

# News on INCLUSION

of persons with a disability

Special issue World Disability Day 2011, The Netherlands

## Top tips to view: The voice of 650 million times one

*"I realise that it is very important to take persons with a disability into account when you design an HIV/AIDS project, otherwise they will easily be left out"*

"It is good to ask attention for inclusion of persons with a disability in HIV/AIDS and reproductive health programmes" says Willem Klaassen, Programme & Linking officer at TEAR Netherlands. He watched the YouTube version of the documentary "The voice of 650 million times one". VSO produced this video to lobby for access to sexual and reproductive health and rights programmes for persons with disabilities. In the documentary several persons with a disability from Africa and Asia share their harsh personal experiences on this topic. They proclaim the voice of 650 million people with disabilities worldwide who are facing the same stigmas. Willem explains: "This documentary clearly shows that persons with disabilities are excluded from programmes, they are often not taken seriously when they want to access services. I realise that it is very important to take persons with a disability into account when you design an HIV/AIDS pro-

ject, otherwise they will easily be left out"

Willem is responsible for the programmes of TEAR in Uganda and Zimbabwe and thus comes across HIV/AIDS programmes regularly. "I just returned from a trip to Uganda. I have talked about inclusion of persons with a disability in HIV/AIDS programmes. In some projects they have identified persons with a disability, but it is rather incidental and not the result of a structural effort. There is attention for the topic and the partner organisations report on it, but it is not first priority. At this moment the organisations are very busy with doing baselines studies and starting up MFS2 (a programme supported by the Dutch Government)". Willem explains that he would like to do more on inclusion of persons with a disability in HIV/AIDS programmes but admits that at this moment the financial and human resources at the partner

organisations are limited. He hopes that the recent decision of TEAR to make disability a cross-cutting issue, will help to pay more attention to this important topic. One of the partner organisations in Zimbabwe already included 50 persons with a disability in their HIV/AIDS programme, that is a nice number to start with. Willem concludes: "During my next trip to Zimbabwe I will bring a copy of the full version of 'The voice of 650 million times one' with me on a memory stick. The internet connections are so bad, that sometimes even e-mail is a problem, so access to YouTube is out of the question. The documentary will surely help me to illustrate why inclusion of persons with a disability in HIV/AIDS programmes is so important."

Got interested? Check the following website for more information about the film: <http://www.thevoiceof650million.com>

The short version can also be watched through: <http://www.endexclusion.eu/resources/media/films>



# Reaping the Fruit - Disability Inclusion in HIV/AIDS Programs in Ethiopia



**The role of the focal person is mainly to ensure that persons with disabilities benefit from HIV/AIDS prevention and control services of the city.**

Persons with disabilities have been denied access to HIV and AIDS prevention and control services for a long time. Information about HIV is largely presented in inaccessible formats. Radio messages often miss the deaf. At Voluntary Counseling and Testing (VCT) Centers, clients with hearing impairment risk lack of confidentiality due to unavailability of counselors trained in sign language. Health institutions are also often inaccessible to persons with physical impairment. A counselor from Zewditu Hospital VCT Center stated: "Wheelchair user clients used to find it difficult to access our VCT services due to the inaccessibility of the physical environment." In addition, due to lack of awareness of disability among different governmental and non-governmental organisations, persons with disabilities are being discriminated, resulting in limited access to HIV related services. Furthermore, literature shows that persons with disabilities are at equal or even increased risk of expo-

sure to HIV.

Based on this background the Ethiopian Centre for Disability and Development (ECDD) conducted a baseline assessment on the service gaps in the Ethiopian context. Subsequently ECDD took the initiative to promote disability inclusion in HIV and AIDS programs and services in Ethiopia through the "Disability Inclusion in HIV/AIDS Prevention and Control Programs in Ethiopia" project, funded by Dark & Light Netherlands, which ran from August 2010-June 2011.

ECDD identified many governmental organisations that desperately needed to close the awareness gap. It emerged that the most effective place for change was Addis Ababa HIV/AIDS Prevention and Control Office (AAHAPCO). This office is responsible for mobilising and coordinating HIV/AIDS activities of the city. AAHAPCO, after ECDD's intervention, has shown clear changes in working towards disability inclusion. This all started after appointing an existing disabled staff member to work as a disability focal person. The role of the focal person is mainly to ensure that persons with disabilities benefit from HIV/AIDS prevention and control services of the city. Since

then, AAHAPCO attempted to collect disability disaggregated data from each sub-city, to ensure the inclusion of persons with disabilities as beneficiaries. They also took steps to plan and budget for disability accommodation and so on. Most importantly, complementary to ECDD's effort to train existing VCT counselors in sign language, AAHAPCO trained people who can use sign language in VCT counseling and deployed them in various health centers and hospitals. Among those trained were people with hearing impairment themselves. What is remarkable is that these trained personnel are recruited as permanent staff in the different health institutions in the capital to deliver the service to clients with hearing impairment. Indeed, this effort is significant because it demonstrates what individuals with disabilities can do to help others as opposed to what others can do to help them. ECDD strongly believes AAHAPCO is able to sustain the changes made to ensure persons with disabilities enjoy equal access to services.

*Retta Getachew (ECDD)*





# Reflections on Disability Inclusion in HIV/AIDS

*“Often it takes just a simple action or even mind change in the beginning to start to make a difference.”*



*“Simple tools like the RARE model have assisted in finding out specific HIV risk moments and adapt health messages and health services accordingly”*

## **Inclusive VCT in perspective**

Dr. Jill Hanass-Hancock completed her dissertation (PhD) in the field of HIV/AIDS and disability in South Africa with the Department of Rehabilitation at Humboldt University in Berlin, Germany. Thereafter she joined the Health Economics and HIV/AIDS Research Division (HEARD) in Durban as a Post-Doc Fellow, where she was involved in the evaluation of HIV prevention interventions. She currently works at HEARD as project-coordinator for the disability and HIV project. Her reflection on the experience of ECDD is as follows: The intersection of disability and HIV has been an overlooked area for a long time and only been discussed within the last 7 years. On the one hand people with disabilities are at increased risk of exposure to HIV [1, 2]. On the other hand since the arrival of ART in resource poor settings more and more people survive – however many of them with HIV-related disabilities [2, 3]. Today, many countries have ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) and are therefore obliged to make health, juristic as well as health services accessible to persons with disabilities [4], yet many National Strategic Plans (NSP) still lack the inclusion of disability [5] and as a result no budgets and programs are allocated to address this issue. In addition many mainstream organizations lack the skills, knowledge and understanding to design programs with universal design and accommodate disability. It is therefore encouraging to read about the work of ECDD and Dark & Light Netherlands and their initiative to promote disability inclusion in HIV/AIDS programs and ser-

vices in Ethiopia. Working in cooperation with the Addis Ababa HIV/AIDS Prevention and Control Office (AAHAPCO) the initiative has focused on some of the crucial areas to address disability inclusion such as 1) including disability in planning processes 2) collecting disability data and 3) training VCT counselors in sign language. It is encouraging to hear that this initiative also includes people with disabilities as key focal persons and as counselors with hearing impairments. Similar programs have been implemented in Kenya and Zambia and their experiences are promising. The evidence from this project can be used as a good practice example that can inspire disability inclusion in other countries and areas. Furthermore, it would be interesting to investigate how this new experience in HIV service delivery can be used to facilitate disability inclusion in other health sectors.

## **Learning for practice**

Friederike Kugler represents Kindernothilfe in the Thematic Learning Programme on inclusion of persons with Disabilities. At Kindernothilfe they started the process of disability mainstreaming in their programmes. Friederike reflected on the story of ECDD: "I find it exciting to read about the progress ECDD is making in their project. What encourages me and has encouraged me ever since I started to become involved with inclusive development is that often it takes just a simple action or even mind change in the beginning to start to make a difference. It truly is remarkable how AAHAPCO with the help of ECDD has initiated changes in their planning process, their data collection and training of their staff. From then on, it takes on a kind of snowball effect - trainees from the AAHAPCO are recruited in other health facilities, reaching out to even more persons with disability. This project is a good example to show the necessity to

select stakeholders in the project phases that are able to pass on the knowledge and learnt skills to other stakeholders."

## **A step further with services**

Dr. Yadira Roggeveen is medical doctor and PhD student at Athena Institute. She is writing her thesis on the development of context specific maternal health services in a hospital in Northern Tanzania.

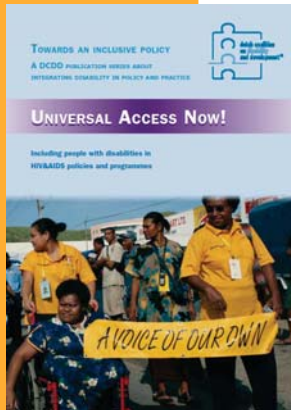
It is great to learn about the initiative of AAHAPCO to increase access to HIV information, testing and treatment for people with a disability. It would be interesting to see if the focal persons would be able to assist in identifying other general and specific sexual & reproductive health needs in the group of people with a disability. Health messages, that take into account the specific HIV risks that groups of people encounter, is of assistance in the prevention of HIV. Insecurity of income for disabled people in low resource settings, social networking and associated HIV risks are some of the topics that have been recognized in literature. In my personal experience in working with non-disabled Maasai women, simple tools like the RARE model have assisted in finding out specific HIV risk moments and adapt health messages and health services accordingly [6]. Tools like this might be of assistance to further tailor HIV services for people with a disability too.

## **References**

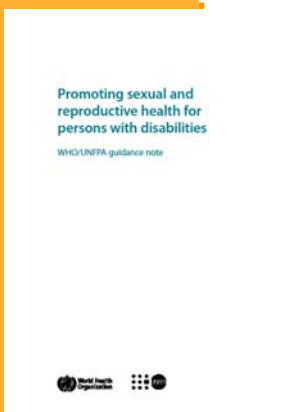
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## Tips for reading

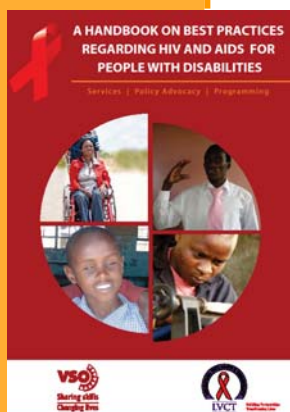
Interested in mainstreaming disability in your Sexual and Reproductive Health and Rights programmes? These documents help you to get started:



Universal Access now! Brochure of Dutch Council on Disability in Development on including people with disabilities in HIV&AIDS policies and programmes. <http://bit.ly/schBwu>



A guidance note on promoting sexual and reproductive health for persons with disabilities developed by WHO/UNFPA. <http://bit.ly/ua8ngp>



A handbook developed by VSO international & LVCT on best practices regarding HIV and Aids for people with disabilities: services, policy advocacy, programming. <http://bit.ly/rH6E9M>



More publications on HIV AIDS and disability can be found on the website of asksource.org. <http://bit.ly/>

## What you always wanted to know, but never dared to ask...

*“It’s like they are always told that they miss something, so they might feel incomplete in building a relation at first”*



During the Thematic Learning Programme on inclusion of persons with disabilities Yetnebersh answers question of participants they never dared to ask to a disabled person.

*Do persons with disabilities trust their partners for love?*

Building trust is not something you can build according to a disability or not. It is something that grows from your relationship by experiencing things together. Persons with disabilities sometimes have low confidence because of their experience with being excluded in their life. Because they cannot follow their partner as they wish, they might be suspicious sometimes. It’s like they are always told that they miss something, so they might feel incomplete in building a relation at first.

*Do persons with disabilities prefer to fall in love with someone with a*

*disability as well or they prefer a non-disabled partner?*

This depends on personal choice. There might be persons with disabilities who prefer this. Some told me that they don’t want to deal with the prejudice of a non-disabled family in law. In a family who has experience with disability they feel more comfortable and accepted.

However, persons with disabilities can also be in favour of a non-disabled partner to complement to their challenges. The aim of marriage is that two will become more together that individually. They think that by marrying a non-disabled person they can complement each other to reach more in life.

*How accessible is Voluntary Counseling and Testing (VCT) for a persons who is hearing impaired?*

Persons with hearing impairment

don’t face difficulties in the physical access to VTC. However, in the counseling the difficulty arise. Here, the confidentiality of counseling is an issue that is difficult to solve.

Some inclusive VCT centers choose to work with a sign language interpreter. In this case the confidentiality is not as intended because there are three people present at counseling. Furthermore, deaf people are sometimes not comfortable with a deaf counselor because the deaf community is very close.

Another solution is to train counselors in sign language. The feasibility of this is a difficult issue. ECDD trained many VCT counselors over the last years. They can learn enough sign language in a short time span. However it is challenging to employ them for all shifts.

Yetnebersh (ECDD)





## Afterword

I have never met a development practitioner who was against inclusion of people with a disability. Also when it comes to Sexual Reproductive Health and Rights Programmes: everyone agrees that it is important to include persons with disabilities. The personal stories of people with disabilities who are trying to access services are touching and exemplary for the discrimination they face. They cannot be ignored. Yet, many development organisations don't come any further than stating that they should do something about it. The reality of development work is harsh: there are deadlines, donors and a dozen of cross cutting issues to think of. So in practice it is very difficult to take time to really do something on inclusion of people with disabilities.

How can development organisations take the step from 'we should include' to 'we do include'? And how can we overcome the feeling that we are doing something 'extra' when we work on inclusion of persons with disabilities? These are just two questions that the participating organisations\* of the Thematic Learning Programme on Inclusion are trying to find an answer to. There are no easy answers here, but one of the learnings in the TLP is that it is important to stress that working on inclusion helps your organisation to reach its own objectives: e.g. empowering marginalized groups, reaching the poorest of the poor or development for all (name it the way you like it). Another lesson is the importance of attitude change. Exclusion is the result of strong prejudices, ignorance and stigma. This can only be overcome if there is a real attitude change at all levels: from the management and staff of the donor organisations to the staff of local partner organisations and communities. The good news is that once people really change their mind about persons with disabilities they often see many opportunities to work on inclusion and good results can be achieved!

Paulien Bruijn

Coordinator Thematic Learning Programme  
on Inclusion of persons with disabilities

\* The following organizations participate: Tear Netherlands, Edukans, Oikonomos, Help a Child, WarChild, ZOA, Dark & Light, Aflatoun, Liliane Foundation, Netherlands Leprosy Relief, Tearfund UK, Kinder Not Hilfe Germany, Mission East Belgium, IAS Denmark + 10 partner organizations in Ethiopia & 11 in India.

In the thematic learning programme on inclusion of persons with disabilities we want to facilitate a Trainers of Trainers (ToT) on Worldvisions' *Traveling together* handbook about 'how to include disabled people on the main road of development'. We are still looking for an organisation that wants to host this TOT and additional participants are welcome to join. You can find more information on *Traveling together* at <http://www.worldvision.org.uk/what-we-do/advocacy/>



The Thematic Learning Programme (TLP) on inclusion of persons with disabilities, funded by PSO, is initiated by five Dutch NGOs. They aim to transform the situation of exclusion of disabled persons in development. Together with their partners in India and Ethiopia they started including persons with disabilities in their programmes with the intention to lead the way for societal change. Disability specific NGOs in India, Ethiopia, and the Netherlands and the VU University, Athena Institute, assist this network in the process of change. Ten other European NGOs join the programme out of enthusiasm for the topic. These organizations together form a learning network on inclusion of persons with disabilities.

This newsletter is one of the outputs to stimulate exchange of experiences within the network.

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