



**REPORT ON:**

**DISABILITY NETWORKING ZONE**

**Access, Inclusion, Disability, Sexuality**

**ICASA 2013**

**7<sup>th</sup> – 12<sup>th</sup> December**

**Cape Town, South Africa**



Background



## Background

As countries have become more knowledgeable about the spread of the HIV pandemic, they have modified their programmes in order to target key vulnerable groups such as Men who have Sex with Men (MSM), injectable drug users (IDU) and sex workers. Despite this, little attention has been given to women, men and youth with disabilities who are exposed to all known HIV risk factors and who often face barriers such as poor access to healthcare, lack of accessible information on sexual and reproductive health and HIV and AIDS, poverty and marginalisation, and high rates of sexual abuse and exploitation<sup>12</sup>. In spite of these increased risk factors, people with disabilities are hardly being included in HIV and AIDS programming, because it is assumed that they are not at risk of HIV infection. In addition, with the arrival of ARVs in resource poor settings such as Africa, more people living with HIV survive longer and many develop disabilities as a result of their illness, treatment or opportunistic infections<sup>3</sup>. Though these issues are increasingly being recognised through the visible recognition of people with disabilities as a key population (as illustrated by UNAIDS' 2009 Disability and HIV policy brief<sup>4</sup> and 2012 Strategy for Integrating Disability into AIDS Programmes<sup>5</sup>), people with disabilities still are often excluded from AIDS development processes as well as programmatic HIV prevention, treatment, care and support services. Rehabilitation in the context of HIV in resource poor settings is with the exception of mental health also largely absent.



The interrelation between disability and HIV has been identified as an emerging issue at the

ICASA 2011 conference in Addis Ababa, Ethiopia and as a necessity to achieve the

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<sup>1</sup> Groce, N.E., et al., *HIV issues and people with disabilities: A review and agenda for research*. Social Science & Medicine, 2013. **77**: p. 31-40.

<sup>2</sup> Hanass-Hancock, J., *Disability and HIV/AIDS - A Systematic Review of Literature in Africa*. Journal of the International AIDS Society, 2009. **12**(34): p.

<sup>3</sup> Nixon, S., et al., *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, 2011. **7**(41): p. <http://www.globalizationandhealth.com/content/7/1/41>.

<sup>4</sup> UNAIDS, WHO, OHCHR. Disability and HIV Policy Brief, Editor. 2009. Available from: [http://data.unaids.org/pub/Manual/2009/jc1632\\_pol\\_brief\\_disability\\_long\\_en.pdf](http://data.unaids.org/pub/Manual/2009/jc1632_pol_brief_disability_long_en.pdf)

<sup>5</sup> UNAIDS. UNAIDS Strategy for Integrating Disability into AIDS Programmes. 2012. This strategy was launched at the 19th International AIDS Conference held in Washington in 2012.

three zeros at the International World AIDS in Washington 2012. This growing recognition was further recently amplified in ICASA 2013, in South Africa. In its tradition, the Disability and HIV Networking Zone (DNZ) at the International AIDS Conference aims to raise awareness for the interrelation of disability and HIV as well as provide a platform for exchange of research, good practice and innovative advocacy ideas. The zone therefore set out to achieve the following objectives:

- To raise awareness on the links between HIV and Disability.
- To provide evidence and good practice examples to build capacity of actors in the field of HIV and disability.
- To heighten the visibility of disability issues at the conference, promoting networking amongst all stakeholders.
- To discuss innovative advocacy strategies in the field of disability and HIV.

The zone included a full 4-day program (see Appendix One) with documentary screenings, project and research presentations as well as other interactive and educational activities. Notwithstanding the networking zone, ICASA 2013 marked an increased visibility of people with disabilities in plenary sessions, a disability symposium, oral and poster presentations and the closing ceremony. This report provides a collective review of all disability-related sessions at ICASA 2013 and lessons learnt for future conferences.

### **Disability Networking Zone, ICASA, 2013**

Fulfilling the vision of the IDDC task team on disability and HIV, the disability zone at the 2013 ICASA conference was led by people with disabilities with partnership with disability-focused organizations. Local disabled people's organisations (DPO) based in the Western Cape of South Africa (chiefly, the Western Cape Network on Disability – a network of DPOs and NGOs in Cape Town as well as DPSA) played a leading role supported by the International disability and Development Consortium (IDDC) task team on disability and HIV (other organisations included Handicap International (HI), DHAT, QASA, HEARD and the University of Johannesburg), while UNAIDS generously provided funding towards the zone.

Situated in the Community Village, the disability networking zone provided ICASA delegates and the general public the opportunity both to learn and identify various strategies to strengthen disability-inclusive HIV responses. The theme of the networking zone was **Access, Inclusion, Disability and Sexuality**. Those who participated in the zone comprised of people with disabilities, people living with HIV, disability and HIV researchers, HIV service providers and programmers and media representatives from South Africa, Zimbabwe, Zambia, Senegal, Rwanda, Canada, Italy, Nigeria, Cameroon, Swaziland, France and Kenya.

### Disability Networking Zone Activities



Vincent Daniels -  
WCND

The zone was officially opened on Sunday 8<sup>th</sup> December, by Jean-Marc Boivin (Executive Director of HI France), Gillian Burrows (HIV Coordinator, DPSA, South Africa) and Vincent Daniels (Chairperson, WCND, South Africa). The activities at the zone were facilitated by Paul Chappell (IDDC/University of Johannesburg), Gavin Maggott (WCND) and Jacques Lloyd (Quad/Para Association). The zone was also well supported by 12 local volunteers who were all people with different disabilities. Some of the activities that took place in the zone included:

- ***Disability inclusion in National AIDS Strategic plans (NSP): where are we at in 2013? Lessons learned, tools and ways forward:*** On 8<sup>th</sup> December, Jill Hanass-Hancock (IDDC/HEARD) and Muriel Mac-Seing (HI) provided an extensive overview of the intersection between HIV and disability. In addition, they introduced participants to the Disability Inclusive NSP framework developed by HEARD, UNAIDS, HI and other organisations in 2011. The session also provided participants with an effective analysis tool in which to assess NSPs on HIV and their inclusion of disability.



Muriel (HI) and Jill (HEARD)

- **Exploring perceptions and experiences of HIV-related health services for people with disabilities living with HIV in Lusaka, Zambia:** On 9<sup>th</sup> December, Phillimon Simwaba (DHAT) outlined a study that examined the experiences of accessing HIV-related services by people with disabilities who are living with HIV. The study indicated both physical and communication challenges and reported on an escalation of disability-related stigma in the presence of HIV, which exacerbated discriminating attitudes from health workers and other HIV patients.
- **Military veterans and HIV awareness:** On 9<sup>th</sup> December, Lieutenant Colonel Phillip Coetzer (South Africa) provided a presentation that looked at the provision of HIV education amongst military veterans. This session also led to an interesting debate concerning the inclusion of people with disabilities and people living with HIV in active military service. To end the session, Phillip Coetzer had arranged for a wine tasting event, which enabled participants to experience local wines from the Western Cape.
- **Skills workshop: Closing the gap: strengthening sexuality education for learners with disabilities:** On 10<sup>th</sup> December, Paul Chappell (IDDC) and



Rebecca Johns - WCFID

Rebecca Johns (Western Cape Forum for Intellectual Disability, South Africa) ran an interactive workshop introducing a sexuality education manual for learners with varying impairments. The manual, which has been produced by HEARD, provides various tools and techniques to equip educators in

teaching sexuality education to learners with disabilities. Besides being introduced to the manual, participants got to experience first-hand some of the teaching activities in the manual.

Other presentations that were conducted in the disability networking zone included:



- How to leverage AU and EU mechanisms and funding for health programmes and projects in your country by Rukia Cornelius (World AIDS Campaign), Fanny Voitzwinkler (Global Health Advocates) and Marie Harakeye (AU Commission).
- Sexuality and HIV testing with people with intellectual disabilities by Rebecca Johns (WCFID).
- DPSA HIV program: What works and what doesn't work by Gillian Burrows (DPSA).
  - Lessons learned and good practices from NPI/Hi project in Rwanda by Elie Mugabowishema (HI Rwanda).
  - Film: 'Life through my eyes' by Hamiida Ismail (DHAT)
  - ACCESS: The HIV inclusive for universal access by Aissatou Diame (HI Senegal).
  - The tide is turning: a model for HIV/AIDS/TB education for people with disabilities by people with disabilities by Jacques Lloyd (Quad/Para) and Vernon Openshaw (Quad/Para).
  - Strengthening HIV legal services for people with disabilities by Namizata Meite (IDLO).



Elie – HI Rwanda

In the ICASA closing ceremony, the rapporteur for the community programme specifically recognised the agenda of the disability networking zone along with other zones, as an 'innovative space'. Furthermore, people with disabilities were identified as a key population.

## Reflections of the disability networking zone

The following table outlines specific strengths, weaknesses, lessons learnt and ways forward based on the experiences of the disability networking zone at ICASA 2013:

<b>Strengths</b>	<b>Weaknesses</b>
<ul style="list-style-type: none"> <li>- Organised &amp; run by people with disabilities, local DPOs and disability-focused organisations.</li> <li>- Increased visibility of people with disabilities in zone (including Speakers &amp; volunteers).</li> <li>- Excellent participation by local volunteers.</li> <li>- Funding from UNAIDS which went directly to local DPOs.</li> <li>- Some inclusion of other populations (e.g. MSM, military veterans).</li> <li>- Strong recognition of disability as key population.</li> <li>- Great space available for wheelchairs and SLI.</li> <li>- Great and very visible posters and key messages.</li> <li>- Little political issues, unity and transparency in the group.</li> <li>- Support from non-DPO organisations to run the zone.</li> <li>- The IDDC HIV task group played a key role in instigating the mobilisation of the DNZ, disability speakers in the plenary and closing ceremony and a disability symposium.</li> </ul>	<ul style="list-style-type: none"> <li>- Difficulties in communication between ICASA organisers and local DPOs.</li> <li>- Lack of information/program in Braille</li> <li>- Poor support from some local DPOs in constructing the disability networking zone. The IDDC task team had to do a lot of the leg work.</li> <li>- Difficulties in opening ceremony due to late arrival of a local speaker &amp; cancellation of entertainment that was planned by the local DPOs.</li> <li>- Some sessions in the zone were poorly attended (due to poor advertising and competing schedule with other presentations).</li> <li>- Background noise (making it difficult for presentations &amp; discussions).</li> <li>- No scientific or implementation orientated presentations on HIV related disability.</li> </ul>
<b>Lessons learnt</b>	<b>Way forward</b>
<ul style="list-style-type: none"> <li>- Need for early communication between local DPOs and ICASA when planning zone. Local DPOs need to be more proactive.</li> <li>- Choose the right DPO partner who will be proactive in the country where the international AIDS conference will be held; this increases networking, effectiveness and efficiency in organising activities.</li> <li>- Interlink disability with other key/vulnerable populations (e.g. MSM, sex workers).</li> </ul>	<ul style="list-style-type: none"> <li>- More attention needs to be given to promoting good practices surrounding disability-inclusive HIV programs.</li> <li>- Skills workshops surrounding M&amp;E processes for disability-inclusive HIV programs.</li> <li>- DNZ is a local hub for people with disabilities, however, other zones are not accessible – if funding is available to the disability zone it could become an accessibility point for the village</li> <li>- Ensure local disability partners are made fully aware of roles &amp;</li> </ul>

<ul style="list-style-type: none"> <li>- Improve advertising of zone both before and during conference (e.g. flyers, posters).</li> </ul>	<ul style="list-style-type: none"> <li>responsibilities.</li> <li>- Given the IDDC HIV task group institutional memory of running the DNZ, they should continue to play a key role in the organising and facilitation of future DNZ.</li> </ul>
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**John Meletse, GALA**

The Disability Networking Zone was supported as well by ICASA itself as the IDDC task team had a representative in the Steering Committee of the conference (Jean-Marc Boivin, HI represented by Jill Hanass-Hancock, HEARD) and was able to make constructive suggestions in regard to disability inclusion. Through these efforts it was possible to reach out into the mainstream sessions of the conference

ensuring that two activists with disability who also live with HIV (John Meletse and Pumzile Kgaka) were included as plenary speakers, that one disability symposium was conducted at the conference and that all oral abstracts were integrated into mainstream sessions in the conference programme. We are particular proud of John's and Pumziles' speeches. These were a global first at an international AIDS conference and enabled us to make disability visible to all participants of this conference.



**Pumzile Kgaka**

### **Conclusion**

The disability networking zone at ICASA 2013 provided a successful platform to amplify the awareness of disability in HIV programming. Furthermore, it also provided the space to promote good practices across Africa for the involvement of people with disabilities in sexual health and HIV initiatives. Given that a local DPO was involved and also proactive in the planning and implementation of the zone, it helped increase the visibility of people with disabilities in the community village. Although people with disabilities were recognised as a key population in ICASA 2013, there is a need to interlink disability with other key populations. In addition, the



voice of children and youth with disabilities in the HIV response needs to be strengthened. This year's Disability Networking Zone did not include one presentation of HIV-related disability or rehabilitation. While the zone was very successful in reaching out to people with disabilities it failed to address the issue of HIV-related disability. The zone needs to better reach out to implementers and scientists in this field.

All proceedings of the presentations, programmes, photos will be available on the HEARD, HI and IDDC websites early 2014.



**Some of our volunteers**



**Gillian Burrows - DPSA**

## APPENDIX ONE – DNZ PROGRAMME



## Access, Inclusion, Disability, Sexuality

### Disability Networking Zone Program

### International Conference on AIDS and STIs in Africa (ICASA)

Cape Town, South Africa

07<sup>th</sup> – 11<sup>th</sup> December 2013

#### Program activities:

 Indicate disability-related sessions in main ICASA Conference

Saturday 7 <sup>th</sup> December			
Time	Session/Activity	Location	Facilitators
15:30 – 16:30	Official opening of Community Village	Community village	All
17:30 – 20:30	ICASA official opening ceremony	ICASA Plenary Hall	All

## Sunday 8<sup>th</sup> December

Time	Session/Activity	Location	Facilitators
10:15 – 10:40	Meeting of Zone organizers	Disability Zone	All
10:40 – 11:20	Opening of Disability Networking Zone	Disability Zone	Jean-Marc Boivin (Director General, HI), Vincent Daniels (WCND Chairperson)
11:30 – 13:30	Disability inclusion in National AIDS Strategic plans: where are we at in 2013? Lessons learned, tools and ways forward	Disability Zone	Muriel Mac-Seing- HI & Jill Hanass-Hancock- HEARD
14:00 – 15:30	How to leverage AU and EU mechanisms and funding for health programmes and projects in your country	Disability Zone	Rukia Cornelius - World AIDS Campaign & Fanny Voitzwinkler - Global Health Advocates
15:45 – 16:30	Film: Inclusive AIDS Conferences	Disability Zone	Muriel Mac-Seing – HI
16:45 – 17:00	Discussing sexuality in Life Orientation lessons with learners with disabilities	ICASA MR 4	Jill Hanass-Hancock - HEARD
16:45 - 18:15	People with disabilities neglected in HIV and reproductive health services: A situation analysis in Ghana, Uganda and Zambia		Waimar Tun et al. - Population Council

## Monday 09<sup>th</sup> December

Time	Session/Activity	Location	Facilitators
10:20 – 10:50	Exploring perceptions and experiences of HIV-related health services for people with disabilities living with HIV in Lusaka, Zambia.	Disability Zone	Phillimon Simwaba - DHAT
11:00 – 13:00	Sexuality and HIV Testing with people with intellectual disability	Disability Zone	Rebecca Johns - WCFID
13:30 – 14:30	Presentation on the programme of DPSA: What works for us and what does not work.	Disability Zone	Gillian Burrows - DPSA

14:45 – 16:15	<a href="#">Increasing the access of young people with visual disability in Oyo state, Nigeria to HIV/AIDS prevention information through Braille</a> Capitalization Of Good Practices On HIV Programming For Persons With Disabilities In Rwanda From 2008 To 2013	ICASA Auditorium 1	Adeyemi Oladeji - Nigeria  Muriel Mac-Seing – HI & Elie Mugabowishema – HI Rwanda
14:45 – 16:15	Symposium: Disability and HIV in Africa: Leadership, Capacity, Strategies	ICASA Ballroom West	Regina A Ombam- NAC Kenya; Toyin Aderemi- HEARD; Sheila Tlou- UNAIDS; Philimon Simwaba- DHAT
16:20 – 17:20	Military veterans and HIV awareness	Disability Zone	Phillip Coetzer and representatives from Dept. of Defence & Military veterans
17:30 – 18:00	Wine reception	Disability Zone	All
<b>Tuesday 10<sup>th</sup> December</b>			
<b>Time</b>	<b>Session/Activity</b>	<b>Location</b>	<b>Facilitators</b>
10:45 – 10:55	Burden Of HIV Infection Among People With Disabilities Living In Sub-Saharan Africa: A Systematic Review And Meta-analysis	ICASA MR 6	Pierre DeBeudrap- IRD; Estelle Pasquier- ANRS; Touko Adonis- FOCAP; Muriel Mac-Seing- HI
11:00 – 12:00	Lessons learned and good practices from NPI/HI project in Rwanda	Disability Zone	Elie Mugabowishema – HI Rwanda
13:00 – 15:00	Closing the gap: strengthening sexuality education for learners with disabilities	Disability Zone	Paul Chappell- UJ; Rebecca Johns- WCFID & Jill Hanass-Hancock- HEARD

15:30 – 16:30	Film: “Life through my eyes”	Disability Zone	Hamida Ismail - DHAT
<b>Wednesday 11<sup>th</sup> December</b>			
<b>Time</b>	<b>Session/Activity</b>		<b>Facilitators/Speakers</b>
08:00 – 09:30	Plenary session	ICASA Plenary Hall	John Meletse Gay and Lesbian Memory in Action Coordinator South Africa “Targeting Zero: Role of Community”
10:00 – 11:00	ACCESS: The HIV inclusive for universal access services”	Disability Zone	Aicha Diame - HI Senegal
11:30 – 12:30	The tide is turning: a model for HIV/AIDS/TB education for people with disabilities by people with disabilities	Disability Zone	Vernon Openshaw & Jacques Lloyd - QASA
14:00 – 14:30	Strengthening legal services for people with disabilities	Disability Zone	Namizata Meite – IDLO
14:40 – 15:15	Disability Networking Zone closing ceremony	Disability Zone	All
16:00 – 17:30	ICASA closing ceremony	ICASA Plenary Hall	Ms Kamogelo Pumzile Kgaka South Africa “Targeting Zero: Role of Community”