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DISABILITY AND HIV POLICY BRIEF

Context

An estimated 650 million people, or 10% of the world's population, have a disability.[1] The relationship between HIV and disability has not received due attention, although persons with disabilities are found among all key populations at higher risk of exposure to HIV. People living with HIV may develop impairments as the disease progresses,[2] and may be considered to have a disability when social, economic, political or other barriers hinder their full and effective participation in society on an equal basis with others.

This Policy Brief discusses the actions needed to increase the participation of persons with disabilities in the HIV response and ensure they have access to HIV services which are both tailored to their diverse needs and equal to the services available to others in the community. These actions, defined in consultation with a broad range of stakeholders including people living with HIV and persons with disabilities, are in line with the commitments made by States to universal access to HIV prevention, treatment, care and support by 2010,[3] the Millennium Development Goal of halting and beginning to reverse the spread of HIV

HIV and Definitions of Disability under International and National Laws

The *Convention on the Rights of Persons with Disabilities* states that:

> "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Article 1)

The Convention does not explicitly refer to HIV or AIDS in the definition of disability. However, States are required to recognize that where persons living with HIV (asymptomatic or symptomatic) have impairments which, in interaction with the environment, results in stigma, discrimination or other barriers to their participation, they can fall under the protection of the Convention.

States parties to the Convention are required to ensure that national legislation complies with this understanding of disability. Some countries have accorded protection to people living with HIV under national disability legislation. Other countries have adopted antidiscrimination laws that either explicitly include discrimination on the basis of HIV status or can be interpreted to do so. Such laws offer a means of redress against HIV-related discrimination in a number of areas, such as employment or education.

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[1] Mont D. Measuring Disability Prevalence, *SP Discussion Paper* No. 0706. The World Bank, March 2007, unpublished WHO document No A29/INF.DOC/1 Geneva, 1976.

[2] Gaidhane, Abhay; Zahiruddin, Quazi Syed; Waghmare, Lalit; Zodpey, Sanjay; Goyal, R. C.; Johrapurkar, S. R. (2008), "Assessing self-care component of activities and participation domain of the international classification of functioning, disability and health (ICF) among people living with HIV/AIDS", *AIDS Care* 20(9):1098-1104; Marise Bueno Zonta, Sérgio Monteiro de Almeida, Mirian T Matsuno de Carvalho and Lineu César Werneck (2005), "Evaluation of AIDS-Related Disability in a General Hospital in Southern, Brazil", *Brazilian Journal of Infectious Diseases* 9(6): 479-488.

[3] *2006 Political Declaration on HIV/AIDS*, UN General Assembly Resolution 60/262 Article 20.

by 2015[4] and the principles and standards of international human rights law, in particular the *Convention on the Rights of Persons with Disabilities*.[5]

Persons with Disabilities and Risk of Exposure to HIV

There are few data on HIV prevalence among persons with disabilities. The few existing studies on the hearing-impaired, or deaf, populations, suggest infection levels equal to or higher than those of the rest of the community.[6] Persons with disabilities may be at risk of HIV infection for the following reasons.

- **HIV risk behaviours**: due to a number of reasons, including insufficient access to appropriate HIV prevention and support services, many persons with disabilities engage in behaviours which place them at risk of HIV infection, such as unprotected heterosexual or male-to-male sex (including in the context of sex work) and injecting drug use.[7] Additionally, persons with disabilities who also belong to groups that may be socially marginalized, such as men who have sex with men, people who inject drugs, or prisoners, may face compounded stigma and discrimination.
- **Sexual violence:** a large percentage of persons with disabilities will experience sexual assault or abuse during their lifetime,[8] with women and girls, persons

[4] Millennium Development Goal 6, UN General Assembly Resolution 55/2, Article 19.

[5] The Convention on the Rights of Persons with Disabilities entered into force on 3 May 2008.

[6] Taegtmeyer, M, Henderson. K, Angala. P, Ngare. C (2006) Responding to the signs: A voluntary counselling and testing programme for the Deaf in Kenya. AIDS 2006 Poster MOPE0876; Monaghan, L. (2006). HIV infection statistics for hearing and deaf populations: Analysis and policy suggestions. In C. Schmaling & L. Monaghan (Eds.), *HIV/AIDS and Deaf Communities*. Gloucestershire: Douglas McLean; Monaghan, L. (2008) "AIDS 2008, Monday August 8" in http://hivdeaf.blogspot.com/2008/09/on-monday-i-presented-paper-on-deaf-hiv.html. Monaghan, L. (In press) HIV/AIDS, Deaf Culture & Civil Rights. In K. Lindren, D. DeLuca, D.J. Napoli, eds., *Deaf in a Hearing World*. Washington, DC: Gallaudet University Press; Touko, A. (2008). Sexual behaviour and prevalence rate among the young deaf population in Cameroon. Paper presented at the XVII International AIDS Conference, Mexico City. http://www.aids2008.org/Pag/PSession.aspx?s=277

[7] Groce, N. E. et al (2004) *Global Survey on HIV/AIDS and Disability* World Bank, Washington DC; The Steadman Group (2007) *HIV and AIDS Knowledge, Attitude and Practices and Accessibility Study in Kenya* Handicap International, Nairobi, Kenya; Moll K (2007) *Too few to worry about? Or too many to ignore? The exclusion of people with disabilities from HIV programmes in India: Final Report* PMO-DFID New Delhi; Taegtmeyer M et al. (2008) A peer-led HIV counselling and testing programme for the deaf in Kenya. Disability Rehabilitation 28:1-7.

[8] American Academy of Pediatrics (2007) "Assessment of maltreatment of children with disabilities" Pediatrics 119:5:1018-1025; Dickman, B. *et al* (2006)."How could she possibly manage in court? An intervention programme assisting complaints with intellectual disabilities in sexual assault cases in the Western Cape" in B. Watermeyer, et al (eds.), *Disability and Social Change: a South African Agenda*. Cape Town: HSRC Press; Young, M. E. et al (1997). Prevalence of abuse of women with physical disabilities. *Arch. Physical Medical Rehabilitation*, 78, 34-38; Hanass-Hancock, J. (2008). *Invisible: The Notion of Disability in the Context of HIV/AIDS in KwaZulu-Natal, South Africa*. Berlin: Humboldt University; The Steadman Group (2007) *HIV and AIDS Knowledge, Attitude and Practices and Accessibility Study in Kenya*. Nairobi, Handicap International; Kvam, M.H., & Braathen, S. H. (2008) "I thought…maybe this is my chance » : sexual abuse against girls and women with disabilities in Malawi" *Sexual Abuse: A Journal of Research and Treatment 20(1)*, 5-24; Nosek, MA et al (2001) "The investigation of abuse and women with disabilities: going beyond assumptions" Violence Against Women 7: 477-99; Sobsey, D. & Varnhagen, C. (1989). Sexual abuse and exploitation of people with disabilities: Toward prevention and treatment. In M. Csapo and L. Gougen (Eds.) *Special Education Across Canada* (pp.199-218). Vancouver: Vancouver Centre for Human Development and Research.

with intellectual impairments and those in specialized institutions, schools or hospitals being at particularly high risk.[9] There is also evidence that in some cultures, persons with disabilities are raped in the belief that this will "cure" an HIV-positive individual.[10]

- **Access to HIV education, information and prevention services:** persons with disabilities may also be turned away from HIV education forums or not be invited by outreach workers, because of assumptions that they are not sexually active, or do not engage in other risk behaviours such as injecting drugs.[11] Even where knowledge of HIV is high among persons with disabilities, this does not always translate into use of HIV testing and counselling services.[12]

In a specific instance, children with disabilities account for one third of the 72 million children out of school in the world,[13] and are excluded from the vital sexual and reproductive health education which is often provided in school settings. Low literacy levels and a lack of HIV prevention information in accessible formats (e.g. Braille) make it all the more difficult for persons with disabilities to acquire the knowledge they need to protect themselves from HIV.[14]

Access to Treatment, Care and Support

Persons with disabilities may not benefit fully from HIV and related sexual and reproductive health services for the following reasons.

- Service providers may lack knowledge about disability issues, or have misinformed or stigmatizing attitudes towards persons with disabilities.[15]
- Services offered at clinics, hospitals and in other locations may be physically inaccessible, lack sign language facilities or fail to provide information in alternative formats such as Braille, audio or plain language.[16]

[9] Sobsey, D. & Doe, T. (1991). Patterns of sexual abuse and assault. *Sexuality and Disability*, 9 (3), 2430259; Sobsey, D. (1994). *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?* Baltimore: Paul H. Brookes Publishing Co.; Valenti-Hein, D. & Schwartz, L. (1995). *The sexual abuse interview for those with developmental disabilities.* James Stanfield Company. Santa Barbara: California; Furey, E. (1994). Sexual abuse of adults with mental retardation: Who and where. *Mental Retardation*, 32, 3, p. 173-180.

[10] Groce, N. E. & Trasi, R. (2004). Rape of individuals with disability: AIDS and the folk belief of virgin cleansing. *The Lancet* 363: 1663-1664.

[11] Ibid.

[12] For example a survey in Malawi found 94% of respondents knew about HIV but only 10% had been tested see Munthali A et al (2004) *Effective HIV/AIDS and Reproductive Health Information to People with Disabilities* University of Malawi Center for Social Research. Those who had never been for a test cited reasons such as thinking they would be okay, not knowing what voluntary counselling and testing was, and not being able to walk or find other transport to the testing site.

[13] UNESCO (2007) *Education for All Global Monitoring Report 2008* UNESCO Paris.

[14] Groce, N. (2005) "HIV/AIDS and Individuals with Disability" *Health and Human Rights* 8(2) 215-224.

[15] South African AIDS Council. (2008). *HIV, AIDS and Disability in South Africa.* Pretoria: South African AIDS Council, Tororei, S.K. (2006) *The Social, Economic and Policy Factors influencing Access to and Utilization of HIV/AIDS Services by Persons with Disability in Kericho District*, Kenya. Moi University, Moi, Action on Disability and Development (ADD) (2005) Challenges Faced by People with Disabilities (PWD). Uganda: ADD, Catalan J, Collins P, Mash B, Freeman M (2005) *Mental Health and HIV/AIDS: Psychotherapeutic Interventions in Anti-retroviral (ARV) Therapy (for second level care)* WHO: Johannesburg, South Africa, Moll, K., (2007) *Too Few to Worry About? Or Too Many to Ignore?: The Exclusion of People with Disabilities from HIV Programmes in India. Final Report.* New Delhi: PMO-DFID.

[16] Action on Disability and Development (2005) *Challenges faced by People with Disabilities* Uganda, ADD.

- Confidentiality for persons with disabilities in HIV testing and counselling may be compromised, for example, by the need for a personal assistant or a sign language interpreter to be present in order to access HIV-related services. The decision to use support services rests with the person with a disability and should be respected by the relevant health service provider.
- In settings with limited access to antiretroviral therapy and post-exposure prophylaxis, persons with disabilities may be considered a low priority for treatment.[17] Where persons with disabilities are receiving HIV treatment, health professionals may not pay enough attention to potentially negative drug interactions between HIV treatment and the medications that persons with disabilities are taking. Some medications may actually worsen the health status of persons with mental health conditions, including depression.[18]

Parents with disabilities may experience multiple prejudices when they are also HIV-positive, because, for example, family members disapprove of their being sexually active.[19] This means they may not have help planning their children's future (e.g. by establishing custody or inheritance arrangements) and dealing with their own declining health status.

It has been estimated that 4–5% of children who have lost one or both parents to AIDS also have disabilities.[20] They may require additional help with daily activities or have extra medical, educational or rehabilitation needs, but are often accorded lesser priority in an already overstretched household.[21] Furthermore, children with disabilities who are also HIV-positive are also more likely to experience exclusion and discrimination in all areas, particularly in the field of education.

Rehabilitation for People Living with HIV

The increasing availability of antiretroviral therapy means many people living with HIV live longer. Some of these people experience activity limitations or participation restrictions as a result of progress of the disease or side effects of treatment.[22] This may be on a temporary, episodic or permanent basis.

Health-related rehabilitation is increasingly important in the continuum of HIV care and can slow deterioration of the individual's condition and enable the person to achieve and maintain independence. This involves assisting those living with HIV in self-care and other day-to-day activities that can minimize the impact of the virus on their health. Rehabilitation professionals play a key

[17] Groce, N. et al (2004) *HIV/AIDS and Disability: Capturing Hidden Voices* World Bank, Washington DC.

[18] Catalan, J. et al (2005) *Mental Health and HIV/AIDS: Psychotherapeutic Interventions in Antiretroviral (ARV) Therapy for second level care* WHO, Johannesburg, South Africa.

[19] Carbone, D. (1997) Uphill struggles: mentally handicapped and HIV-positive The Body 10(5). http://www.thebody.com/bp/may97/mental.html.

[20] UNICEF (2002) *Care and Support for Orphans made vulnerable by HIV* UNICEF New York.

[21] Groce, N. et al (2004) *HIV/AIDS and Disability: Capturing Hidden Voices* World Bank, Washington DC.

[22] Rusch, M. et al (2004). Impairments, activity limitations and participation restrictions : prevalence and associations among persons living with HIV/AIDS in British Columbia. *Health Qual Life Outcomes* 2:46., O'Dell MW. Rehabilitation medicine consultation in persons hospitalized with AIDS. An analysis of thirty cases. *Am J Phys Med Rehabil.*1993 Apr;72(2):90-6.

role in accurately assessing and addressing the complex impairments people living with HIV may experience.[23]

Vocational rehabilitation, income support and other benefits also help a person with an HIV-related disability to maintain a healthy and productive lifestyle.[24] Service models for people with disabilities such as community-based rehabilitation, personal assistance schemes and other independent living services are often appropriate or can be adapted for people living with HIV.[25]

Policy Position

The 2006 *Convention on the Rights of Persons with Disabilities* commits State Parties to:

> *"provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other people, including in the area of sexual and reproductive health and population-based programmes"* (Article 25)

and to

> *"take appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life"* (Article 26).

Persons with disabilities have the right to participate in decisions which affect their lives, and should be fully involved in the design, implementation and evaluation of HIV policies and programmes.[26] This is the best way of ensuring these policies and programmes are responsive to the needs of persons with disabilities.

HIV services themselves must be inclusive of persons with disabilities. Eliminating physical, information and communication, economic and attitudinal barriers not only increases access to HIV programmes, but may assist people in accessing broader health and social services. These services are essential to fulfilling the right of persons with disabilities to the highest attainable standard of physical and mental health.[27]

Recommendations

Actions for Governments

- Ratify and incorporate into national law instruments that protect and promote the human rights of persons with disabilities, including the *Convention on the Rights of Persons with Disabilities*.[28]
- Incorporate the human rights and needs of persons with disabilities into national HIV strategic plans and policies.

[23] Philippes, A et al (1998). *Rehabilitation services : A comprehensive guide for the care of persons with HIV disease*. Toronto, Canada: Wellesley Central Hospital.

[24] Ogden, R., *Policy Issues on Rehabilitation in the Context of HIV Disease: a Background and Position Paper* (the Canadian Working Group on HIV and Rehabilitation, CWGHR), (2000) Toronto, Canada, Cross, S. et al. (2000) *Strategies to address the barriers to and gaps in the implementation of HIV/AIDS content in the curricula of under-graduate physical therapy programmes in Canada*, University of Toronto, Department of Physical Therapy, Course Requirement Module.

[25] See e.g. Nganwa A et al (2001) "HIV/AIDS and Community Based Rehabilitation" in Hartley S (ed) *CBR: a participatory strategy in Africa* http://www.asksource.info/cbr-hartley.htm.

[26] 2006 *Convention on the Rights of Persons with Disabilities* Article 4(3).

[27] 1966 *International Covenant on Economic, Social and Cultural Rights* Article 12. General Comment 14 on the right to the highest attainable standard of health (E/C.12/2000/4).

[28] See also UNAIDS and OHCHR (2006) *International Guidelines on HIV and Human Rights* UNAIDS Geneva and ILO (2001) *An ILO Code of Practice on HIV/AIDS and the World of Work* ILO, Geneva.

- Include HIV as prohibited grounds for discrimination in national legislation.
- Prohibit all forms of discrimination against persons with disabilities which may hinder access to:
  - social security, health and life insurance, where such benefits are mandated by national law; and
  - health services such as sexual or reproductive health education and services, measures for the prevention of mother-to-child transmission, and post-exposure prophylaxis for victims of sexual assault.
- Establish age-, gender-, culture- and language-appropriate HIV prevention programmes and provide HIV information in tailored formats for people from different disability groups.
- Develop appropriate programmes and mechanisms to prevent sexual assault or abuse of persons with disabilities focusing on those settings which place persons with disabilities at greatest risk e.g. specialized institutions, schools or hospitals.
- Provide comprehensive HIV testing, treatment, care and support services which:
  - adhere fully to ethical principles such as confidentiality and the need for free and informed consent; and
  - include early intervention and referral to rehabilitation and support services for people experiencing activity limitations or participation restrictions as a result of their HIV infection.
- Provide persons with disabilities with the same range and quality of affordable HIV, sexual and reproductive health services as the rest of the population by:
  - adapting mainstream services for persons with disabilities or if appropriate implementing disability-specific services;
  - providing support and reasonable accommodation; [29]
  - accounting for all persons with disabilities, irrespective of the related impairment, and eliminating all barriers in accessing services; and
  - supporting empowerment and capacity-building of people with disabilities to take part in all relevant processes, including decision-making processes.
- Ensure the national AIDS monitoring and evaluation system has the necessary resources to evaluate the response to the HIV epidemic within the context of disability, and the HIV needs and rights of persons with disabilities.
- Involve persons with disabilities in the planning, implementation and evaluation of HIV programmes.
- Include training on the rights of persons with disabilities for professionals working in the area of HIV, by persons with disabilities, including those that are HIV-positive.
- Integrate HIV education into training for rehabilitation professionals.
- Ensure that persons with disabilities are appropriately supported to train and engage in HIV counselling and care provision.
- Provide adequate training and support for personal assistants or people who support persons with disabilities in households affected by HIV.

[29] "Reasonable accommodation" is defined by the Convention on the Rights of Persons with Disabilities 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 of all human rights and fundamental freedoms".

Actions for Civil Society

- Increase networking and information exchange between HIV and disability service, disability advocacy and human rights organizations.
- Ensure disability services, such as support for independent living, are available to people living with HIV.
- Advocate for persons with disabilities to have full sexual and reproductive rights, and freedom from physical and sexual abuse.
- Advocate for persons with disabilities to be included in the planning, implementation and evaluation of HIV programmes.
- Ensure campaigns to combat stigma and discrimination of persons who are HIV-positive are accessible to persons with disabilities.

Actions for International Agencies in Partnership with Governments and Civil Society

- Ensure HIV policies, guidelines and programmes are designed and implemented to be accessible to all persons with disabilities, and make it mandatory that all HIV programmes incorporate access to information, support and services for persons with disabilities.
- Develop, validate and support the use of impairment-specific and disaggregated indicators in the national AIDS monitoring and evaluation system.
- Promote and fund research on HIV and disability, ensuring that persons with disabilities are included on the research team designing, implementing and analysing the research.

Policy and Practice - an example from South Africa

A policymaker from the South African Parliament, Hon. Hendrietta Ipeleng Bogopane-Zulu, reflects on what has worked in making the national HIV policy and programmes inclusive of persons with disabilities.

South Africa first included disabled people in the National AIDS Strategic Plan (NSP) in 2007–2011. The 2000–2005 Plan acknowledged disabled people but was not explicit or clear. What promoted the recognition was a combination of leadership from champions within Government, the strong organization of the disability sector and self-representation in the South African National AIDS Council.

Today, while South Africa's policy legislation and AIDS programming is highly inclusive of disabled people, the challenge is implementation although real efforts in terms of access and participation are under way. For example, disability issues are included in the South Africa *HIV Treatment Guidelines* in light of the increasing number of disabled people in need of HIV medical care. The Government has also undergone the process of *accreditation of disability organizations* to increase access to treatment. Today *counsellors with disabilities* are placed in voluntary testing centres to counsel both disabled and non-disabled clients and free HIV testing is encouraged at disability meetings. In order to improve access to information and services for deaf people, sign language interpreters are being trained in matters related to HIV in recognition of the real limitations of sign language to communicate key messages effectively. These trained sign interpreters are being assigned to HIV clinics in many urban areas.

In terms of *advocacy and communication*, disabilities and vulnerability to the impact of HIV are part of the broader media campaign in South Africa. The South African National AIDS Council also makes available to disability groups resources for ongoing HIV awareness through seminars, training, dialogue and "Indabas".

Monitoring and evaluation is still a major challenge. The Government of South Africa has set disability-specific targets within the broader AIDS monitoring and evaluation framework for the country. Data collected will be measured against pre-defined targets so that Government will not be in a position to ignore the evidence.

While this all seems like a lot, much still needs to be done.

People living with HIV are not classified as "disabled" people in South Africa. This is in part due to the refusal of disabled people to be seen as "sick", which is implied by HIV infection. There is common ground when it comes to the stigma and discrimination faced by both groups, and in South Africa both disabled people and people living with HIV can benefit from the Disability Grant, a social security cash transfer. Unfortunately, the high numbers of people claiming the Disability Grant pushed the budgetary envelope to unaffordable heights. Disabled people have since lobbied for a "chronic illness grant" as this grant will distinguish between people with pre-existing disabilities and people who also need chronic medical care. Finally, we all know that HIV infection can cause temporary or permanent loss of function. This implies that the rehabilitation sector must be equipped to address not only pre-existing disabilities but also impairment related to HIV.

I believe firmly that disabled people are part of society. What happens in their communities affects them as well. Weak recognition of disability rights by Government becomes a danger when lack of information contributes to continued HIV risk behaviour among disabled people. A lot has been learned in South Africa over the past 25 years about the impact of the AIDS epidemic on the lives of disabled people. We have learned that we cannot meet the objectives of our National AIDS Strategic Plan without addressing the needs of disabled people. We have learned that there are unintended consequences of disability and/or AIDS policy due to HIV being a changing and evolving virus. We have also learned that it is only through involving disabled people themselves in their diversity that we will be successful in addressing HIV and AIDS in our country.