilities and respond to the specific vulnerabilities of women with disabilities. Staff in the health, education and judicial sector need to be trained and equipped with needed resources to ensure full and meaningful inclusion of people with disabilities.</p>

Additional Documents Submitted

- *Ward E, Hanass-Hancock J, Amon JJ. Left behind: persons with disabilities in HIV prevalence research and national strategic plans in east and Southern Africa. Disability and Rehabilitation. 2020 May 13:1-0. <https://doi.org/10.1080/09638288.2020.1762124>*
- *J. Hanass-Hancock and Amon JJ. INFORMING DISABILITY INCLUSIVE HIV PROGRAMMES. PowerPoint Slides introducing FGD for UNAIDS meeting. July 21, 2020*