

CLOSING THE GAP BUILDING CAPACITY TO ADDRESS THE RELATIONSHIP BETWEEN DISABILITY AND HIV

END OF COURSE REPORT

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Workshop participants (persons with disabilities) discussing the relevance of the Convention on the Rights of Persons with Disabilities in relation to access to health care

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Summary

The Closing the Gap project aimed at building capacity in the field of disability and HIV in the context of KwaZulu-Natal. The interrelationship between disability and HIV is a long overlooked area. On the one hand, people with disabilities are at increased risk of exposure to HIV. On the other hand, since the rollout of ART, more people survive however many of them with experiences of disability. This relationship is still poorly understood and not addressed within the health system in southern and eastern Africa. The Closing the Gap project aimed to fill this gap by building upon HEARD's work on disability and HIV. It adapted and piloted three workshops on disability and HIV targeting three different groups 1) health care management 2) health care workers and 3) people with disabilities. The concept and approach to these workshops have been piloted in cooperation with the Department of Health (DOH), the QuadPara-Association (QAK) and the Physiotherapy Department of the University of KZN (UKZN) all situated in KwaZulu-Natal. The adaptation and rollout of these workshops is envisioned as the next crucial step in order to build capacity and HIV programmes that include disability. The final products of these workshops include three workshop manuals, workshop material and case studies. This material informs future intervention and has the potential to be carried into other settings in Africa. This project provided knowledge and skills to 60 participants.

1. Introduction: Why a workshop on disability and HIV?

People with disabilities are particularly vulnerable to HIV and AIDS, yet research shows that they are often not sufficiently included in HIV prevention, treatment, care and support programmes. In addition as treatment for HIV is becoming increasingly available more people survive; however this may also lead to new experiences of disability. On the one hand only very few studies have examined the disabling effects of HIV in resource-poor settings and consequently the current health system pays little attention to this issue. On the other hand South Africa has already identified disability as an issue for HIV and included it in their national strategic plan on HIV. However there is still a lack of skills and understanding of disability and HIV among health care workers as well as people with disabilities. Following a series of consultative workshops and meetings HEARD, QAK, the KZN DOH and the READ initiative developed a workshop that aimed to build capacity of people with disabilities as well as health care workers in order to facilitate the inclusion of disability in HIV programming in KwaZulu-Natal. The workshop series of the "Closing the Gap Project" developed the training manual and piloted three key workshops for this purpose in 2012.

Workshop one

The first two day workshop (3-4 September 2012) targeted people with disabilities and brought together women, men and youth with disabilities, people working in the disability sector and a few community workers. The workshop provided insight into the relationship between HIV and disability, the human rights approach, as well as an overview about the relevance of certain policies and national strategic frameworks, advocacy opportunities and good practice examples to address disability within the context of HIV and AIDS. The participants also developed a personal action plan

Workshop two

The second two day workshop (8-9 October 2012) focused on health care workers caring for people living with HIV and/or disability. This workshop included health care workers, community outreach workers and social workers. It aimed to provide insight into the relationship between HIV and disability as well as an overview about current relevant policies and national frameworks. The workshop predominantly provided opportunities to discuss and learn good practices for disability inclusive health services, possible referral systems between health professions (e.g. VCT-physiotherapy) and examples of low cost rehabilitation. The participants also developed a personal action plan.

Workshop three

The third workshop on 11 October 2012 was a short 4 hour workshop targeted managers. This workshop highlighted the concepts covered in the previous workshops for management staff who were not able to spare two working days.

2. Training goals and specific objectives

A. Development objective

- To develop skills and competencies for the design and implementation of disability inclusive HIV and AIDS interventions with selected health care providers and the disability sector in KZN
- To strengthen the capacity of HEARD to develop and deliver training and/or manage disability and HIV capacity building workshops by training two facilitators during the workshops for possible scaling up of these workshops
- To strengthen the exchange of knowledge and information on HIV and disability with relevant stakeholders such as the DOH
- To strengthen advocacy and the capacity of HEARD and its partners (DOH, UKZN, QAK) to respond to the interrelationship of disability and HIV
- To develop two or three model workshop manuals for possible scaling up within RATN member institutions.

B. Immediate objectives

- To conduct one 4 hour introduction and sensitisation workshop for middle management and stakeholders in decision making positions
- To conduct a 2 day workshop targeting health professionals (including people with disabilities if they work in such positions) such as nurses, rehabilitation staff, VCT counsellors, social workers and educators. This workshop would focus on sensitisation as well as on practical solutions
- To conduct a 2 day workshop targeting people with disabilities (including people living with HIV who have developed disabilities). The workshop would focus on the understanding of the interrelationship of disability and HIV, human rights as well as practical solutions on how to cope with the double burden of disability and HIV

C. Expected deliverables

- 1 or 2 workshop manuals for management and health professionals (including PWD who are health care professionals)
- 1 workshop manual for people with disabilities who are not health care professionals)
- 10 people in senior management positions trained in disability and HIV issues
- 20-30 health professionals trained in disability and HIV issues
- 20-30 people with disabilities trained on the interrelationship of disability and HIV.

D. Anticipated results

- 20-30 people in senior management positions developed skills and gained knowledge on how disability can be integrated within HIV programming
- 20-30 health professionals developed skills and gained knowledge on how disability can be integrated within their daily work schedules
- 20-30 people with disabilities gained knowledge on the interrelationships of HIV and disability and how it affects their lives.

3. Course participants

Table 1: Workshop Participant Characteristics

Workshop	No. attended	Sex	Organizations represented
People with disabilities	27	13 Males 14 Females	Disabled People South Africa Department of Health KZN Society for the Blind Association for the Physically Challenged Children's Rights Centre QuadPara Association KZN (QAK)
Health care workers	27	2 Males 25 Females	Saint Mary's Community Outreach Centre Oxfam (NGO) University of KwaZulu Natal Peaceville Clinic Clermont Clinic. St. Mary's Hospital Umlazi Clinic Kwa-Dabeka Clinic
Management workshop	6	6 Females	Mbumbulu Clinic KwaMakhutha Clinic Umlazi Clinic

4. Course activities

What is disability?

Day one kicked off with a discussion of the concept of disability. Participants introduced themselves and their background and explained their understanding of disability. The definition of disability was discussed based on an overview of the different models and theories. Participants described different types of health conditions and impairments such as polio, blindness, deafness etc., the impact of these impairments on life activities such as looking after children, dressing, toileting, working, providing food as well as participating restrictions in the community life caused through negative attitudes or barriers in the environment. The keywords associated to these issues were clustered under impairment, activity or participation restrictions. Consequently the ICF Model of disability and the definition of the UN Convention on the Rights of Persons with Disabilities (CRPD) were used thereafter to understand disability. Disability was therefore understood as a *“complex phenomenon that manifests itself at the body, person and social level and appears on three levels namely body structure or function impairment, activity level and participation in society” (CRPD).*



Workshop co-facilitator
Verusia Chetty using a
keycard

Learning about the interrelationship between disability and HIV

Participants learned that the United Nations Programme on HIV/AIDS recognises that vulnerable populations with limited access to their basic human rights are often at increased risk of exposure to HIV. Participants learnt that people with physical, intellectual or sensory disabilities are as likely, if not more likely, to be at risk of HIV infection. Additionally, there is a growing understanding that people living with HIV or AIDS are also at risk of developing disabilities on a

permanent or episodic basis as a result of their illness. Participants were introduced to disability and HIV as an emerging issue. The short film *Stepping into the Unknown* was screened and participants discussed the interrelationship between disability and HIV, identifying issues on keycards. Thereafter participants used case studies to a) identify the different levels of disability using the ICF model and b) describe the interrelationship of disability and HIV in the given cases.

"I learnt how HIV and disability interact and about people who are already HIV positive."

"The case studies and short film was very insightful and posed questions around how we can improve our work."

Health care workers



Co-facilitator Saul Cobbing explaining the link between disability and HIV

Learning about the relevance of national strategic plan and legal obligations

Participants gained knowledge on relevant legal obligations such as the CRPD and the degree of inclusion in the current South African NSP on HIV. They used this knowledge in their case studies and identified which articles of the CRPD articles, other legal obligations and sub-chapters in the NSP can help to address the challenges of their case studies. They also discussed ways forward and possible solutions.



Participants from health care worker workshop discussing the CRPD

"Information on the National Strategic Plan was insightful and will help us to participate more effectively"

Workshop participant and person with disability

Accessing HIV services for people with disabilities



Participants from health care worker workshop mapping interventions

needed for people with the four main impairment types (deafness, blindness, physical impairments and intellectual impairments) specifically in relation to VCT, ART, rehabilitation and poverty alleviation. Participants thereafter discussed these services and clustered the issues in 1) services that can be implemented without any extra resources 2) services that need minor resources 3) services that need more financial and human support from the health care department. It was surprising to see with how many low or no-cost examples were identified by the participants.

"This workshop has improved health care workers knowledge on disability and HIV. We can involve NGOs, CBOs to help improve access to services."

Health care worker

Learning about rehabilitation and disability in the context of HIV in resource poor settings

Participants learnt that people living with HIV may be at risk of developing impairments and disabilities in much the same way as in other chronic diseases. They also learnt that besides a change in medication, rehabilitation and mental health interventions are another way of addressing HIV-related disability. These interventions are designed to address disability including HIV-related disability. Rehabilitation, for instance, is designed to facilitate the "process of recovery from injury, illness, or disease to as normal a condition as possible" ([http://medical-](http://medical-dictionary.thefreedictionary.com/rehabilitation)

"The use of screening tools and postures for rehabilitation was helpful. Real life examples of patients were given as a strength of the workshop."

Health care worker



Participants from health care worker workshop discussing screening tools

[dictionary.thefreedictionary.com/rehabilitation](http://medical-dictionary.thefreedictionary.com/rehabilitation)) as well as to adapt and develop an enabling environment so as to accommodate disability. Participants were provided with case studies and identified impairments and disability. They were introduced to possible screening tools that can assist in the process of screening for disability as well as to provide the right referral. Additionally participants learnt about community based

rehabilitation approaches that are useful for resource poor settings. Good practice examples and tools from the HEARD resource centre and the Hesperian book website were provided.

Learning how to provide disability inclusive health care services

“The introduction of the Health Care Services checklist is helpful in ensuring that we make our services more disability inclusive”

Health care worker

At the end of the two day workshop participants developed a personal action plan to improve their local or vocational health care services so that it becomes more accessible and disability inclusive. A Health Service Checklist provided the participants with a guiding tool to identify gaps in their services as well as the opportunity to identify three practical areas that the individual participants feel comfortable to tackle in the next few months. This exercise will also allow the facilitators to follow up with the long term impact of the overall the workshops.

Is your health care facility designed universal?				
Do you have the following:	Yes	No	Not sure	Things I can change/influence
Ramps to access your buildings and outside areas				
Crucial services on the ground floors				
Doors that fit a wheelchair and open easily				
Wheelchair accessible toilet				
Railings along the corridors or outside areas				
Directions on key areas in Braille (e.g. lifts, signposts)				

Picture of checklist see also attachment below

5. Workshop monitoring and evaluation

The workshop was accompanied by a pre- and post-workshop evolution as well as the use of the disability inclusive health service checklist for the evaluation of the possible needs of the participants and long term outcomes of the workshop. The results of this evaluation are presented here (attachments A, B, C).

The evaluation for this project used a process evaluation design and takes place at three points in time:

Time 1: At the beginning of the workshop (pre-evaluation see attachment A)

Time 2: After the workshop (post evaluation form see attachment B and health care services check list see attachment C),

Time 3: Three months after the workshop (phone call as follow ups with checklist/action plan see appendix 3).

While the workshop participants were given a survey questionnaire prior to the workshop and after the workshop as well as a health service checklist (attachment A, B and C) a questionnaire/telephonic interview will be conducted with participants three months after the workshop. These will include open and closed ended questions. The main aim will be to determine if the workshops had an impact on the work or experience around disability and HIV and which challenges people faced during implementation of their new knowledge.

5.1 Participants pre-workshop exposure to disability and HIV

Participants were asked about their expectations of the workshop as well as the skills and knowledge they hoped to gain and how they intended to use this. The majority stated that they wanted to learn about the relationship between HIV and disability and how to respond to needs. They hoped to use the knowledge and skills gained in the workshop in their respective jobs as well as providing information to the community and other professionals working in the field. Below are some of the responses that participants gave:

“My expectation is to learn about HIV and disability – it will give me guidelines on how to care and treat disabled people. They are also capable and should have access to everything, be accepted by health care workers and the community.” (health care worker)

“My expectations are to know more about other disabilities and how to empower people with disabilities.” (person with disability)

“I expect to learn how to collaborate with the disability sector, how to adapt HIV programmes for the disabled and understanding legal obligations of the NSP.” (management health care)

“My intention is to produce better service to patients. To provide the required empathy and understand patients with disabilities and HIV.” (health care worker)

“I will give feedback to all health care providers, clients and the community. This will include daily health education to clients visiting the clinic and information on the interrelationship of disability and HIV.” (management health care)

“I will be able to answer many questions about the relationship of HIV and disabled. I can pass my knowledge to many people, so they can know what is right for them.” (person with disability)

5.2 Participants perception of workshop

After the workshop was completed, participants were requested to fill in an evaluation form for the workshop. Highlighted below are the results that were obtained. The majority of the participants felt that the workshop met their training needs; the methodology improved their understanding of the subject matter; the workshop provided new skills and knowledge; and the workshop met the stated objectives. The participants also reflected positive responses regarding the facilitation of the workshop.

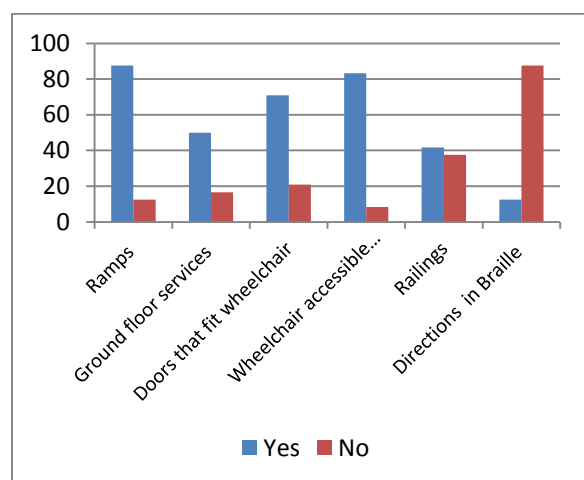
Questions	PWD/HCW	PWD/HCW	PWD/HCW	PWD/HCW	PWD/HCW
	Strongly agree	Agree	Neutral	Disagree	Strongly Disagree
1. Have the course objectives met your training needs?	16/12	9/12	1/0	0/1	0
2. The training course methodology enabled you to improve your understanding of the subject matter.	16/7	7/17	2/1	1/0	0
3. The training course has provided new knowledge and practical skills ideas for improving your professional work?	14/12	10/10	1/0	0	0
4. The information and concepts covered met the stated course objectives?	12/5	10/18	4/1	0	0
5. The sequencing of the various topics within the session/module was appropriate.	12/7	12/15	2/1	0	0
6. The course methods used for training appropriate for your learning.	12/10	12/12	0/3	1/0	0
7. Concepts and information covered during the course did not meet the stated course objectives?	4/2	5/0	3/0	4/17	6/5
8. The training materials were easy to comprehend.	11/7	10/13	2/4	1/0	0
9. The quality of training materials used to facilitate learning were of low quality.	5/2	6/0	2/0	8/16	4/7
10. Delivery of the overall course content was effective.	10/10	12/14	0/1	2/0	0
11. The facilitators made use of illustrations to simplify concepts.	11/12	12/13	2/0	0	0
	Excellent	good	fair	Somehow fair	Poor
12. How would you rate the range (i.e. breadth) of topics within the various sessions/modules for this course?	12/8	14/15	0	0	0
13. The course duration was :	4/0	6/1	13/18	3/5	0/1
	Very relevant	Relevant	Fairly relevant	Somehow relevant	Not relevant
14. To what extent was the course content relevant to your work responsibilities?	13/14	9/9	2/2	1/0	1/0

5.3 Participants perception of current local health care facility

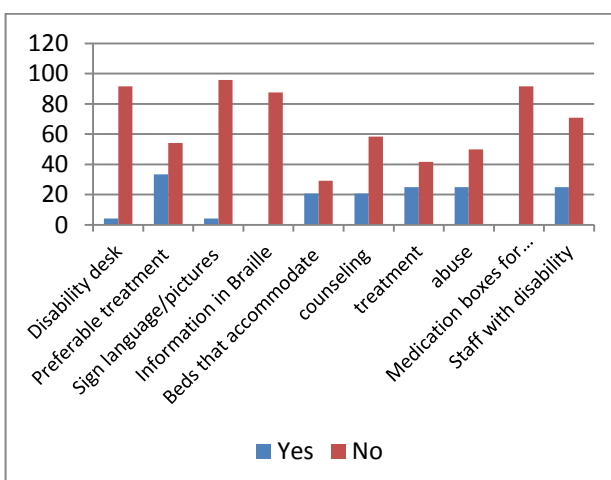
The workshop participants were asked about the design of the health care facilities and services. Health care workers analyzed the facilities they worked for to determine if it was designed in a disability friendly manner. They used the HEARD Health Service Checklist (see attachment). While people with disabilities were asked if the health facility and services they utilized were designed to accommodate people with disabilities. Presented below are the results.

People with disabilities

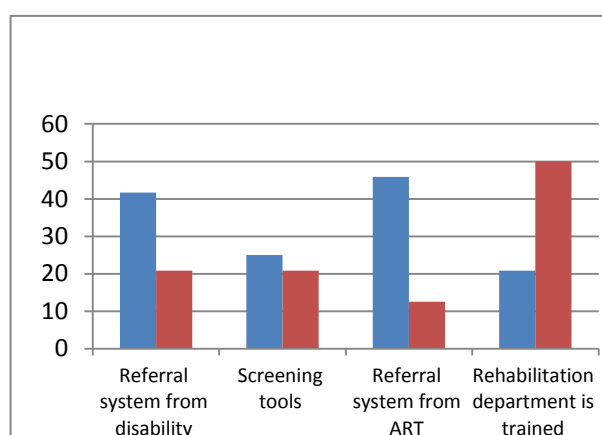
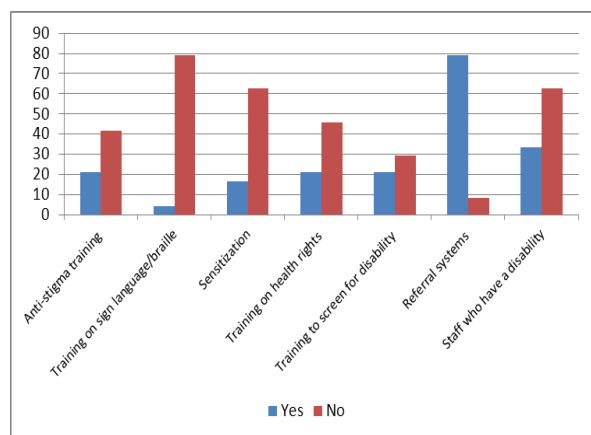
Graph 1: Is your health facility designed universal?



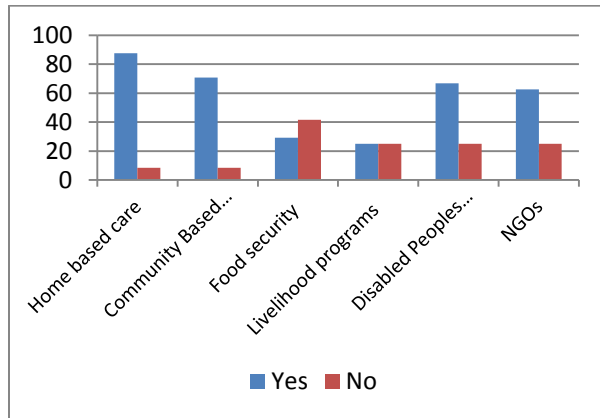
Graph 2: Does your health facility accommodate special needs?



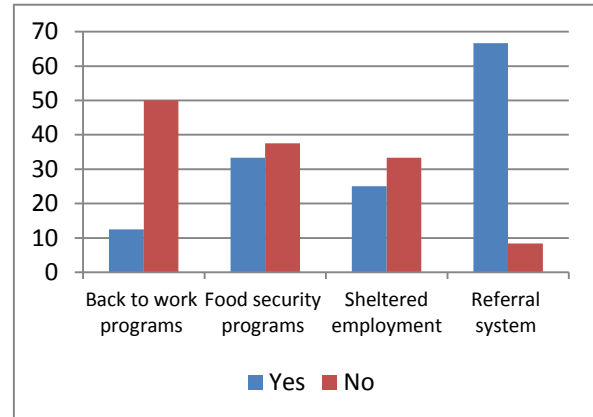
Graph 3: Are staff trained to screen for disability and referral? Graph 4: Is your HIV programme linked to disability and rehabilitation?



Graph 5: Is your health service linked to community service?

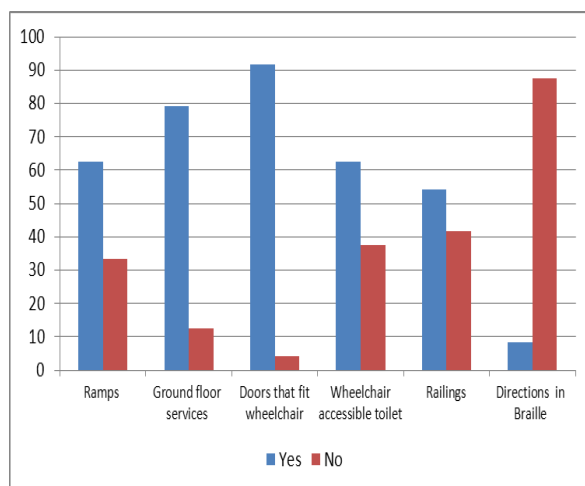


Graph 6: Is your health service linked to poverty alleviation?

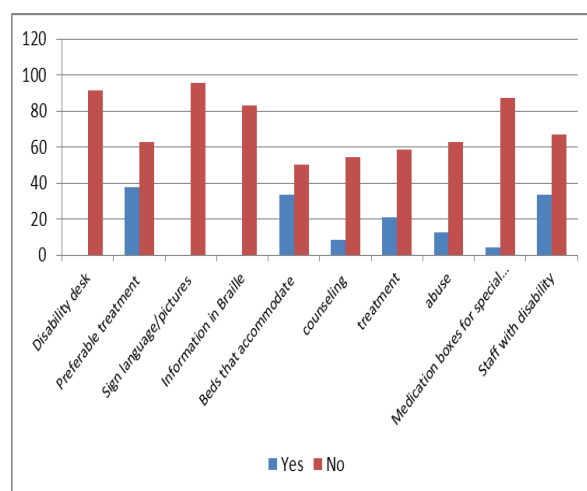


Health care workers

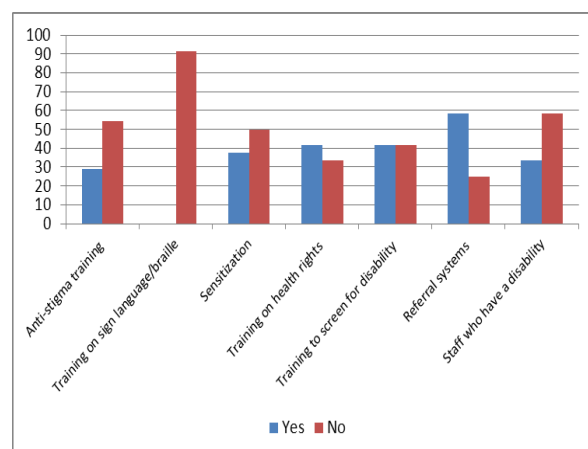
Graph 7: Is your health facility designed universal needs?



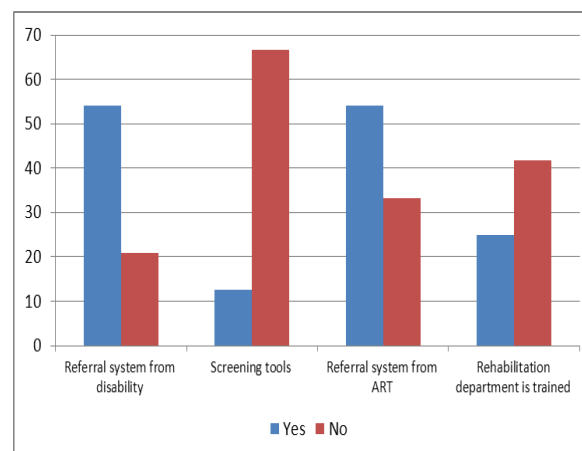
Graph 8: Does your health facility accommodate special



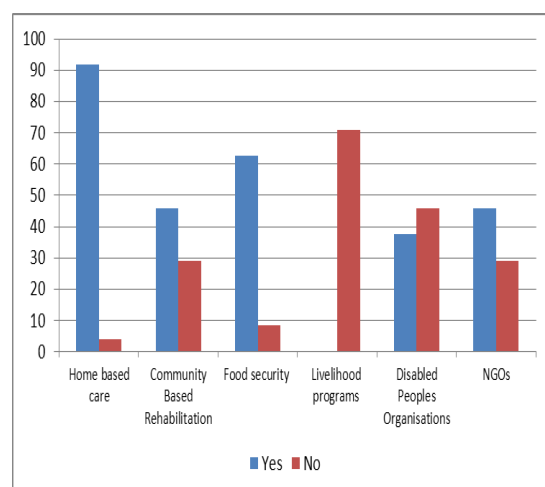
Graph 9: Are staff trained to screen for disability and referral?



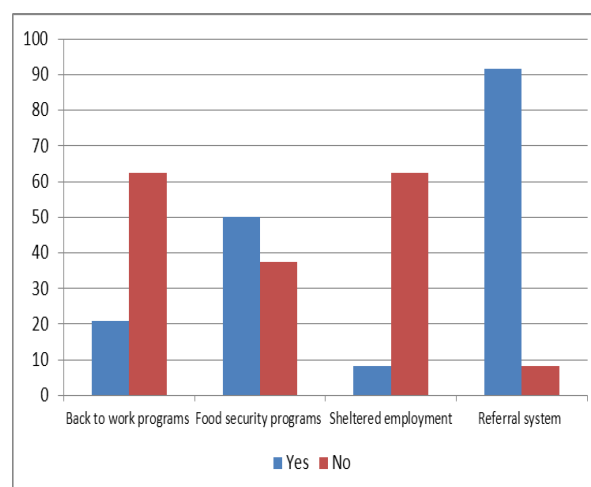
Graph 10: Is your HIV programme linked to disability and rehabilitation?



Graph 11: Is your health service linked to community service?



Graph 12: Is your health service linked to poverty alleviation?



In general, health care facilities and services were perceived as physically accessible as they included ramps and doors (universal design). However other crucial disability accommodations such as braille, sign language, simplified information, disability desks, linkages to other disability interventions such as rehabilitation, mental health, etc. were often lacking. In addition, participants identified a lack of training of health care staff in regards to disability as an issue in most facilities. Not surprisingly they also felt that disability screening tools were lacking at the clinic level. While clinics had close links to home based care, food security services and appeared to use referrals, they lacked links to disability organisations, community-based rehabilitation or programmes addressing livelihoods on a broader level.

5.4 Participants areas of action

The assessment with the health care checklist also included a question around areas that the participants identified as being able to influence based on the knowledge and skills they had gained in the workshop. Below are the top 10 areas that participants identified that they could change after the workshop.

<i>People with disabilities</i>
1. Disability desk at the entrance area
2. Sign language interpretation and information in pictures for the deaf
3. Directions on key areas in braille (example: lifts, signposts)
4. Training on sign language interpretation and braille
5. Information in braille or audio format
6. Accommodate staff who have a disability
7. Preferable treatment so people with disabilities don't have to stand in long queues
8. Sheltered employment
9. Ground floor services
10. Training on health rights

<i>Health care workers</i>
1. Sign language interpretation and information in pictures for the deaf
2. Disability desk at the entrance area
3. Preferable treatment so people with disabilities don't have to stand in long queues
4. Railings along the corridor or outside area
5. Information in braille or audio format
6. Simplified information related to treatment, abuse, counseling
7. Training on sign language interpretation and braille
8. Beds that accommodate physical disabilities
9. Sensitisation on disability and HIV
10. Back to work programs for people who acquired a disability

5.5 Long term impact assessment

The evaluation does also include a long term impact assessment. The data collection and analysis will be presented in a follow up report. This evaluation will be based on follow up telephone interviews with participants at three months post workshop interventions.

6. Lessons learnt

The workshop was useful for participants and the adaptations for people of different disabilities worked well. The cooperation between the research institution HEARD, the KZN DOH and QAK was crucial for the success of the workshops and helpful in identifying the right information and participants. The Health Service Checklist was welcomed by everybody and seems to be useful beyond its evaluation purpose. It is recommended to develop this further in the years to come.

The workshops need to be integrated into the training of health care workers and disabled peoples organisations' work-plans. For this purpose the collaborators have to be supported to respond to suitable calls that can ensure that more resources become available for this kind of training.

7. Conclusions

HEARD and its partner are very grateful for this opportunity and would like to support the upscale of these workshops in the eastern and southern African region.

8. Recommendation

The workshop manual will be made available on the HEARD website as well as through dissemination via conferences and meetings. RATN as well as HEARD's collaborators UKZN, DOH and QAK need to identify opportunities to upscale this initiative. In South Africa the workshop needs to go through an accreditation process. How this applies to other contexts will have to be investigated further.

9. List of Appendices

Attachment A – Pre workshop evaluation form

Attachment B – Post workshop evaluation form

Attachment C – Health care services checklist

PRE WORKSHOP EVALUATION FORM

INSTRUCTIONS: Please complete this form accordingly to help the workshop facilitators gather necessary information that will ensure that the workshop adequately meets your training needs.

1. Participant name: _____
2. Gender _____
3. Date of birth: _____
4. Name of employer: _____
5. Current job position: _____

6. Have you attended a similar workshop before? Yes ☐ No ☐

7. If yes, when and where did you attend the course?

8. State your key responsibilities in your current job

9. What are your key expectations of this workshop?

10. How do you intend to use the knowledge and skills from this workshop in your work?

11. How do you intend to use the knowledge and skills from this workshop as an individual?

END OF WORKSHOP EVALUATION FORM

INSTRUCTIONS: Please complete this form accordingly to help the workshop facilitators gather necessary information that will ensure that the workshop adequately meets your training needs.

Participant name: _____

Gender _____

Date of birth: _____

Name of employer: _____

Please rate the following statements on a scale from 1 to 5 with 1 = strongly agree and 5 = strongly disagree

1. The objectives of the workshop met my training needs

1	2	3	4	5
---	---	---	---	---

2. The workshop content was relevant to my work

1	2	3	4	5
---	---	---	---	---

3. The workshop improved my understanding of the subject matter

1	2	3	4	5
---	---	---	---	---

4. The workshop provided new knowledge and practical skills ideas for improving my professional work

1	2	3	4	5
---	---	---	---	---

5. What are the key ideas that you have taken away from the workshop to implement or use

6. How do you intend to use these ideas at work



Appendix C - Health Services Checklist

The following checklist provides you with some guidance in order to make your health services more accessible and disability friendly. Please answer yes/no/not sure if your facility is designed in an accessible and disability friendly manner. Please tick the last column “things I can change/influence” if you feel that you can influence or change these aspects.

Is your health care facility designed universal?				
Do you have the following:	Yes	No	Not sure	Things I can change/influence
Ramps to access your buildings and outside areas				
Crucial services on the ground floors				
Doors that fit a wheelchair and open easily				
Wheelchair accessible toilet				
Railings along the corridors or outside areas				
Directions on key areas in Braille (e.g. lifts, signposts)				

Does your health facility accommodate special needs?

Do you have the following:	Yes	No	Not sure	Things I can change/influence
Disability desk at the entrance area				
Preferable treatment so people with disabilities don't have to stand in long cues				
Sign language interpretation and information in pictures for the deaf				
Information in Braille or in audio format				
Beds that accommodate physical disabilities through height adjustments particularly in the maternity ward				
Simplified information for people with intellectual disabilities related to counseling				
Simplified information for people with disabilities related to treatment				
Simplified information for people with disabilities related to abuse				
Medication boxes with symbols, pictures or Braille to accommodate special needs				
Staff who have a disability				

Is your staff trained to screen for disability and refer to the right services?				
Have your staff been exposed to the following:	Yes	No	Not sure	Things I can change/influence
Anti-stigma training focusing on disability and HIV				
Training on sign language interpretation and Braille				
Training course focusing on the interrelationship of disability and HIV (sensitization)				
Training on health rights of people with disabilities				
Training to screen for disability including mental health in general services such as ART				
Referral systems to rehabilitation including Community Based Rehabilitation				
Staff who have a disability				

Is your health service linked to poverty alleviation for people with disabilities?				
Are your health services linked to the following:	Yes	No	Not sure	Things I can change/influence
Back to work programs for people who acquired a disability				
Food security programs that include people with disabilities				
Sheltered employment				
Referral system to social work, disability grants or business loans				

Is your HIV program linked to disability services and rehabilitation?				
Do you have the following:	Yes	No	Not sure	Things I can change/influence
Referral system from disability services to reproductive health services and VCT				
Screening tools to identify disability including mental health problems in your ART program				
Referral system from ART and VCT program to rehabilitation and mental health services				
Rehabilitation department is trained and equipped to address HIV-related disability				

Is your health service linked to community services?				
Are your health services linked to the following:	Yes	No	Not sure	Things I can change/influence
Home Based Care				
Community Based Rehabilitation				
Food security programs				
Livelihood programs that focus on people with disabilities				
Disabled Peoples Organisations				
NGOs that focus or include people with disabilities				