Medicus Mundi Suisse
Santé pour tous

MMS Bulletin #134
Many HIV-positive people are still left behind

Access to HIV and AIDS care: Persons with disabilities still left behind

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Persons with disabilities are at equal or higher risk of HIV infection than the rest of the community for several reasons: poor access to information and services related to sexual and reproductive health and HIV and AIDS; poor access to health care; poverty and marginalization; and high rates of sexual abuse and exploitation. Despite these increased risk factors, persons with disabilities are hardly being included in mainstream HIV and AIDS policies and programs – and are still left behind. This article presents disability-inclusive good practices, policy and program related opportunities.

Photo: Workers with disabilities in Dong Nai. Nguyen Thi Thanh Hieu is one of the 25 workers with disabilities featured in a photo exhibition titled "Live and Work". The exhibition was co-sponsored by LO Viet Nam. © ILO/Nguyen A./ flickr

We cannot run away from the needs of people with disabilities

At the opening plenary session during the 20th International AIDS Conference held in Melbourne in 2014, Michel Sidibé, Executive Director of UNAIDS, clearly stated that "we cannot run away from the needs of people with disabilities". And yet, still very little progress has been made to meet the needs and rights of persons with disabilities in the response to HIV and AIDS despite the following facts that highlight the risk and vulnerabilities of persons with disabilities to HIV:

- Persons with disabilities constitute approximately 15.6 % (11.8-18.0 %) of the world's population[1]; the rate is estimated to be 19% among the female population.
- The prevalence of violence against persons with disabilities - irrespective of the type of impairment- is 1.3 times higher than that in the general population, 1.39 times higher among women with disabilities and 3.86 times higher among people with mental health conditions[2]; and among children with disabilities, the experience of violence is 3.7 times more than that of their non-disabled peers[3].

- Based on a recent meta-analysis on the HIV prevalence among adults with disabilities in Sub-Sahara Africa4, data show that there is a gradient in the risk of HIV infection according to gender and disability status with a risk increasing from 1.48 for men with disabilities to 2.21 in women with disabilities when compared to non-disabled men.
- People living with HIV (PLHIV) are at risk of developing disabilities on a permanent or episodic basis as a result of their illness and/or side effects of ARV[5].

Interrelationships between HIV and disability

Disability, defined as "an evolving concept and (which) results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others ..."[6], intersects with HIV at multiple levels. On one hand, as reported above, persons with disabilities are at risk to HIV infection; on the other hand, PLHIV can develop various chronic impairments due to the course of the illness and side effects of medication. Also less studied is the impact on young and old people caring for PLHIV that may develop disability associated with increased child healthcare task, decreased school attendance in children, food insecurity and negative educational outcomes. These three interrelationships are illustrated in the Figure 1 [7,8].

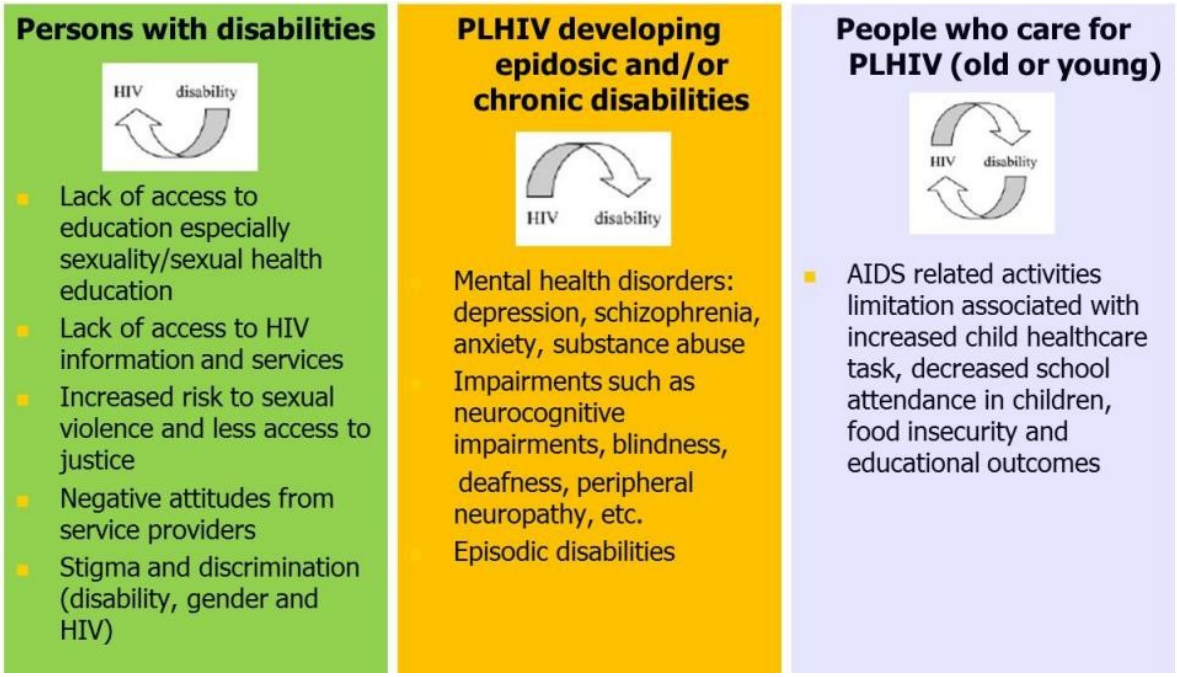

Figure 1. Interrelationships between HIV and disability.

More specifically, HIV is now considered a chronic and cyclical disease, with periods of wellness and illness. HIV is a complex and multi-systemic disease affecting the cardio-respiratory and musculoskeletal systems of the body. This, in turn, requires a multi-dimensional response to disease prevention and rehabilitation interventions[9]. Indeed, any person living with HIV is likely to experience temporary and/or chronic impairments (such as musculoskeletal impairments, neuro-cognitive disorders, blindness and hearing impairments), at different phases of the illness,

due to acquired infections and/or side effects from taking antiretroviral drugs. People with disabilities who become HIV positive might also undergo similar processes of activity limitations, in addition to existing impairment(s).

In spite of all this and the fact that more than 150 countries have ratified the UN Convention on the Rights of Persons with Disabilities (UN CRPD)[10] (including Switzerland), there are only a few initiatives in the world which respond to the needs of persons with disabilities who are also at risk to HIV.

Handicap International is proposing to remove HIV-related barriers for persons with disabilities

Handicap International[11] is a federation of eight national associations based in France, Belgium, Germany, Luxembourg, Switzerland, UK, USA and Canada, and is present in 59 countries worldwide, and works in the fields of Rehabilitation, Prevention and Health, Disability Rights, Support to Civil Society, Social Inclusion, Anti-Mine Action and Emergency.

Handicap International has experience in implementing HIV prevention and care for persons with disabilities in 11 countries in the Global South [12].The organization adopts among others, the following main approaches to include disability into development processes, for persons with disabilities to full have access to services. The global Twin Track Approach[13] (Figure 2) used by the organization posits that it is necessary to work on two simultaneous tracks to achieve equality of rights and opportunities for persons with disabilities by: 1) addressing inequalities between persons with and without disabilities in all strategic areas of our work; and 2) supporting specific initiatives to enhance the empowerment of persons with disabilities.

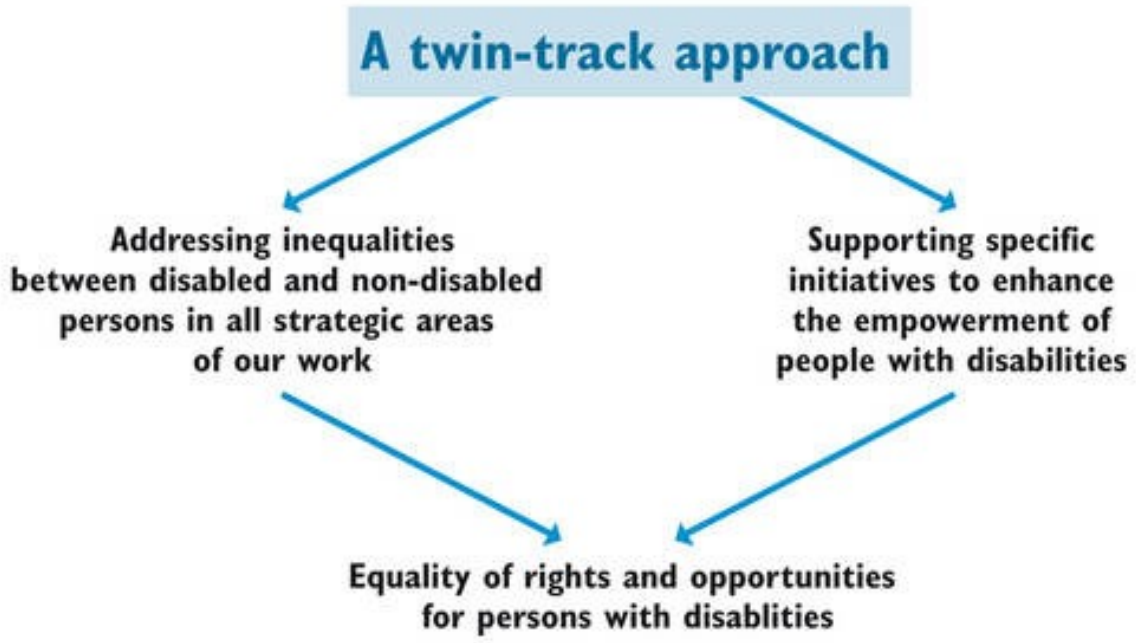

Figure 2. Twin Track approach to disability.

Furthermore, access to services for persons with disabilities underpins that efforts in programs are based on a "systematic vision of services, which includes the policy of a given country or sector (sector-based policies), practices (the service offering) and the lives of the individuals concerned" as promoted in the Access to Services Approach[14] adopted by Handicap International (Figure 3).

Figure 3. Access to services for persons with disabilities.

Examples of good practices to include disability at HIV policy and program levels

Based on more than a decade of field experiences in HIV and disability, Handicap International has gained significant experience and developed good practices with regard to including disability in HIV policy and programming [15]. Indeed, our organization has learned important lessons about programmatic and political processes and dynamics, before the international community had even recognized disability as an issue to be addressed. Here is a summary of six good practices taken from Senegal, Rwanda, Ethiopia, Kenya, Cambodia and international AIDS conferences.

1. Inclusion of disability into the national AIDS strategic plan in Senegal

The good practice that led to disability being included in the 2011-2015 Senegalese national AIDS strategic plan (NSP) was the result of a combination of key programmatic and advocacy activities such as: advocacy initiatives among the National AIDS Council's (NAC) decision-makers, especially at strategic meetings and during the drafting of the last NSP in 2011; regular feedback to the multi-stakeholder National Platform on Disability and HIV on project programmatic progresses and successes in terms of accessibility; implementation of a seroprevalence and Knowledge, Attitudes and Practices (KAP) survey among persons with disabilities in the region of Dakar prior to the decision taking on who was to be included in the NSP's final list of Vulnerable Populations; dissemination of the study's results to the NAC director and directors of other departments, such as the Monitoring, Evaluation (M&E) and

Research Department, showing that HIV prevalence among persons with disabilities in the region of Dakar was almost twice that of non-disabled people; sharing of project's strategic information to the NAC on a regular basis; and several follow-up meetings to ensure that the needs of persons with disabilities were taken into account from the initial draft version of the new NSP right through to the final version.

2. Inclusion of disability by mainstream US-funded AIDS organizations and implementing partners in Ethiopia

This example of good practice involved a series of strategies and activities that led to the mainstreaming of disability issues by US-funded AIDS organizations and projects (Figure 4). The first stage in this process consisted in organizing a disability accessibility audit with the organizations' top managers, the results of which would provide the starting point for a joint project on accessibility. As a consequence of this audit, all the key stakeholders, i.e. each organization, their partners and the project team, were made aware of the absence of disability inclusion at physical, communication, products, services, M&E and human resources levels. Consequently other activities were implemented in a logical order so as to reinforce disability mainstreaming and to respond to specific barriers related to knowledge, skills, attitudes and environment faced by persons with disabilities when accessing HIV related services.

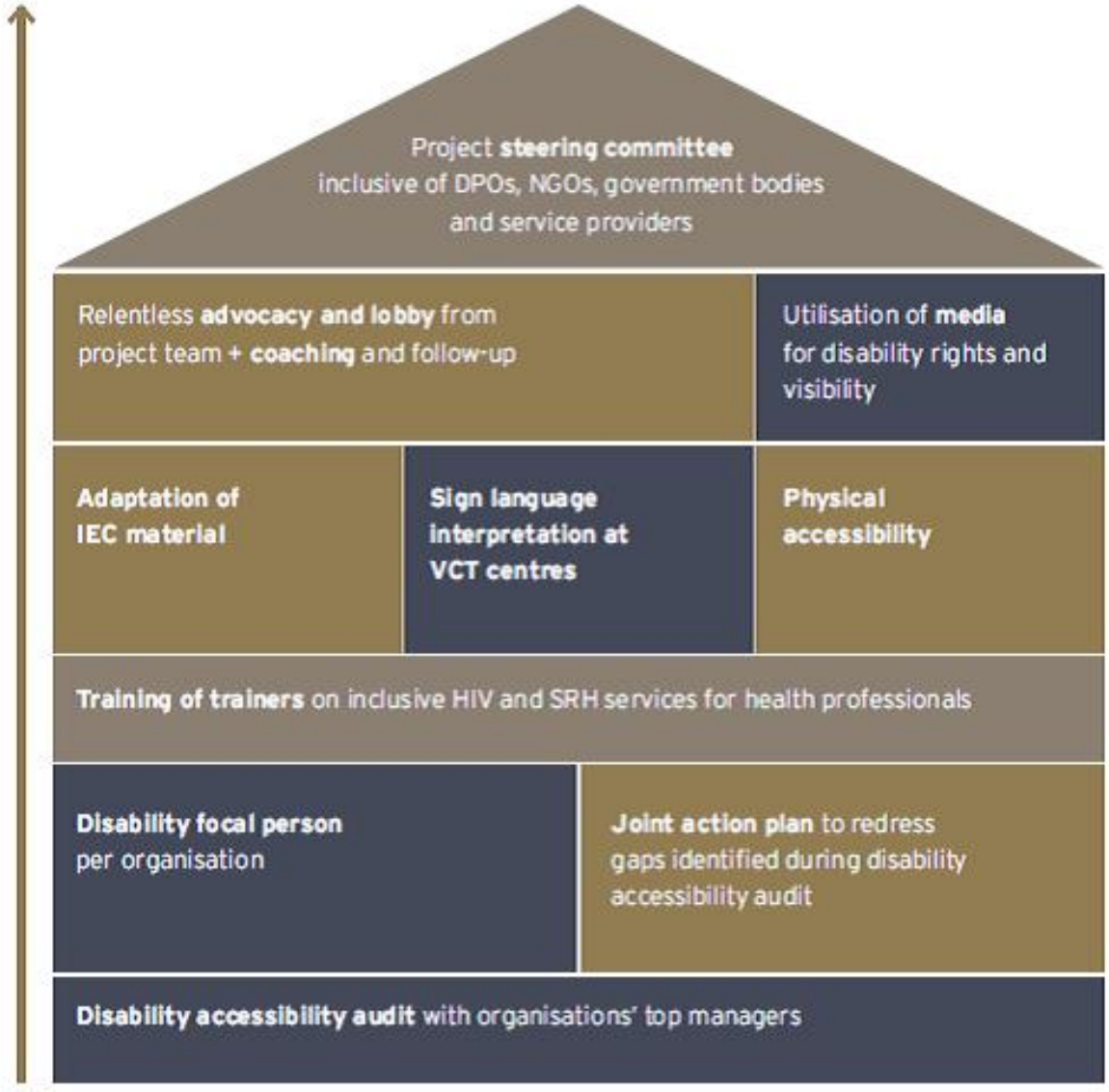

Figure 4. Activities implemented from bottom to top in terms of disability mainstreaming.

3. Strengthening the role of disabled people's organizations in the HIV response in Rwanda

Strengthening the organizational development capacities of disabled people's organizations (DPOs) and community-based organizations (CBOs) helped them to mobilize financial resources and increase their institutional credibility vis-à-vis donors and also government decision-makers. Moreover, strengthening the capacities of these civil society organizations was seen to be essential to enabling them to better promote and defend the rights and needs of persons with disabilities and other highly marginalized populations. The organizational capacity-building process used for this key component of the project is illustrated in Figure 5 which illustrates the annual cycle for organizational development. As a result, with improved structured technical and financial support, local partners were able to hire more staff to work on specific tasks instead of all staff working on different tasks at the same time. Training on proposal writing and resource mobilization enabled DPOs and CBOs to plan project proposals

ahead of time and in accordance with donors' requirements using their newly acquired skills. This increased capacity development directly led to two of them receiving funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria.

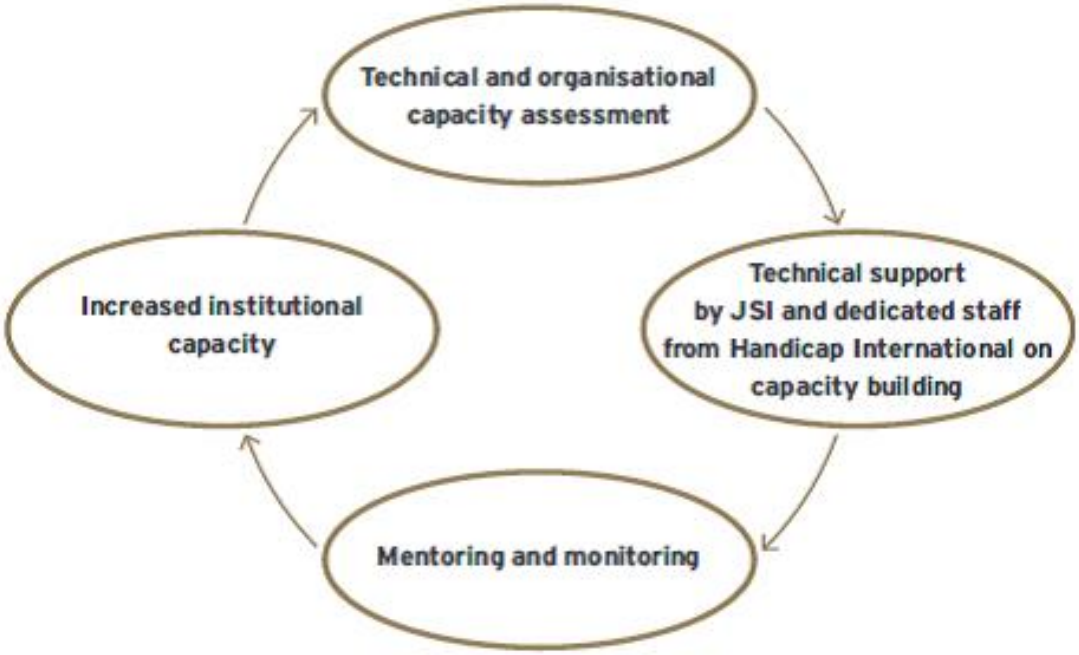

Figure 5. The organizational capacity-building process adopted by the concerned project.

Also organizational capacity-building enabled these DPOs and CBOs to better reach out to persons with disabilities on HIV and sexual violence prevention and care.

4. Disability-sensitive HIV information and services for persons with visual impairments in Kenya

This example of good practice concerns a project that focused on increasing access to HIV information and services for people with visual impairments in Kenya. It started by setting up a committee of people with disabilities and their DPO representatives to be part of a consultative body that would advise and guide the project in designing information, education and communication (IEC) material that met the communication needs of persons with visual impairments and effectively conveyed HIV related messages to them. Strategic partnerships were forged with DPOs with considerable experience of working for and with people with visual impairments. The involvement of people with disabilities and DPOs in adapting the IEC materials promoted by the Kenyan National AIDS Council in accessible formats for people with sensory impairments was vital for ensuring more targeted interventions. Materials were produced in large print and Braille and audio messaging was used for topics such as: HIV prevention; the challenges faced by people with visual impairments in disclosing their HIV status; multiple stigma faced by persons with disabilities in relation to HIV; the challenges experienced by persons with visual impairments in accessing voluntary and counseling testing services; or barriers faced by them while attempting to use ARV as they cannot see to

distinguish the different drugs they have to take. Radio talk shows were also organized so that persons with visual impairments as well as non-disabled people could tune in and learn more about HIV, STI and TB. All this was supported by community mobilization and awareness-raising by disabled peer educators who also carried out home visits to help persons with visual with impairments learn how to use condoms in the privacy of their homes. This enabled them to gain confidence and learn in a confidential environment. As a result, 8,796 persons with visual impairments were reached with HIV information on prevention, treatment and care; 23 community discussion sessions were organized; and 3,064 people with visual impairments went for counseling and testing.

5. Specific initiative for deaf women and the integration of sexual violence protection in rural areas of Cambodia

Working in rural communities with deaf women to raise their awareness of HIV, sexual and reproductive health and sexual violence protection was a crucial component of a project on HIV and disability implemented in Cambodia from 2008-2012. The activities focused on helping deaf women to learn more about HIV and sexual violence prevention and services. A number of key good practices were identified through a participative and longitudinal exercise which included the following: mapping of persons with disabilities and, in particular, deaf people living in target villages; conducting home visits and mobilizing local leaders to encourage community 'buy-in'; close partnership with the Deaf Development Programme of Maryknoll (DDP); training educated deaf women to become future trainers and awareness-raising facilitators for other deaf women and girls; training deaf women and girl to learn Cambodian sign language before they could learn about HIV and sexual violence prevention; and development of visually-friendly IEC material.

6. Disability-inclusive international AIDS conferences from 2008 to 2014

The good practice of including disability into international AIDS conferences was the evolution of joint and tireless efforts from the members of the HIV and Disability task group of the International Disability and Development Consortium (IDDC)[16], of which Handicap International is an active member and co-chair from 2010-2012. The following table shows the building blocks of disability inclusion in such conferences and the successive successes.

AIDS conference	Member of the International Steering Committee	Disability specialists and experts in scientific committee	Disability accessibility audit	Disability and HIV abstracts selected	Special session or satellite session or forum on HIV and disability	Non-abstract driven session on HIV and disability	Skills building workshops or symposium on HIV and disability	Disability networking zone	Active involvement of local DPOs and partners in organising activities	Persons with disabilities living with HIV in plenary sessions	Disability and HIV officially in the rapporteurs' session
IAC 2008	No[A]	No	No	Yes	Yes	No	No	Yes[B]	No	No	No
ICASA 2008	No	No	No	Yes	Yes	No	No	No	Yes[C]	No	No
IAC 2010	No	No	Yes	Yes	Yes	No	No	Yes[D]	No	No	No
ICASA 2011	Yes	No	Yes	Yes	No	Yes	No	Yes	Yes	No	Yes
IAC 2012	No	No	Yes	Yes	No	No	Yes	Yes	Yes	No	Yes
ICASA 2013	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes
IAC 2014	No	No	Yes	Yes	No	Yes	Yes	Yes	Yes	No[E]	No

A: But AIDS Free World was
B: A small one
C: Through the Africa Campaign
D: First group effort
E: But disability mentioned by speakers

Table 1. Disability inclusion progression in various international AIDS conferences.

Upon reflection, lessons learned from each conference were carried over to the next one. Having key members who had attended earlier AIDS conferences also greatly helped with not reinventing the wheel. More specifically, the facilitating factors are as follows: representing the voice of many through IDDC and moving forward as a multi-stakeholder alliance; keeping the memory of key events alive via key IDDC HIV and Disability Task Group members over the years; official membership of the International Steering Committee through Handicap International at the International Conference on AIDS and STIs in Africa (ICASA); harnessing the passion of activists and advocates; having an office or members or their partners in the city

where meetings and the AIDS conference were taking place; involving local DPOs and their members with experience on the intersection between HIV and disability; getting UNAIDS on board through joint presentations, funding of some of the activities, or co-organization of skills-building workshops; and involvement of research organizations.

Key challenges and opportunities to include disability into HIV and AIDS

- There is still insufficient evidence such as HIV prevalence studies among persons with disabilities and a lack of comprehensive national data on HIV and AIDS and disability; more investment in research is needed
- Though numerous funding for "vulnerable groups" exist, there is still a limited number of organizations and donors prioritizing on this largest world minorities (around one billion people)
- Lack of scaling up of disability inclusive approaches and initiatives in HIV and sexual and reproductive health (SRH) programming
- Limited partnership between AIDS and disability-focused organizations/disabled people's organizations
- The UN Convention on the Rights of Persons with Disabilities is a binding international tool. Many articles such as article 9 on accessibility, 25 on health (including HIV/SRH), 31 on statistics and 32 on international cooperation calls upon states' obligations that are often not respected
- The UNAIDS Investment Framework (2011) recommends all countries to know the HIV epidemic patterns. But how much is known when 15% of any population is not accounted for?
- The UNAIDS Gap report (2014) devotes a whole chapter on persons with disabilities, but how concrete are the actions to bridge this gap?
- The Global Fund's Human Rights on HIV, TB, Malaria and Health System Strengthening information Note (2013) includes persons with disabilities in the partial list of key populations. However no specific funding for persons with disabilities has been seen as of now.

Ways forwards

- To support mechanisms for disability-related data collection in HIV and AIDS as part of the national M&E system (epidemiological and behavioral information)
- To support the inclusion of disability in national AIDS strategic plans (NSP)
- To strengthen the health system through disability inclusion, accessibility and universal access principles and interventions
- To ensure significant participation of persons with disabilities in decision-making processes, implementation and M&E
- To promote gender equality and disability inclusion

- To support and monitor the application of the UN CRPD and national laws and policies (articles 9,25, 31, 32 especially)
- To strengthen and facilitate networking and partnership between HIV and disability at international, national and grass-roots levels
- To engage the private sector in AIDS and disability such as for using mobile technologies

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