Mobilising ability: working with HIV, AIDS and disability in Zambia

Authors: Dr Terri Collins, Dr Alex Simwanza and Mr Mwilu Mumbi in consultation with the Forum on HIV and AIDS for Persons with Disabilities, Zambia

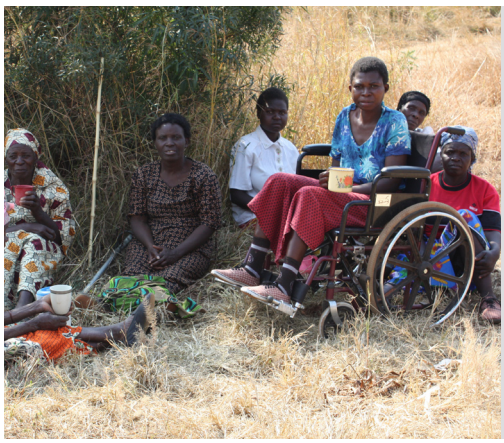

Image: Members of Nadezwe Disabled Cooperative Society Mazabuka District, Southern Province

STARZ in context

The Strengthening the AIDS Response Zambia (STARZ) programme provided technical support to NAC Zambia from May 2004 until August 2009. This has included support for improved participation of civil society and the private sector in the national multisectoral response to HIV and AIDS. The STARZ programme was funded by the UK's Department for International Development (DFID), with technical assistance supplied by HLSP in partnership with JHU-CCP, HDA and PMTC(Z) Ltd.

Introduction

A recent UN Policy Brief on Disability and HIV (UNAIDS et al. 2009) has made the case for greater inclusion of persons with disabilities (PWD) in national responses to HIV and AIDS. Despite a growing body of evidence to suggest that PWD are at risk of HIV infection and vulnerable to its impact (see, for example, World Bank/Yale University 2004), there has been relatively little documentation of how, in practice, National AIDS Coordinating Authorities can support the inclusion of PWD in national programmes and ensure that their specific needs are met.

In Zambia, PWD have been strong advocates for their inclusion in HIV and AIDS programmes. Citing evidence from international literature, as well as information and testimonies gathered locally, they have argued that they should be explicitly included as a vulnerable group in national HIV strategic plans and policy statements.

Some facts about disability and HIV

- Available data on HIV prevalence among PWD suggest that, in many countries, infection levels are equal to or higher than those of the rest of the population.
- A disproportionately large percentage of PWD will experience sexual assault or abuse during their lifetime, with women, girls and those in institutions being especially at risk.
- Children with disabilities account for one third of the 72 million children out of school in the world and are, thereby, excluded from the vital sexual and reproductive health education provided in these settings.
- Low literacy levels and a lack of HIV prevention information in accessible formats (e.g. Braille) make it more difficult for PWD to acquire the information they need to protect themselves.
- Even when knowledge of HIV is high, PWD can face particular difficulties in accessing appropriate HIV testing, counselling and treatment services.
- People living with HIV (PLHIV) who acquire disabilities associated with the disease are protected by the 2008 Convention on the Rights of Persons with Disabilities.

Source *UNAIDS et al. 2009*

They have also argued (and demonstrated) that they are a group that can mobilise multiple *abilities* to address the HIV epidemic at individual, community and national levels.

This paper describes how the STARZ programme has worked with the National HIV/AIDS, STI, TB Council (NAC) in Zambia to strengthen partnerships with Disabled People's Organisations (DPOs). It also describes how efforts have been made to address the specific concerns of PWD relating to HIV, and ensure their interests are reflected in national strategic plans and the deliberations of the NAC.

The working model complements the "capacity development approach" described in an earlier technical approach paper (Mundy et al. 2008) and is intended to assist practitioners in better defining the desired outcomes of work with civil society and applying concepts such as consultation, participation and involvement.

The challenge of disability and HIV in Zambia

Zambia is currently experiencing a generalised HIV epidemic. The national prevalence rate among adults is 14.3%, with heterosexual sex and mother-to-child transmission being the principal modes of infection. Prevalence varies significantly by age, sex and geographical area, with the highest prevalence rates being found among young women aged 15-24 years, and those living in urban areas and along major transport routes. In accordance with the principles of the "Three Ones", the NAC has been legally mandated to coordinate and provide leadership for the national response to HIV through adherence to a single strategic plan (currently the National HIV and AIDS Strategic Framework (NASF), 2006-10) and a single monitoring and evaluation plan.

The targeting of vulnerable groups or "populations at higher risk of HIV infection or vulnerable to its impact" (UNAIDS 2007) has been central to successive national HIV strategies in Zambia. Yet, until recently, PWD were rarely considered as a vulnerable group because it was incorrectly assumed they were not sexually active, or exposed to sexual violence and substance abuse (Rule et al. 2008, World Bank/Yale University 2004).

There has also been little attention to the fact that PLHIV may develop impairments that lead to disability (UNAIDS et al. 2009).[1] What is more, HIV positive parents with disabilities may experience multiple prejudices, while HIV positive children with disabilities are more likely to experience exclusion and discrimination in all areas, especially in education (ibid).

> "It is related to the belief that people with disabilities have less sex and are HIV-free. Some able-bodied people believe they can sleep with them without protection."
>
> Source *Rule et al 2008*

> "Men don't normally want to be in a long-term relationship with a disabled woman. They leave her with the children. One way of raising money is to go into a relationship with a man. It is a common trend among women with disabilities – raising money through sexual relations with men. As a result, many die of HIV/AIDS."
>
> Source *Rule et al 2008*

[1] Here disability is defined as "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, 2007 Convention of the Rights of Persons with Disabilities)

It is estimated that 650 million people, or an estimated 10% of the world's population have a disability (ibid). There is, however, little reliable data on the number of PWD in Zambia. Estimates range from just over 300,000 to 2 million, depending on the definitions used.[2]

In Zambia, disability sub-groups are generally identified as the deaf and hard-of-hearing, the blind and visually-impaired, people with physical disabilities and people with intellectual impairments (or "mental health users"). There are numerous civil society groups and DPOs working with PWD. Most specialise in work with particular types of disability, but a growing number work on cross-cutting issues such as HIV and AIDS, human rights, gender and support for parents of children with disability. There are a small number of umbrella organisations (such as ZAFOD, the Zambian Federation of Disability Organisations) that offer technical, capacity building and resource centre support, as well as funding for income generation activities (IGA). Nearly all DPOs are based in urban centres and rural outreach is weak.

Government support for PWD is overseen by the Ministry of Community Development and Social Services (MCDSS), with responsibility for services relating to welfare, rehabilitation, registration and regulation being delegated to the Zambia Agency for Persons with Disabilities (ZAPD). Unfortunately, ZAPD is widely perceived as being under-funded and under-staffed, a situation which, it is argued, reflects the marginalisation of PWD in Zambian society (Rule et al 2008).

The response of the National HIV/AIDS, STI, TB Council (NAC)

In recent years, PWD have become an increasingly vocal advocacy group in Zambia, especially in the field of HIV and AIDS. As the NAC began to develop a more systematic approach to its work with civil society,[3] it emerged that partnerships with DPOs needed to be addressed. As a first step, a stakeholder workshop was convened to review shared issues and reach consensus on the way forward. The key issues identified were largely consistent with the available literature (see, for example, World Bank/ Yale University 2004 and Rule et al 2008) and included issues of social isolation, multiple stigma and discrimination, sexual exploitation and dependent relationships, as well as lack of accessible and appropriate HIV services and information. It was also apparent that women and children with disabilities are most acutely affected[4].

> "Since the deaf community is small, all deaf men know that I'm not worth loving because I'm a 'death trap'. There is a lot of discrimination from deaf men against me. That's why many [deaf] women don't want to disclose their status."
>
> Source *Rule et al 2008*

The workshop emphasised the need to differentiate different types of disability in the context of HIV. For example, access to information and counselling are crucial barriers for the blind and deaf, but physical access to service sites and appropriate transport are important factors for the physically impaired.

A number of organisational issues were also identified. These included lack of knowledge and skills within DPOs to address issues of HIV among their membership, as well as lack of resources for developing

---

[2] The Zambia's Persons with Disabilities Act No 33 of 1996 defines disability in terms of personal impairment and deviation from "the range considered normal for a human being". However, within the NGO sector, disability is regarded more as a human rights issue or social phenomenon that extends beyond medical definitions (Rule et al. 2008).

[3] See Mundy et al. 2008 for a more detailed description of how the STARZ Programme supported development of this more systematic approach.

[4] This observation is supported by Sobsey & Doe 1991.

HIV programmes and evidence-based advocacy campaigns. It was also suggested that DPOs were poorly coordinated, and did not share information, work collaboratively or undertake joint planning.

During the stakeholder workshop, it was agreed that NAC should work with national DPOs to systematically address the issues and challenges raised. Drawing on resources made available through the STARZ programme, technical assistance was secured to assist DPOs in identifying "possible solutions" to inform programme design and advocacy. Table 1 below provides an illustration of the approach developed.

Table 1: Developing solutions to address issues identified by PWD – selected examples

DISABILITY TYPE	ISSUE	POSSIBLE SOLUTIONS
Visual impairment	Can't read small print in leaflets	Large font in printed material
	Can't read instructions on condom packets	Large font generic leaflet on condom use
	Can't read expiry dates on a condom packet	Large print or Braille date
	Difficulty in accessing health clinics	Larger signs
Total deafness	Unsympathetic health providers	Training and sensitisation for all staff
	Unable to access radio, TV, drama and other spoken media	• Clear printed material • Signers on TV programmes and videos related to HIV
	Difficulty in understanding health workers	• Sensitisation of health workers • Signers available in health centres and clinics by arrangement
	Difficulty in negotiating safer sex with a hearing partner	Assertiveness sessions related to sexuality issues
Physical disability	Access to health services and clinics is difficult	• Peripatetic services (outreach and mobile) • Hand rails, ramps, and toilets for PWD installed in health centres and clinics
	Difficulty with achieving comfortable sexual positions & sexual satisfaction	Sexual counselling
	Difficulty in manipulating condoms and condom packages	Assertiveness training to request help
	Vulnerability if coerced or forced into unwanted sex	Personal rape alarm provided
	Lack of confidence in asking for help	Assertiveness sessions related to sexuality issues
Mental disability or Learning impairment	Inability to understand complex messages about sex and safer sex	Specially created simplified materials on safer sex and reproductive health
	Less likely to be able to ask for safer sex	Assertiveness sessions
	Lack of self esteem & self awareness	• Individual counselling and group sessions with role plays, videos and safe games • Help for parents
	Inability to recognise dangerous situations	
	Less likely to be able to access and use condoms	Training in asking for and using condoms

In addition NAC, working in partnership with STARZ programme and PWD themselves, undertook the following activities:

Establishment of a DPO Forum on HIV and AIDS. This Forum meets quarterly to support DPO self-coordination. NAC provides technical and financial inputs, while ZAPD provides secretariat support. The focus of the meetings is on sharing information, building partnerships, skills exchange, electing representatives, development of advocacy initiatives, accessing resources, problem-solving and sharing of best practice.

> "The family members are the first to discriminate. As a result you enter into self-denial. Instead of dying [of AIDS] next year you die this year because you can't share."
>
> Source *Rule et al 2008*

Ensuring PWD participation in national HIV planning, reviews, proposals and policy dialogue. This activity has included consultation with PWD on development of the NASF, Joint Annual Programme and Mid-Term Reviews, development of national guidelines, UNGASS[5] reporting and development of Global Fund proposals.

Support for election of PWD representatives for participation in NAC structures. This activity has focused on transparent election of PWD representatives from each disability sub-group to participate in selected NAC structures such as Theme Groups, the Sector Advisory Group and the Partnership Forum (see also Mundy et al. 2008 for a account of how this activity was situated within a "capacity development approach").

Provision of technical support for DPOs and ZAPD. This activity has focused on providing information, tools and capacity building support, especially in relation to HIV planning, mainstreaming, research/data collection, advocacy and outreach at decentralised levels. Partnerships have also been built with international NGOs for the provision of ongoing technical support to DPOs and ZAPD.

Support for resource mobilisation. This activity has included development of a Directory of Funding Sources, advocacy on behalf of DPOs, as well as regular DPO updates on the changing resource environment. The STARZ administration of the DFID Civil Society Fund also made provision for targeting of resources to DPOs undertaking HIV activities.

> "Here in Zambia, professional jobs for blind people are only begging and teaching. If you don't go to school, you will go straight to the streets."
>
> Source *Rule et al 2008*

Development of relevant IEC materials. Technical assistance was recruited through the STARZ Programme to work with DPOs to produce two booklets that now form supplements to the NAC Communication Strategy. The first booklet entitled *Disabilities and HIV: An Urgent Call to Action* provides guidance to service providers on how to make HIV services more accessible, appropriate and user-friendly for PWD. The second booklet entitled *Disabilities and HIV: Guidelines for HIV and AIDS Educational Resources* provides information on how to make HIV IEC materials relevant to PWD. Both booklets are available through the NAC Zambia Resource Centre and website, **www.nac.org.zm**.

Regular dissemination of information. Information updates on the national response, new initiatives and opportunities are regularly communicated to DPOs, not only through Forum meetings, but also through emailing groups and regular civil society consultation meetings. Key documents relating to the national response have also been made available in Braille.

---

[5] United Nations General Assembly Special Session (on HIV and AIDS) – NAC Zambia is responsible for facilitating compilation of national reports for submission to bi-annual UNGASS meetings.

The Results

Although national information systems are not yet sufficiently disaggregated to provide data on HIV and PWD, successive annual reviews indicate that progressively more attention is being paid to PWD. Moreover, qualitative information on PWD participation is now a feature of many national reports. In addition:

- PWD are now explicitly referenced in the NASF (2006-2010) and Zambia's Fifth National Development Plan (FNDP).
- The Mid-Term Review of the NASF (2006-2010) and the STARZ programme indicated that there have been positive gains in partnerships with PWD and their engagement in the national response to HIV and AIDS. Feedback from DPOs indicated perceived improvements in information exchange, capacity development and mutual accountability.
- Minutes of PWD Forum meetings suggest improved self-coordination among key actors: meetings are being convened regularly and are contributing to shared objectives, such as establishment of collaborative networks and referral mechanisms; PWD are preparing and chairing meetings themselves and ZAPD is providing secretariat support.
- A Task Team of the PWD Forum undertook a review of NAC to access physical, social and information accessibility. The findings and recommendations of the assessment are now under consideration by the Council.
- Elected PWD representatives are now actively participating in selected NAC structures and are using the Forum as a mechanism for consultation and feedback.
- A number of DPOs (such as ZAFOD, Zambia Deaf Vision (ZDV), the Mental Health Users Network of Zambia (MHUNZA) and the Zambia Disability HIV/AIDS Human Rights Programme (ZAMDHARP)) have produced impressive situation analyses and reports on how HIV affects their membership. Some organisations, such as ZAFOD, have incorporated strategies for action on HIV and AIDS into their planning.
- Resource tracking reports indicate that, since 2005, more DPOs are receiving funding for HIV and AIDS activities. Several DPOs are using these resources to work with health care providers to improve service delivery for PWD. A best practice study on how STARZ funding has supported the activities of ZAFOD in relation to HIV is now available through the DFID website.

Lessons learned

- The progressive involvement of DPOs in the national response to HIV and AIDS is testimony to the power of advocacy. It is also clear that active engagement of DPOs can lead to positive contributions to the national response.
- Work with PWD is most successful when it focuses on empowerment and building on the abilities of PWD. Sustainability is best supported by working with existing PWD structures (including those associated with government) and DPOs.
- It is important to recognise that PWD are not a homogeneous group. There are different issues and experiences associated with different disability types. Moreover, distinctions that apply to the general population (such as gender and age) can be particularly significant in designing effective HIV responses for PWD. This underscores the need for equitable representation from disability groups and allowing PWD to articulate the nuances of their own experience.
- Experience in Zambia has shown that involvement of PWD in the national HIV response requires active engagement and commitment to a dynamic process. This will involve joint planning, mobilisation and allocation of resources for implementation, participation in data collection and M&E, and mutual accountability for deliverables. Tokenistic inclusion of PWD in meetings is insufficient.
- There is an ongoing need to educate policy makers, planners, service providers and communities on the role of PWD in the national response to HIV. PWD and their organisations can play an important role in raising awareness and providing training on effective communication.
- There is a need to actively document and critically evaluate work with PWD to support progressive improvements in programme design for involvement of PWD in responses to HIV.

The Results

- Although significant progress has been made in working with PWD at the national level in Zambia, there is a need to extend successful initiatives to decentralised levels.
- There remains an ongoing need for capacity development programmes to build the skills of PWD representatives and DPOs to enable them to better participate in the national response to HIV and AIDS.
- There is an urgent need to make resources available to strengthen service delivery to PWD. Service providers need training in the needs of PWD and effective communication strategies. PWD themselves need to be mobilised and trained to support improved service delivery (such as counselling, behaviour change communication and treatment support).
- There is a need for more resources to be dedicated to production of IEC materials that are tailored to the needs of PWD in general, and the needs of particular disability groups in particular.
- Further local research is required on the specific needs of parents and children in relation to HIV, including identification of practical strategies to address these needs.
- There is a need for strengthened M&E systems to monitor PWD as a vulnerable group, and assess the effectiveness of interventions to address their needs in relation to HIV.

Conclusion

People with disabilities have an increased vulnerability to HIV and AIDS. Advocacy by PWD in Zambia has led to a growing recognition that PWD constitute a vulnerable group. The Civil Society Unit of NAC Zambia has demonstrated that, with appropriate technical support, systematic engagement of PWD and their organisations can lead to positive results. The voice of PWD is now being heard in national decision making structures and there is systematic inclusion of PWD in HIV planning processes. The next step is to translate consultation into improved service delivery for PWD based on their full involvement. Work with PWD is, then, an ongoing process. It requires regular monitoring to identify and address challenges, and build on lessons learned. There is also a continued need to document initiatives of this nature to promote shared learning, both nationally and internationally.

Talk about HIV/AIDS with the deaf

References

Mundy J et al. 2008. Strategic partnerships for coordinating the AIDS response: lessons emerging in Zambia. Technical Approach Paper. London: HLSP Institute/National AIDS Council Zambia.

NAC. 2006a. Disabilities and HIV: An Urgent Call to Action. A publication compiled by Hazel Slavin in collaboration with the NAC Forum on HIV and AIDS for Persons with Disabilities. Lusaka: National HIV/AIDS, STI, TB Council.

NAC. 2006b. Disabilities and HIV: Guidelines for HIV and AIDS Educational Resources. A publication compiled by Hazel Slavin in collaboration with the NAC Forum on HIV and AIDS for Persons with Disabilities. Lusaka: National HIV/AIDS, STI, TB Council.

Rule et al. 2008. HIV/AIDS and Disability: Three Country Study – Uganda, Zambia, South Africa. A Report commissioned by the World Bank. South Africa: University of KwaZulu-Natal.

Sobsey D & Doe T. 1991. Patterns of sexual abuse and assault. Sexuality and Disability, 9 (3), 2430259.

UNAIDS, WHO & OHCHR. 2009. Disability and HIV Policy Brief. Geneva: UNAIDS.

World Bank & Yale University. 2004. HIV/AIDS and Disability: Capturing Hidden Voices. A report for the Global Survey on HIV/AIDS and Disability. Available through the project website: http://cira.med.yale.edu/globalsurvey

UNAIDS. 2007. UNAIDS' Terminology Guidelines. Geneva: UNAIDS.