Enough of well-intended rhetoric and objectives, urgent and comprehensive action is needed for disability inclusion in HIV response!

Statement from the Disability and HIV/ Inclusive Health Task Group of the International Disability and Development Consortium (IDDC) to the organisers and delegates of the 2018 International AIDS Conference

It is estimated that 1 billion people, or 15% of the world's population, have some form of disability (1). Many of them live in resource-poor settings with limited access to HIV prevention, treatment, care and support, while they are at increased risk of exposure to HIV and people living with HIV are at an increased risk of developing disabilities (2, 3, 6, 7). Persons with disabilities can be found among all key populations that are highlighted in the global fight against HIV/AIDS. Still, **persons with disabilities are largely invisible and excluded[1] from the 22nd International AIDS Conference** in Amsterdam, as demonstrated by the absence of disability in all mainstream and allied sessions, including poster presentations. The *Amsterdam Affirmation: People, Politics, Power*[2] makes a strong point of ending exclusion, but not for persons with disabilities.

The fight against HIV and AIDS will only be successful when the world's biggest minority – persons with disabilities – is included, disability is treated as a cross-cutting issue and the impetus of the Sustainable Development Goals (SDGs) of "leaving no one behind" is taken seriously. As the UNAIDS Executive Director Michel Sidibé said in his opening address in the 2014 International AIDS Conference in Melbourne, "Too many are being left behind today. If the world wants stability, peace and sustainable development, we cannot run away from the needs of lesbian, gay, bisexual, transgender and intersex people, sex workers, people who inject drugs, prisoners, migrants, women and girls, and people with disabilities".

Years later, very little progress has been made.

[1] While AIDS conferences in previous years were more disability inclusive, this year there were no oral and poster presentations on disability accepted, no disability-related sessions in the mainstream conference programme, and only limited availability of sign language interpretation.

[2] The statement highlights a focus on key populations (gay men and other men who have sex with men, people who inject drugs, people in prisons and other closed settings, sex workers and transgender people), gender justice and addressing the needs of priority populations (migrants, refugees, indigenous people and racial minorities). http://www.aids2018.org/Get-Involved/Take-part/The-Amsterdam-Affirmation

To date, 161 countries signed the UN Convention on the Rights of Persons with Disabilities (5). They have committed themselves to including disability in their programmes and, in particular, to protecting and defending the rights of people with disabilities. Yet, this right to inclusion still needs to be implemented in HIV and AIDS programmes and initiatives, such as international AIDS conferences where thousands of researchers, advocates, community leaders and representatives of various constituencies convene to.

Firstly, **persons with disabilities are at increased risk of exposure to HIV** (6, 7) and also found among all commonly known key populations such as men who have sex with men, sex workers and drug users. In fact, in some countries they are already recognised as a key population as such, hence they are the largest overlooked population in the fight against HIV and AIDS.

Secondly HIV, its co-morbidities and treatment are causing health conditions leading to disability (8, 9) that threatens not only health but also the livelihood of the infected individual as well as their families and social systems. This is relevant in particular in resource-limited settings where HIV is endemic.

Thirdly**,** despite many years of advocacy and research, the relationship between disability and HIV is still largely ignored in the debate around HIV as well as in the response to HIV (10). Consequently, **persons with disabilities still lack access to routine HIV interventions such as sexuality education, volunteer counselling and testing as well as treatment.** Similarly, people living with HIV, particular those in resource poor settings, lack access to even the most basic rehabilitative interventions (11, 12). This threatens livelihoods and weakens already fragile economic systems. Hence, the lack of disability inclusion in the response to HIV has now become a developmental issue.

In response to this, the International Disability and Development Consortium (IDDC) Disability and HIV/Health Task Group organises, in the conference Global Village, the **Disability Networking Zone (DNZ) "Disability Inclusive AIDS Response"** (#DNZ2018 @iddcconsortium @AIDS_conference). The DNZ welcomes conference participants and the general public to participate in presentations and activities offered at the DNZ, or to stop by throughout the conference to speak to disability advocates and researchers and pick up information on a series of presentations, papers and tools for interventions relating to HIV and disability.

In conclusion, we will fail to reduce new HIV infections and AIDS related deaths without including the world's biggest minority – persons with disabilities. Hence, IDDC would like to take this opportunity to reiterate that the SDGs, universal health coverage and UNAIDS' 90-90-90 and 95-95-95 goals cannot be achieved without the effective inclusion of disability in HIV response and health agenda.

IDDC urges UNAIDS, WHO, UN sister organisations and development partners alike to recognize and address the exclusion persons with disabilities face in access to prevention and services, and undertake comprehensive actions to ensure that member States, donors, international and national partners are accountable to a disability-inclusive and AIDS-free world in the humanitarian and development continuum settings – for ALL.

For further information please contact the following members of the IDDC Disability and HIV/Inclusive Health Task Group:

Verusia Chetty, chettyve@ukzn.ac.za, University of KwaZulu-Natal, South Africa
Saul Cobbing, cobbing@ukzn.ac.ca, University of KwaZulu-Natal, South Africa
Philip Coetzer, drpcoetzer@vodamail.co.za, South Africa
Zoe Gray, zgray@iapb.org, IAPB, United Kingdom
Jill Hanass-Hancock, jillhanass@gmail.com, South African Medical Research Council, South Africa
Laura Honders, LHonders@lilianefonds.nl, Liliane Fonds, Netherlands
Betty Kwagala, kwagalabetty@yahoo.com, TASO, Uganda
Jacques Lloyd, reablejac@gmail.com, Afrique Rehabilitation & Research, South Africa
Muriel Mac-Seing, macseing@yahoo.ca, University of Montreal, Canada
Pulchérie U. Mukangwije, ageneral@hi.org, Humanity & Inclusion, France
Vernon Openshaw, vernon.openshaw@gmail.com, Afrique Rehabilitation & Research, South Africa
Lieke Scheewe, l.scheewe@lightfortheworld.nl, Light for the World, Netherlands
Phillimon Simwaba, simwabap@gmail.com, DHAT, Zimbabwe

References

1. World Health Organization, The World Bank. *World report on disability*. Malta: World Health Organization; 2011. 350 p.
2. Hanass-Hancock J. *Disability and HIV/AIDS-a systematic review of literature on Africa*. Journal of the International AIDS Society. 2009;12(1):34.
3. O'Brien KK, Davis AM, Strike C, Young NL, Bayoumi AM. *Putting episodic disability into context: a qualitative study exploring factors that influence disability experienced by adults living with HIV/AIDS.* Journal of the International AIDS Society. 2009;12(1):30.
4. Mac-Seing M. *Including disability in HIV policy and programming: Good practices drawn from country-based evidence.* Handicap International; 2014.
5. United Nations Enable. *Rights and dignity of persons with disabilities* United Nations; 2018 [Available from: http://www.un.org/disabilities/.
6. De Beaudrap P, Mac-Seing M, Pasquier E. *Disability and HIV: a systematic review and a meta-analysis of the risk of HIV infection among adults with disabilities in Sub-Saharan Africa.* AIDS Care. 2014;26(12):1467-76.
7. De Beaudrap P, Beninguisse G, Pasquier E, Tchoumkeu A, Touko A, Essomba F, et al. *Prevalence of HIV infection among people with disabilities: a population-based observational study in Yaoundé,* Cameroon (HandiVIH). The Lancet HIV. 2017.
8. Hanass-Hancock J, Nixon S. *HIV, Disability and Rehabilitation. Consideration for Policy and Practice.* Issue Brief. 2010. Health Economics and HIV/AIDS Research Division (HEARD): Durban.
9. Nixon S, Forman L, Hanass-Hancock J, Mac-Seing M, Munyanukato N, Myezwa H, et al. *Rehabilitation: A crucial component in the future of HIV care and support.* Southern African Journal of HIV Medicine. 2011;12(2):12, 4, 6, 7.
10. Groce NE, Rohleder P, Eide AH, MacLachlan M, Mall S, Swartz L. *HIV issues and people with disabilities: a review and agenda for research.* Social Science & Medicine. 2013;77:31-40.
11. Cobbing S, Hanass-Hancock J, Deane M. *Physiotherapy rehabilitation in the context of HIV and disability in KwaZulu-Natal, South Africa.* Disability and rehabilitation. 2014;36(20):1687-94.
12. Chetty V, Hanass-Hancock J. *A rehabilitation model as key to comprehensive care in the era of HIV as a chronic disease in South Africa.* AIDS care. 2016;28(sup1):132-9.