

3rd STAKEHOLDERS' DIALOGUE ON DISABILITY AND RESEARCH

12th of April 2016, Nob View Hotel, Kampala

Organized by

Disability & Technology Research Group

www.disabilityandtechnology.uzh.ch

WORKSHOP REPORT

To cite this report: Disability & Technology Research Project: Stakeholders' Dialogue on Disability and Research, Workshop Report, 2016, 3.



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1 Introduction

The third Disability & Technology stakeholders' dialogue took place on the 12th of April 2016 at Nob View Hotel in Ntinda, Kampala. The meeting was intended to deepen the discussions between various stakeholders in sharing and discussing research results and to provide insight into project approaches. Through presentations by researchers as well as by one representative of a Disabled Persons Organization, perspectives and arguments, as well as experiences were made explicit.

2 Organization

In this half-day workshop, three researchers of the D&T research group (Marie-Theres Schuler, Ambrose Murangira and Ronald Luwangula) presented preliminary findings and put them up for discussion in the plenum. Additionally, the executive director of Uganda National Action on Physical Disability (UNAPD), Mukasa, Apollo, introduced their current work on accessibility and accessible technologies, especially in the field of Water, Sanitation and Hygiene (WaSH) of the organization, which was followed by a discussion. The workshop was organized by the research group Disability & Technology (www.disabilityandtechnology.uzh.ch) and funded by the Swiss national Science Foundation.

3 Presentations

The aspects presented by the researchers were selected findings that were deemed to have a possible practical implication. Theoretical discussions and concepts were not directly introduced or discussed – although of course underlying directions and approaches of data collection.

3.1 Categorizing PwDs in Kyangwali Refugee Settlement: Challenges and Opportunities

Marie-Theres Schuler

Marie-Theres Schuler does her research among people with physical disabilities in Kyangwali refugee settlement in Western Uganda. In her presentation she focused on the following questions: How are people with physical disabilities categorized in the refugee settlement? How do they and their families experience this categorization system? And what consequences does the categorization system have for their daily lives?

Uganda's self-reliance strategy expects refugees to cultivate a plot of land in order to become self-reliant. In order to identify, protect and especially support people with specific needs, UNHCR and its partner organizations work with two categorizations: PSN (Person with Specific Needs) and EVI (Extremely Vulnerable Individual). People with disabilities, like orphans, single mothers, elder-

ly, or for example pregnant women are automatically considered as people with specific needs (PSN). Once considered as such, special support in terms of building a shelter, a latrine, or other material support can follow. The EVI category protects a person first of all by not reducing or completely withdrawing food rations provided by the World Food Programme (WFP).

Categorizations are the basis on which organisations in Kyangwali provide support to vulnerable people. The budget is outlined along these lines and often donors decide, which category of vulnerable people should receive specific aid items. Limited funds sometimes also require a further selection of who is most deserving within a category of vulnerable people. Marie presented experiences of people with physical disabilities and mentioned they often did not understand or not agree with these logics of distribution. Furthermore, humanitarian workers face dilemmas on who deserves which support in situations of limited funds.

Marie also looked at the definition of disability and how vulnerability of people with disabilities is assessed. In comparing UNHCR's universal codes of physical disability with the definition of disability in the International Classification of Functioning, Disability and Health (ICF), Marie revealed the rather medical perspective within UNHCR's categorizations. The environment, in which a person lives, as well as the social assistance he or she receives, is not captured in these universal codes. Marie exemplified how, depending on environmental and social factors, the same impairment can result into quite different disabilities. She however emphasized, that despite the rather medical definition of the categories, humanitarian workers on the ground actually do consider environmental and social factors when they assess the vulnerability of a person. Even when institutional support is provided, daily activities like cooking, collecting firewood or washing clothes often demand further social support. The humanitarian organizations recognize this necessity and help in mobilising the community to assist people that do not have any family support.

After looking at the different challenges that come along with a categorizations system, Marie pointed to opportunities. She suggested that categorizations could also be looked at as an instrument of funding opportunities for innovative projects. She also recommended a contextualization of the universal tools to assess vulnerability and of definitions of disability.

3.2 Discussion

Marie's presentation triggered a discussion and critical thinking specifically about the categorisation system and about issues of dependence on external aid among the people concerned.

3.2.1 Determining Disability, Vulnerability and Support

Participants discussed the question about the definitions of disability and its practical use. It was noted that an assessment should never be left to medical specialists alone. The discussion clarified that assessments are a task of a multi-functional team in Kayngwali.

It was also noted that the categorisations themselves are important especially due to the fact that organisations such as UNHCR are faced with limited resources on the one hand, and overwhelming needs on the other. Social relationships are included in the criteria of the categorisation EVI, and if a person with a disability has a spouse for example, they may not be considered as extremely vulnerable. It was noted however that this method might not regard the quality of these social relationships enough.

Another factor that determines the allocation of support for people with disabilities is the source of the funding and the conditionality of the donors. “The way we receive donations determines how we give them. When we receive items for all, we give all. In case of the goats (as an example mentioned in the presentation which some participants felt excluded from), the budget was under child protection. They decided to prioritise children with disabilities, and not all people with disabilities and so we couldn’t give all people with disabilities” as noted by one of the participating stakeholders from Action Africa Help (AAH).

3.2.2 Social, environmental and bodily factors

Due to the limited available resources, social networks are being emphasized and promoted. People in the community need to be sensitised on the needs of people with disabilities, in order to change their attitudes towards these people. This will supplement the limited organisational support available.

The given organisational support should be mindful of the environment. There is no need, for example, to give out wheelchairs when the environment in which the individual lives or the bodily condition does not allow the use of the wheelchair. Such assessments, however, may not be clearly understood or appreciated by the potential beneficiaries. A case in point is when a child with a disability was assessed and refused a tricycle due to the physical strength it requires to operate - the parents however were unhappy with the service providers for not giving their child a tricycle.

3.2.3 Dependence on humanitarian assistance

Another important issue was the question if people with disabilities can be graduated from this support system at some point, or if they remain dependent on it for their time in the camp. Supporting organisations should be mindful of the fact that such systems are important but may create dependence if no capacity building is done for the people.

3.3 Communication Technologies and Access to HIV/AIDS Education Messages among the Deaf

Ambrose Murangira

Researching on how Deaf people access HIV information, Ambrose's presented his preliminary findings.

Radio - Despite radio being audio, 100% Deaf respondents are interested in accessing radio information due to its wide coverage and cost effectiveness. They access radio information through other people, mainly family members and friends. They revealed that a "very helpful" category of people are young persons who usually try different ways such as using basic signs and writing notes to make them understand information being disseminated on radio. They also point out some challenges they encounter as a result of depending on others such as keeping them waiting and telling them that they "disturb too much".

Television - all respondents have a similar view that if televisions are provided with sign language interpreters on all programmes broadcasted it can be easily accessed especially by sign language users who do not know how to read. Ambrose's preliminary data also reveals that there are three televisions (UBC, Bukedde, and NTV) providing sign language interpretation services. A challenge is that the sign language interpretation services are provided only during news hours. That leads to the situation that Deaf people are likely to miss education messages on HIV and AIDS which are disseminated as adverts, in live talk shows or through 'health focus' programs.

NTV provides sign language interpreters once a week during the "week in focus" program. In dealing with these challenges, some Deaf record some programs of interest using smartphones and look for a sign language interpreter or a friend to interpret for them. Others send text messages or whatsapp to their sign language interpreters or hearing friends, asking them to 'summarize' what is being said. A good example is the *bulamu* advert on sexual reproductive health. Others watch first news e.g. NTV@7PM and if they get interested in certain issues, they get someone for the next news e.g. NTV@9PM.

Films/ DVDs - Some respondents revealed that they once received DVDs from UNAD and NUDIPU. The DVD was in Ugandan Sign Language and had subtitles. They note that information was very clear and they had an opportunity to rewind the film to clearly understand. They note that other DVDs do not have sign language and subtitles hence benefit those already with basic information who can manage to relate what is being shown to what is already known.

Posters/ bill boards - these are common around Kawempe at major junctions and the Deaf interviewed indicate that they are usually reminded of HIV and AIDS. However, they note that sometimes they are confused as some bill boards appear as if they are promoting sexual activities. For instance, a respondent directed Ambrose to a bill board of *bulamu* reading: "I have no problem; I

use a condom". In the picture on this bill board is a young man and a young woman holding each other's hands.

For those who can't read or understand the bill board/ poster take pictures using their smartphones and post such pictures on social media, especially whatsapp and facebook asking friends to help them understand.

Mobile phone – 100% of respondents consider mobile phones as the best communication technology, which can make HIV and AIDS education messages accessible to Deaf persons directly. Deaf persons use mobile phones in a number of ways aimed at making them access HIV and AIDS education messages and other information. For instance, they use their phones to take pictures of posters or bill boards with HIV and AIDS education messages and then ask friends about the meanings of such education messages. They also use mobile phones to access internet and surf the net especially social media. *"I have opted to facebook where people post educative messages which are usually first spread audibly. I read to my best understanding and satisfaction"*, a female respondent noted. They also use their phones to download short videos on HIV and AIDS education from the web but mainly those in a sign language easily understood by Deaf Ugandans. They share such videos among themselves through mainly whatsapp and they also discuss contents. The phones are also used to make appointments with Doctors and sign language interpreters when going to a health centre. Parents are also finding mobile phones convenient in communicating with their Deaf children. For instance a young person (respondent) said that his parents bought her a phone so that they are able to communicate with her. They send her health tips and verses from the Bible to keep her away from risky sexual behaviours. The functions of a phone used the most by the Deaf are vibration; SMS and MMS. Though mobile phones are viewed by the Deaf to be convenient for them, they noted that they spend more time than the hearing people – they have to send text messages and wait for a response or send reminders unlike the hearing who calls and get instant feedbacks. Downloading videos and pictures takes a lot of MBs hence they are costly.

Newspapers – some respondents also mentioned that they get educative information about HIV and AIDS through newspapers. They mentioned Straight Talk as being a "good newspaper" for them because of simple English, focus on SRH and "good presentation" (question and answer approach). They do not like reading long stories/ information. They also keep such newspapers for the next gathering like after church services where they get together for those who can read to translate in sign language. They are more interested in pictures and drawings, which they easily follow to understand the message being disseminated. However, all respondents noted that the English used in daily newspapers such as New Vision, Monitor, Red Pepper and Observer is hard to understand.

Workshop – all respondents had attended at least one workshop on HIV and AIDS. They find workshops interesting as sign language is used lively so questions are asked and answered as

the training goes on. Respondents noted that workshops benefit both educated and uneducated and helps to build networks and peer clubs.

3.3.1 Information accessed

The respondents noted that using above communication technologies, they have been able to access the following information about HIV and AIDS: AIDS kills; AIDS cannot be cured; anybody can get it; how AIDS is spread (they mentioned only sex and blood); how to prevent AIDS (they mentioned only condom use); effects of HIV and AIDS to the community; how to care about people living with HIV/AIDS.

The findings so far indicate that Deaf persons are accessing both audio and visual HIV and AIDS education messages through a number of ways. Access to information by the Deaf appears to be “bargaining to access” as there is no system in place to ensure the Deaf are able to access such information on equal basis as others and/ or as a right apart from the three television stations mentioned.

Uganda was recently reviewed (for the first time in history) by the United Nations Experts on the Convention on the Rights of PWDs (CRPD) in April 2016 in Geneva. One of many questions from the experts to the Government of Uganda (Minister for Disability and Elderly, the head of the delegation) was about how Deaf persons access websites and other related communication technologies. The Minister did not respond to this question. What is the role of DPOs (our stakeholders) in this? Will you use these findings to lobby your government to implement CRPD as well as SDGs, which aims at “Leave No One Behind”?

3.4 Discussion

The discussion highlighted areas where the researcher could focus more or put more emphasis: The study seems to focus more on deaf people who live in urban areas and have access to all these different communication technologies. What about deaf people in the rural areas? It would be important to focus on what challenges are experienced by the deaf people while trying to use these technologies because it may not be as easy to access and use as has been presented. Possibly there is need for an advocacy campaign that all TV stations should have sign language interpreters.

3.5 UNAPDs Involvement in Technologies for People with Disabilities

Mukasa Apollo, Director of the Uganda National Action on Physical Disabilities

UNAPD is a national organisation of persons with physical disabilities that started in 1998 and has currently over 5000 fully registered members with 40 member district associations. It is their overall aim to remove barriers in society that prevent people with physical disabilities from enjoying full rights on an equal basis with other citizens.

UNAPD is focussing on inaccessible environment and environmental barriers limiting the access to services, programmes, or performing the rights.

What is meant by physical accessibility? The ability of a person to reach a place and manoeuvre within it, to use the service, receive and use information; participate in daily activities.

Apollo introduced the members to Uganda's legal framework regarding disability, but also the limited implementation of the laws. Against the background of the ratification of the UNCRPD, and especially article 9 (accessibility), UNAPD mobilized the disability movement to develop the Accessibility Standards. UNAPD, in collaboration with different partners, launched the Accessibility Standards in 2010. Furthermore, they established a National Accessibility Audit Committee to supervise and monitor different constructions and to make sure that they are in line with the Accessibility Standards. responsible for assessing the accessibility status of buildings in 2011. In 2013, the Parliament of Uganda passed the Building Control Act and adopted the Accessibility Standards as a reference document in the construction industry.

Furthermore, in 2014, the UN Committee of Experts on Human Rights and Policies awarded the Accessibility Standards as among the 65 most innovative policies in the world and there is hope of the Accessibility Standards to become an international document. Other countries, like Ghana, took over the idea.

One challenge is to implement such standards in the awareness of the architectures and planners. The department of architecture at Makerere University has adopted accessibility as a module in the training curriculum of architects involving disability & inclusive design.

UNAPD engages itself in advocacy and lobbying (meetings with relevant stakeholders, accessibility audits, public media campaigns, influencing policies and legal frameworks) and participation in the design process (review of building plans / drawings, technical advise on site, participation in the designing of drawings, evaluation of on-going projects on accessibility like WASH programmes (e. g. in cooperation with World Vision). For accessibility, the design processes, as well as the production processes are critical. The production processes takes place in cooperation and is a process through learning, planning and accommodation that is localized and owned by all participants.

Apollo also presented the gaps identified in the use of technologies. He mentioned that people often have limited skills to translate accessibility indicators into practice. Another problem is that there are often negative attitudes of the concerned stakeholders on issues of accessibility inclusion. It is a wide-held assumption, that making a place accessible is very expensive. There is furthermore a lack of funds to enforce the monitoring mechanisms of accessibility in the construction industry.

UNAPDs concrete recommendations are to follow up with the Ministry of Works and Transport to ensure that the regulations of the act are accessibility compliant. There is need for increased advocacy for the implementation of the relevant policies and laws on inclusive designs. The different development partners have to be lobbied to fund the inclusive design advocacy work. The government needs to be lobbied to officially enforce the implementation of the Building Control Act; there are no resources of the government body to monitor accessibility in the construction industry. Different stakeholders should form a coalition for the joint advocacy on inclusive designs.

3.6 Discussion

3.6.1 Different models for different types of disabilities?

It was inquired how different types of disabilities can be considered by a single type of technology. As there is definitely no technology that is equally accessible for all, it is the aim to build for example a latrine that is user-friendly for the majority. To assess the user-friendliness, one or more prototypes are developed, while feedback is collected and adjustments continuously made in the testing phase. It is key to combine the ideas and skills from the different participants in the process and especially people with disabilities themselves, and to use local materials, in order to be able to fix the devices without importing material or without power. It is also important to consider the different needs of women and men/ girls and boys in using technologies like latrines.

Furthermore, it is important to select the material of the construction/technology depend on the users and other environmental aspects. E.g. for children, such technologies need to be different because they might play with it).

It is also of importance to paint supporting technologies in bright colours for persons with visual impairments, and to make sure that the ground can not become slippery – neither for shoes nor for assistive devices.

3.6.2 Engaging stakeholders and fostering implementation

UNAPD could try to make money with their accessibility audits and monitoring services, for example by being engaged for their work by KCCA. The Building Control Act should be used by UNAPD

vis a vis the Accessibility Standards. Instead of waiting for regulations, the institutions can already be taken to courts of law, and then institutions will act.

Apart from working together only with universities, UNAPD should try to engage associations of professionals (e.g. association of architects, Uganda professional engineers). This would be helpful to assess the specific needs of people with disabilities in regard of specific professions, but UNAPD has made the experience so far that they are not easy to get access to and that they are not very responsive. It has also been argued that it is more important to engage people with disabilities in the planning process instead of professional consultants, as they are the real experts.

3.7 Disability and Road Transport: Experiences of Persons with Physical Disability (PWPD) and the Visually Impaired

Ronald Luwangula

Ronald Luwangula's research interest and focus is the interaction of PwPDs and visually impaired persons with road transport in and around Kampala. He documents the experiences of these two constituencies in relation to: the modes of public transport available for and/or used by these PwPDs, road design, road safety, road space, and the abilities to reach their destinations.

Road transport is the most common and used means of public transport in Uganda like in many other developing countries. The modes of public transport available to the general public includes among others taxis (Matatus), buses operating between Kampala city and up country towns, inter-country buses, intra-city buses ("Pioneer" Buses and "Awakula Enume" Buses), motorcycles (boda-bodas), bicycles (non motor boda-bodas), and special hire cabs.

The road transport system - the nature of roads, pavements, traffic lights and zebra crossings demonstrate the kind of terrains on which PwPDs are entangled as they struggle for opportunities to also participate in their day-to-day civil, political, social, cultural and economic lives of their communities in Uganda. This comes at a time when disability is argued to be a "constitutive element of social relations" in that disabled persons are significant actors in history and development discourses as well as structuring thoughts about social hierarchies in society.¹ In this case, if PwPDs are appreciated as development actors and have to relate with other actors to make society better, their interaction with transport technologies is paramount.

Evidence gathered reveals that PwPDs and the visually impaired are far from enjoying the different modes of public transport. First, the faults with the interior design of different transport modes exclude these PwPDs. Buses, taxis and cabs are not necessarily tailored to the needs and

¹ Baynton, D. (2005). Immigrants and Suffragists: The uses of Disability in citizenship debates. *PMLA*, 120(2), pp. 562-567

demands of PWDs—they lack space to accommodate the mobility technologies of PWDs, lack ramps to facilitate entry and exit while boda-bodas visibly lack any space or provision to accommodate the wheelchairs and tricycles. The road design has inherent defects and largely frustrates PWDs' participation in civil, social and political life of their communities. Pavements expected to offer mobility space for PWDs and the visually impaired are a host of electric poles, sign posts, gullies and sometimes terraces. They are also used as parking lots for vehicles and boda-bodas. Flowerpots intended to close deadly manholes and beautify the city present a blockade to mobility of PWDs along the pavements. The continuous (re)construction of drainages means pavements are disorganized and the PWDs are among the most effected.

This pushes the PWDs to compete for space with other road users—taxis, trucks, boda-bodas and cars. In this competition for road space, PWDs are inevitably the underdogs. In terms of safety, human technology (traffic officers) competes with electronic technology (traffic lights) in their instructions yet PWDs in the low wheel chairs are often only able to see the traffic lights, not the traffic officer. Crossing roads is considered unsafe and for this reason, some PWDs keep wrong lanes for fear of crossing. Another safety concern is that wheelchairs and tricycles lack headlights and reflectors. While for the visually impaired, several zebra crossings are too dull/faint to be observed by partially blind, they are not provided for by the non-audio traffic lights, and the taxis and buses lack audio technology that pronounces the next stage/stop. The blind are also taken advantage of by some uncouth taxi operators who cheat them while others take them past their board off point without any sense of courtesy to support them get back to where they ought to board off. In view of all these experiences, PWDs are treated as second-class citizens, something that the stakeholders during the dialogue argued to be even a better representation given of what actually they go through.

3.8 Discussion

3.8.1 Parking challenges for PWDs with personal cars and wheel chairs

The discussion raised a dimension of possible inquiry. Based on lived experiences, some stakeholders indicated that it would be also interesting to document the experiences of PWDs who have their private cars. Of interest is how much space is available for not only parking but also to allow this PWDs to get out of the car into a wheelchair and proceed to wherever he or she is to conduct business.

3.8.2 Legal framework that regulates road usage

An argument was advanced that in order to make a case, it is imperative to interrogate the different legal frameworks with a bearing on road usage, tease out any provisions for PWDs and estab-

lish the extent to which these are lived up to. In particular, the Road Safety and Traffic Act was alluded to.

3.8.3 Common advocacy agenda

Stakeholders challenged themselves—as members of organisations of and for PWDs to have a common advocacy agenda as opposed to doing what they referred to as piecemeal and isolated advocacy and lobbying. The government body does not have enough funds to monitor and access the accessibility of buildings. But even without these funds, it needs to be possible to take concerns further and start for example by examining public places and especially government buildings themselves for accessibility. With a good plan and agenda (including expected outputs, who should advise such a meeting), it should be possible to make compromises in this sense with administrators. Especially the KCCA needs to be engaged, and for this it is enough, to present the observations made and relate it to the legal frameworks. It is furthermore important to engage the practitioners on the ground, like for example, transport officers, or officers who supervise the construction and adjustments of buildings. There is no need to wait longer for engaging the different people in regard of implementing policies. For this matter, a proposal was made to start up a working group specifically aimed at engaging KCCA officials and Road Authority officials such that our discussions do not just end while in workshops or conferences or dialogues but take on the action points to engage concerned stakeholders.

3.8.4 Wheelchairs and tricycles as a means of transport not just assistive technology

The discussion also argued for the reflection on wheelchairs and tricycles as a means of transport not just assistive technology. The visually impaired for instance own cars and each time they need to use their cars, they compulsorily have to hire drivers. It means besides thinking about the cost of fuel, the cost of a driver equally sets in. A further question is, if there are minimal professional standards for the transport provided (e. g. what are the services that a cab or a bus driver has to provide for a person with a disability).

3.8.5 Exhaustion and inconvenience suffered by the visually impaired

A recommendation was made to reflect upon the exhaustion and inconvenience that the visually impaired suffer from as they continuously negotiate with public transport operators at any one moment of interaction with public transport. Such negotiations as “help me put me at this particular point” does not come without inconvenience, compromised dignity, compromised competence and some level of dependence.

3.8.6 Tax waivers for modified disability friendly cars

The discussion also raised a positive concern that the government offers tax waivers for vehicles adjusted to suit disability friendliness. Of concern however was how public transport vehicles can be encouraged to move towards that trend. What needs to be done to see that one time, PWDs enjoy disability friendly public transport? These are some of the issues that the proposed working group on road transport will contend with in its engagement with targeted stakeholders.

3.8.7 Gender dimensions

What do blind women versus blind men go through? For instance, if a taxi drops a blind female at a wrong stage or destination and only men are available at that stage to guide this woman to where she should be going, what does that mean to her? What are the safety concerns? How does she react? Is the experience the same as men's?

4 Way Forward

The organisers of the conference asked for a feedback from the participants of the dialogue, especially in regard of the organisation of the next dialogue in July/ August 2016. It is the aim to have mutual benefits out of these dialogues. It was agreed that the content of the presentations will be shared with the participants. Any kind of event that might be interesting for the research group should be communicated to them as well. The researchers furthermore offered to help accessing relevant information for the stakeholders on specific topics. This can be requested for through email, and by approaching the researchers personally.

It was furthermore suggested to invite the following stakeholders for future meetings: sector heads of relevant ministries; Office of the Prime Minister; Ministry of Works and Transport. The research group will consult the stakeholders in advance of the next dialogue in order to identify further relevant stakeholders for the respective studies. A format, which is often used in the US in regard of advocacy, is that researchers write a letter to key persons with key recommendations – even if it is still work in progress. It was suggested that the researchers draft such letters for the stakeholders' dialogue and circulate it in advance, so that they can be discussed, agreed on, signed and taken forward in all our names to the key people. This was especially suggested in regard of the research on road use and transport. As the roads in Kampala are going to be renovated very soon, a communication from our side should happen before it is too late and the mistakes repeated. A working group has been formed for the practical part of it.

5 APPENDIX 1: List of Participants

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