

Background

The interrelationship between disability and HIV is an emerging area and its impact on health systems in eastern and southern Africa (ESA) is not fully understood as yet. Between 2009 and 2010, HEARD conducted a series of systematic reviews on disability and HIV establishing that (HEARD 2010): People with disabilities (PWD) are a key group at increased risk of exposure to HIV (Groce 2004; J. Hanass-Hancock 2009; J. Hanass-Hancock and Satande 2010) as they have less HIV-related knowledge, less access to education, are more likely to live in poverty, and are more likely to be victims of sexual abuse. Yet in 2010 there were very few HIV interventions that targeted PWD in Africa (see figure 1).

Additionally people living with HIV (PLHIV) are at risk of developing a disability related to HIV, its opportunistic infections and the treatment of both

(J. Hanass-Hancock and Nixon 2009, 2010; Nixon et al. 2011), yet up until 2010 there was little data available on how this unfolds in ESA, and no population-based data available at all in the region. Not surprisingly, previous National Strategic Plans (NSPs) and legal obligations in relation to HIV (2010 data) predominately failed to include disability, and capacity building in this area was urgently needed (Gerntholtz et al. 2010; Grant et al. 2009) (figure 1).






Figure 1: Emerging responses within NSPs in eastern and southern Africa



About HEARD Thematic Briefs

Working as HEARD does in the complex arena of human and social health and development, HEARD's research projects and advocacy activities frequently cut across more than one programme or research programme area. These thematic briefs aim to synthesise important progress in selected focal areas across the organisation's work.

HEARD has three programmes: African Leadership, Gender and Research. Under Research there are three programme areas: 'Prevention and Social Mobilisation'; 'Health Systems and Health Care Access'; and 'HIV and Health in an Urban Context'. HEARD's recent position paper provides more information on its work and offers a framework for these thematic briefs, visit www.heard.org.za

	NSP fails to recognise disability as an issue
	NSP does not specifically identify disability as an issue but includes some reference to disability
	NSP identifies disability as an issue but fails to operationalise this concern
	NSP identifies disability as an issue and takes selective steps to operationalise this concern
	NSP identifies disability as an issue and takes extensive steps to operationalise the issue

Key Areas 2011-2012

Based on its 2009-2010 systematic disability research, HEARD identified two main research areas to be taken forward within the new funding cycle:

Theme 1: Intervention research on the inclusion of PWD in HIV prevention, treatment, care and support.

Theme 2: Research on the disabling effects of HIV including development of good practices.

Research Area/ Topic	Example (2010-2012)
Theme 1	Prevention, access to health
Access to health services (Study 1)	SEPO 1 in Zambia Experiences of PWDs and HIV (2011)
Sexuality Education of PWD (Phase 1)	Pilot study of teachers' experience with sexuality education of PWD (2012). Qualitative & quantitative study
Children, disability and HIV (Strategic Consultancy)	Repssi consultancy – situation analysis in regards to psycho-social interventions (2012)
PWD and peer education (Strategic Consultancy)	Evaluation of Rolling Positive Peer Supporter Programme (2012)
Theme 2	Treatment, care and support
Depression Intervention study (phase 1)	Understanding of depressions in PLHIV (2011). Qualitative study
Depression Intervention study (phase 2)	Process evaluation of developed intervention (2012/2013). Quantitative study
Disabling Effects of HIV (Pilot study)	Nathi Singabantu – pilot Experiences of disablement among PLHIV (2011-2012)
Evaluation of training on disability and HIV for health-care workers	Formative evaluation of training on disability and HIV for health-care workers (2012)

Results indicate that disability and HIV are more interrelated in ESA than in any other region in the world (see figure 2); countries that have high HIV prevalence are also countries with high disability prevalence. This double burden threatens already fragile health systems in ESA.

Some of the new NSPs in ESA recognise this link and have started to include disability more rigorously. Moreover, HEARD's work indicates that health-care workers and educators alike need training in order to be able to implement the integration of disability in HIV programmes.

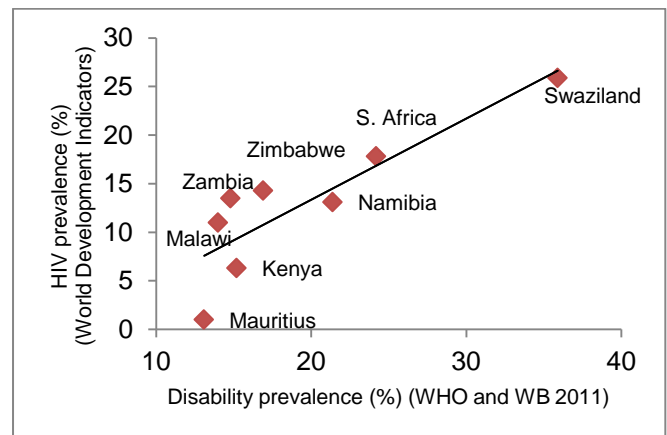


Figure 2: Disability and HIV prevalence (Pearson $r=0.87$) (J Hanass-Hancock et al. 2013)

For instance, theme 1 results from HEARD's work with educators indicate that, although sexuality education fits within the South African Life Orientation curriculum, teachers do not feel confident to teach this subject to learners with disabilities, and lack the skills and resources to accommodate these learners. HEARD is currently developing one of the first educator training on sexuality education for learners with disability. This intervention will be piloted in 2014. The training includes a comprehensive manual and toolkits for teachers and has the potential to provide an intervention suitable for teachers across the region.

Similarly, results from HEARD's work with health care workers (Alli et al. 2012) indicate that although some elements of disability inclusion can be found at health-care facility level (e.g. ramps), there is still a lack of disability-accommodating structures and approaches. HEARD's health-care workers project developed a sensitisation workshop which included knowledge about the relationship between disability and HIV, as well as practical tools for work at health facility level. It also included a personal action plan for each health-care worker. The intervention has since been taken up by the KZN Department of Health through a 'train-the-trainer' model. Funding is still needed and HEARD would like to further develop

this intervention and make it accessible to trainers across the region.

Theme 2 results from HEARD's pilot study on HIV-related disability (J Hanass-Hancock et al. 2012b) indicate that PLHIV experience a variety of disabling conditions on all three levels of disability namely: body function, activity and participation. Health conditions associated with HIV such as HIV-dementia, peripheral neuropathy, lipodystrophy, mental health conditions (e.g. depression) and pain, have been described in the literature. However, the levels of activity limitations and participation restrictions are widely under-researched and the impact of these levels of disability is therefore not understood, particularly in regard to its impact on livelihood and ART adherence.

Parallel to the development of a research portfolio on disability and HIV, HEARD identified several opportunities to build capacity of people working on HIV and AIDS in order to improve the inclusion of disability in HIV programming. In the timeframe between 2011 and 2012, HEARD completed the following:

- Development of the disability inclusive NSP framework with UNAIDS and others, as a result of HEARD's previous NSP work (NSP task group on disability and HIV 2011).
- A skills building workshop on the inclusion of disability within NSPs and legal obligations (Jill Hanass-Hancock et al. 2012c)
- Development and piloting of training of health-care workers on disability and HIV (J Hanass-Hancock et al. 2012a)
- Capacity building of young academics on disability and HIV in the form of support for Master, PhD and Postdoc students
- Two five-day disability networking zones at ICASA 2011, Addis Ababa and at the International AIDS Conference 2012, Washington (Handicap International 2011)
- HEARD also disseminated new literature, information on good practices, research results etc. via its newsletter and good practices collection on www.heard.org.za.

Research and Capacity Building – 2013 onward

From 2013 onwards, HEARD's disability programme aims to build on its pilot projects, develop and evaluate interventions for PWD and increase the body of research on HIV-related disability in the region (see table 2013 onwards). HEARD also continues to build capacity in relation to disability and HIV in the ESA region.

Research Area	Example (2013 onwards)
Theme 1	Prevention, access to health
Sexuality education of PWD Phases 2 and 3	Development and evaluation of intervention. Qualitative and quantitative study
Sexual abuse and PWD	Assessing challenges with reporting, investigating and prosecution of sexual abuse in KZN
Deafness and access to health services	Assessing challenges and good practices regarding the inclusion of deaf people in HIV prevention and care
Disability and multi-dimensional poverty	Assessment of national data (General Household Survey) to determine link between disability and multidimensional poverty in PWD
Theme 2	Treatment, care and support
HIV and co-morbidities	Comorbid Affective Disorders, HIV and AIDS and Health – HEARD is part of a bigger intervention study
Access to health (Study 2)	SEPO 2 study in Zambia. Experiences of disablement in people on ART (qualitative)
Disabling effects of HIV (HIV-Live)	HIV-related cross-sectional and cohort study determining disability prevalence and impact on livelihoods in PLHIV on ART over time
Rehabilitation in the context of HIV (HIV-Live sub-studies)	One RCT on standard retaliation in the context of HIV and one study focusing on an alternative Model of Care (both PhDs) One cost-effectiveness study in relation to the interventions

The following activities will be undertaken:

- A regional workshop and a skills building workshop on the inclusion of disability within NSPs and legal obligations (UNCVF grant)
- Training of health-care workers on disability and HIV (with Department of Health)
- Development and training of educators of children with disabilities in regard to sexuality education and HIV (with Department of Education)
- Capacity building of young academics on disability and HIV in the form of support for Master, PhD and Postdoc students
- Support for a five-day disability networking zone at ICASA 2013, Cape Town and at the International AIDS Conference 2014, Australia.

Rationality of the Programme

HEARD's Disability and HIV programme reaches into the ESA region via a) a vibrant network using HEARD and the IDDC Disability and HIV task group b) a resource centre on HEARD's website c) the facilitation of networking zones and skills building workshops d) collaborative research work e.g. studies in South Africa and Zambia and e) regional workshops. HEARD also informs key stakeholders such as national AIDS councils, UNAIDS, and the disability sector in several countries through its work. HEARD's work has influenced the development of new NSPs as well as the UNAIDS Disability Strategy (UNAIDS 2012). It is an advisor for regional disabled peoples' organisations such as DHAT and SANAC, as well as implementing NGOs (e.g. Handicap International) and government structures.

References

www.heard.org.za/african-leadership/disability/good-practice-overview

Alli, Farzana, et al. (2012), 'Closing the Gap: Building Capacity to Address the Relationship between Disability and HIV', (Durban: HEARD).

Gerntholtz, Liesl, Grant, Kitty, and Hanass-Hancock, Jill (2010), 'Disability Rights and HIV/AIDS in Eastern and Southern Africa . A review of international, regional and national commitments on disability rights in the context of HIV/

AIDS in eastern and southern Africa. Report', in HEARD (ed.), (Durban: HEARD).

Grant, Kitty, Strode, Ann, and Hanass-Hancock, Jill (2009), 'Disability in National Strategic Plans on HIV and AIDS. A review on the national response to the interrelations of disability and HIV in Eastern and Southern Africa', (Durban: Health Economics and HIV/AIDS Research Division).

Groce, N. E. (2004), 'Global Survey on HIV/AIDS and Disability', <<http://cira.med.yale.edu/globalsurvey>>, accessed 01.09.

Hanass-Hancock, J, Chetty, Verusia, and Cobbing, Saul (2012a), 'Closing the Gap: Training Health Care Professionals on the Interrelationship of Disability and HIV. Workshop Manual for Facilitators', in J Hanass-Hancock (ed.), *Closing the Gap* (Durban: HEARD, RATN).

Hanass-Hancock, J, Regondi, I, and Naidoo, K (2013), 'What drives the interrelationship between disability and HIV in Eastern and Southern Africa (ESA)?', *AJOD*, 2 (1), 1-6.

Hanass-Hancock, J, et al. (2012b), "Nathi Singabantu" an Exploratory Study of HIV-related Disability in KwaZulu-Natal', in J Hanass-Hancock (ed.), (Durban: HEARD).

Hanass-Hancock, J. (2009), 'Disability and HIV/AIDS - A Systematic Review of Literature in Africa', *Journal of the International AIDS Society*, 12 (34), http://www.jiasociety.org/series/hiv_aids_and_disability

Hanass-Hancock, J. and Nixon, S. (2009), 'The Fields of HIV and Disability: Past, Present and Future', *Journal of the International AIDS Society*, 12 (28), http://www.jiasociety.org/series/hiv_aids_and_disability.

Hanass-Hancock, J. and Satande, Loveness (2010), 'Deafness and HIV/AIDS – a systematic review of literature', *AJAR, African Journal of AIDS Research*, 9 (2), 187-92.

Hanass-Hancock, J. and Nixon, S. (2010), 'HIV, Disability and Rehabilitation. Consideration for Policy and Practice. Issue Brief', (Durban: Health Economics and HIV/AIDS Research Division (HEARD)).

Hanass-Hancock, Jill, Mac-Seing, Muriel, and Timpo, Emelia (2012c), 'HIV-related Policy and National Programming: How to Include the World's Largest Minority? Report Skills Building Workshop, XIX International AIDS Conference, Washington DC', (Durban: HEARD).

Handicap International, UNAIDS, HEARD, IDDC, DPOD, Sighsavers (2011), 'Report: Disability Networking Zone at ICASA Conference 2012, Theme: Sustainable disability-inclusive HIV response for universal access', (Addis Ababa).

HEARD (2010), 'HEARD Strategy 2010-2015. Knowledge and Evidence for Impact', (Durban: HEARD).

Nixon, S., et al. (2011), 'The Increasing Chronicity of HIV in Sub-Saharan Africa: Re-thinking "HIV as a Long-Wave Event" in the Era of Widespread Access to ART', *Globalisation and Health*, 7 (41), <http://www.globalizationandhealth.com/content/7/1/41>.

NSP task group on disability and HIV (2011), 'Framework for the Inclusion of Disability in the National Strategic Plans on HIV and AIDS', in Jill Hanass-Hancock (HEARD) and Emelia Timpo (UNAIDS) (eds.), (Durban and Geneva: AIDS-Free World, Barrett Advocacy and Training, CWGHR, DHAT, Handicap-International, HEARD, School of Law, UKZN, University College London, UNAIDS).

UNAIDS (2012), 'UNAIDS Strategy for Integrating Disability into AIDS Programmes.', (Geneva: UNAIDS).