Disability Inclusion: HIV/AIDS

The facts

- People with a disability have equal or greater vulnerability to all known risk factors for human immunodeficiency virus (HIV) infection.[1]

- People with a disability are as sexually active as those without a disability and rates of homosexuality and bisexuality are comparable to the general population.

- Women and children with a disability are more likely than others to be victims of violence or rape, yet are less likely to obtain police interventions, legal protection or prophylactic care.[2]

- People with a disability do not have equal access to HIV information, education and prevention services.[3]

Reasons for disability inclusion in HIV/AIDS programs

- People with a disability are frequently turned away from testing or treatment services due to false assumptions about people with a disability not being at risk of contracting HIV or acquired immunodeficiency syndrome (AIDS).

- Once infected, people with a disability are likely to have reduced support due to factors such as limited access to health care, poor nutrition, social isolation and low levels of income and assets.

- HIV/AIDS can be a cause of temporary or permanent disability, particularly when people do not have access to appropriate health care and antiretroviral medication.

- People with a disability may be unable to access accurate information about HIV/AIDS in an appropriate format such as Braille or plain language.

- Health centres, clinics and other locations can be physically inaccessible which inhibit access to HIV/AIDS information and treatment for people with a disability.

How to include people with a disability in HIV/AIDS programs

The field of HIV/AIDS and disability is rapidly developing, but the majority of HIV/AIDS programs and programmers would still benefit from training, resources and commitment to ensure their activities are disability-inclusive.[4] Pilot programs in countries in Africa, Asia and the Americas have shown that it is

possible to successfully include people with a disability in HIV/AIDS prevention, treatment and care programs.[5]

The following principles, which adhere to a human-rights approach to disability, are used to demonstrate inclusion of people with a disability in all development programs and sectors.

Awareness of disability and its implications
Participation and active involvement of people with a disability
Comprehensive accessibility through addressing physical, communication, policy and attitudinal barriers
Twin track identifying disability specific actions combined with mainstream approaches

---

Awareness
- Identify the number of people with a disability within the community. This information can be gathered, for example, through meeting local people with a disability and DPOs, census data, household surveys, Community-Based Rehabilitation (CBR) and disability services and facilities for inclusive education.

- Ensure billboards, posters, brochures or other information relating to HIV/AIDS depict people with a disability as part of the general population.[6]

- Ensure program staff are aware of HIV/AIDS incidence and risk factors for people with a disability.

- Work with Disabled Peoples Organisations for awareness raising and information on HIV/AIDS risk factors for people with a disability.

- Collaborate with disability service providers including Community-Based Rehabilitation (CBR) staff and community health workers to understand how HIV/AIDS impacts the lives of people with a disability.

Participation
- Advocate for the inclusion of people with a disability into all HIV/AIDS programs.

- Ensure people with a disability are able to contribute to and participate in information and training sessions.

- Allocate a budget to cover travel and participation expenses along with attendance time for people with a disability and DPOs to actively be involved in consultations.

- Employ or contract people with a disability or a DPO to be active in all phases of HIV/AIDS programs.

- Consult widely with a range of stakeholders including women, men and children from different disability groups.

- Consider capacity-building activities for DPO members on HIV/AIDS work, advocacy, program management or other relevant skill areas.

- Use people with a disability through a DPO to conduct disability awareness training within HIV/AIDS programs.

Comprehensive accessibility

Comprehensive accessibility = physical, communication, policy and attitudinal access

- Hold consultations and other meetings in physically accessible venues.

- Identify the preferred communication mode for individuals with a disability. Note that not all people who are blind will have been taught Braille, likewise, not all individuals who are Deaf or hard of hearing will have sign language skills.

- Be prepared to source alternative communication options including large print, Braille, pictorial, audio and sign language based on individual requirements. These may be arranged through local partners, inclusive education services, CBR and disability organisations.

- Ensure health/HIV/AIDS clinics are accessible for people with a disability.

- Ensure HIV/AIDS service policies reflect disability-inclusive practices and access rights.

- Advocate for laws and policies to reflect the rights of people with a disability including in the justice system when reporting sexual assault.

- Challenge negative and incorrect attitudes about people with a disability not being at risk of contracting HIV/AIDS.

- Dispel myths such as curses which can be inaccurately perceived as causes of disability.

- Dispel the myth of 'virgin cleansing'[7]. This myth carries the belief that having sex with a virgin can cure HIV/AIDS. As people with a disability are often thought to be sexually inactive, there is a risk they will be the targets of sexual assault and therefore also more likely to contract HIV and other sexually transmitted diseases.

Twin track

Twin track enables full inclusion through mainstream access working alongside disability specific supports

Mainstream	Disability specific
Include people with a disability in mainstream community education programs.	Incorporate HIV/AIDS education into existing disability-focused programs.
Educate staff within mainstream HIV/AIDS programs on disability inclusion strategies in regard to communication, attitudes and accessibility.	Identify and promote HIV/AIDS programs for people with a disability that have worked well in the past.
Advocate to ensure people with a disability are included in all HIV/AIDS programs.	Build up capacity of DPOs to deliver HIV/AIDS training to their members and to mainstream programs.
Advocate for laws and policies to reflect the rights of people with a disability, including in safety and protection measures.	Support DPOs in advocating for the rights of people with a disability in regard to HIV/AIDS policy and programs.
Work with DPOs in advocacy for rights in policy and service inclusion in HIV/AIDS programs.	Ensure information is converted into accessible formats for people with a disability.
Collect data on disability types, age and gender in mainstream HIV/AIDS programs.	Identify people with a disability to dispel myths about HIV/AIDS in promotional and education activities.
Employ staff with a disability within mainstream programs.	

Case study: The 'Inclusion for All' Project

World Vision India

World Vision India implemented the three-year *Inclusion for All* project (2009–2011), with a dual goal of generating awareness of HIV and AIDS among people with a disability and increasing inclusion of people with a disability within other existing development projects and the wider community.

Multi-sectoral Area Development Programs (ADPs) that included projects responding to HIV and AIDS had been running in the three locations targeted by this project, but an evaluation of one of the ADPs found that the impact of these HIV and AIDS projects had not reached people with a disability living in the target communities. The *Inclusion for All* project was developed to address this gap.

The *Inclusion for All* project evaluation demonstrated:

- increased awareness of HIV and AIDS among people with a disability
- increased awareness of disability rights and support services among people with a disability and the broader community
- significant positive attitudinal change toward disability – both from people with a disability themselves and from the broader community.

The outcome areas of the project included: raising inclusion-awareness and capacity among Community-Based Organisations (CBOs); increasing accessibility of HIV and AIDS programs for people with a disability; increasing inclusion of children and adults with a disability in education and livelihood opportunities; and influencing district and state level HIV and policy and programs to become more inclusive.

Raising awareness of disability rights and inclusion among CBOs was a very effective approach, which led to significantly increased representation of people with a disability as members, office bearers and leaders among CBOs and self-help groups. In the project evaluation, the majority of respondents from all stakeholder groups felt strongly that the level of confidence, esteem, self-worth, respect and dignity of people with a disability had been significantly enhanced through the implementation of this project.

Implementing the *Inclusion for All* project brought a greater focus on disability and inclusion to programming within WV India, leading to development of organisational strategy and revision of a range of guidelines covering sponsorship, construction of infrastructure and staff recruitment.

Lessons learned

Although greater awareness of HIV and AIDS was generated among people with a disability through this project, the evaluation found that knowledge regarding the link between disability and HIV and AIDS was still weak. It's not clear from the evaluation why this was so, but this area clearly needs more attention.

The impact of the project among people with a disability was influenced by the person's gender and impairment type. Generally there was less participation from girls and women with a disability, and less project impact for people with an intellectual disability, psychosocial disability and/or a multiple or profound disability.. From the evaluation report, project staff felt they lacked capacity and technical skills needed to address the double disadvantage of gender and disability and higher support needs of some project participants.

More knowledge and skills are needed in the area of legislation, policies, human rights instruments and frameworks among all stakeholders including DPO representatives and World Vision staff.

In some cases livelihood support extended to people with a disability was misused by family members who ignored and/or excluded the person from managing this support themselves. Clearer targeting and training of selected families needs to occur before providing livelihood support.

Checklist for disability inclusion in HIV/AIDS programs

☐ Is data being collected regarding the needs and priorities of people with a disability during planning and throughout the entire program cycle?

☐ Has awareness-raising on dispelling myths on HIV/AIDS and disability been delivered?

☐ Have HIV/AIDS health staff been trained in communicating with people with a disability?

☐ Is there budget allocation to cover participation expenses and attendance time for consultations with people with a disability and DPOs?

☐ Are people with a disability employed within the program?

☐ Are DPOs being engaged with for consultation in all phases of HIV/AIDS programs?

☐ Have people with a disability been identified within DPOs for targeted capacity building on HIV/AIDS awareness so as to deliver training to DPO members?

☐ Is data on disability type, age and gender being collected in HIV/AIDS programs?

☐ Is promotional and educational material available in accessible formats such as large print, Braille, plain language, pictorial and audio formats?

☐ Are meetings being held in accessible venues?

☐ Are alternative communication options available for HIV/AIDS services based on individual requirements?

☐ Is transport made available for people with a disability to access HIV/AIDS services?

☐ Are financial barriers for people with a disability being addressed, including in access to medication?

☐ Are the lived experiences of people with a disability being shared in awareness raising and training?

☐ Are statistics on disability and HIV/AIDS being used in advocacy efforts?

☐ Are justice systems representing the rights of people with a disability?

☐ Are program outcomes and impacts for people with a disability being measured?

Useful resources for disability inclusion in HIV/AIDS programs

Resource Manual for Disability and HIV/AIDS Training. (2005). Disabled People South Africa:
http://www.miusa.org/idd/resources/files/hivaidsresources/dpsaresourcedahiv/view

HIV & AIDS 'Train the Trainers' Manual. (2007). African Union of the Blind:
http://www.miusa.org/idd/resources/files/hivaidsresources/hivtrainmanual/at_download/file

Morrow, M., Arunkumar, M.C., Pearce, E., & Dawson, H.E. (2007). 'Fostering disability-inclusive HIV/AIDS programs in northeast India: A participatory study.' *BMC Public Health*, 7: 125:
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1924853/

References

1 World Bank. (2004). *Disability and HIV/AIDS at a Glance* [Fact sheet]. Retrieved from http://v1.dpi.org/files/uploads/publications/factsheet.pdf

2 Groce, N. & Trasi, R. (2004). 'Rape of individuals with disability: AIDS and the folk belief of virgin cleansing*.' The Lancet*, 363, pp. 1663–1664.

3 UNAIDS, United Nations Office of the High Commission for Human Rights, WHO. (2009). *Disability and HIV Policy Brief*. Retrieved from http://www.who.int/disabilities/jc1632_policy_brief_disability_en.pdf

4 Interagency Coalition on AIDS and Development. (2008). *HIV, AIDS and Disability*. Retrieved from http://www.icad-cisd.com/index.php?option=com_content&view=article&id=60&Itemid=73&lang=en

5 World Bank. (2004). *Disability and HIV/AIDS at a Glance* [Fact sheet]. Retrieved from http://v1.dpi.org/files/uploads/publications/factsheet.pdf

6 World Bank. (2004). *Disability and HIV/AIDS at a Glance* [Fact sheet]. Retrieved from http://v1.dpi.org/files/uploads/publications/factsheet.pdf

7 Groce, N., Trasi, R. (2004). 'Rape of Individuals with Disability: AIDS and the Folk Belief of Virgin Cleansing'. *The Lancet* 363(9422), 1663-1664.