

# THE WORK AND LIVELIHOODS OF PERSONS WITH DISABILITIES IN UGANDA

## MARKET-BASED SOLUTIONS FOR THE EXTREME POOR PROJECT

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**This report was authored by members of the Peer Research Group:**

Richard Rubangakene  
Apiyo Nancy  
Sylvia Obol  
Emmanuel Rubangakene  
Lawoko Filda  
Florence Amito  
Roseline Laker  
Akello Scovia  
Okello Simon  
Lawoko Filda  
Justine Namyalo  
Joseph Kimbowa  
Robinah Namutebi  
John Bbosa  
Sumaiya Nansubuga  
Aisha Nava  
Namaganda Rose  
Harriet Nalule  
One further anonymous researcher

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## Introduction

This document presents the analysis of research carried out by persons with disabilities in two localities in Uganda, using a life story analysis method. The research explored their experiences of work and their ability to sustain a livelihood. This work is part of a wider project, Market-based Solutions for the Extreme Poor, funded by The Rockefeller Foundation, described below.

The research in Uganda was designed and facilitated by Danny Burns and Erika Lopez Franco from the Institute of Development Studies (IDS), University of Sussex. It was extensively supported by the Uganda office of ADD International Uganda – coordinated by Josephine Alidri. All data collection and analysis was carried out by local peer researcher teams. This document is a report of that analysis.

The report is divided into three main sections: [Section 1](#) describes the methodology, research design and research process. [Section 2](#) presents the overarching analysis of the peer researchers based on clustering and system mapping exercises. [Section 3](#) presents the analysis done by peer researchers grouped under the eight themes that they thought were most relevant to deepening the analysis.

## 1 Methodology, research design and research process

Authored by Danny Burns and Erika Lopez Franco

### 1.1 Aim of the research

The aim of this research is to understand the lived realities of persons with disabilities and the choices they face when trying to find and sustain a livelihood. We want to understand – from persons with disabilities and not through secondary analysis – how livelihood options are constrained by the systems within which persons with disabilities live, and what pathways can be opened up to enable better access to secure and sustainable livelihoods.

As indicated above this research is situated within a wider project which has three research elements. The first of these is desk research carried out by the Institute of Development Studies (IDS), the Coady International Institute, and ADD International. This has produced a [typology of market-based approaches](#) (Thorpe *et al.* 2017) available for people living in extreme poverty and marginalisation based on a series of case studies in various contexts and not only targeting persons with disabilities. The second element, carried out by the two peer research teams and facilitated by IDS, is the analysis of 91 stories of persons with disabilities (the subject of this report). The third element, carried out by the Coady International Institute, is a multi-stakeholder analysis, developed through focus groups and interviews with local market actors, of the markets and value chains that might be relevant and/or accessible to local people within the specific localities we worked in (Ghore 2017). Finally, through a [deliberative panel](#), peer researchers, traders and government officials, representatives of organisations of persons with disabilities, private sector and non-profit sector actors came

together to make sense of all of the evidence gathered in the previous activities (as reported in Burns and Lopez Franco 2017).

All of this material fed into a meeting held at The Rockefeller Foundation's Bellagio Centre in Italy in October 2016 where a selection of international policy makers discussed the issues generated by the research.

## 1.2 Assumptions and approach

The first assumption underpinning this work is that persons with disabilities know more about and understand better the issues relating to their own life experiences than any external researcher could. In other words, they are experts. This does not mean that they have the only relevant knowledge – which is why their work has been developed alongside the other elements described above. But it does mean that their work should not be framed by 'external knowledge'. Once they have articulated their own knowledge and understanding through the life stories method, the deliberative panel allowed them to juxtapose it and compare it with knowledge generated by others.

The second critical assumption is that whether or not people are able to read, or can see or hear or speak etc., they have as strong an ability to analyse as anyone else. The methods used were adapted to enable this in a meaningful way; effective support (resource people, carers, recorders, interpreters, etc.) was also provided throughout all the steps, but there was never any doubt in our mind that the quality of the research would be very high – and so it proved to be.

The underpinning approach of this research is participatory. By this we mean that the research stories are collected and analysed by persons with disabilities from other persons with disabilities (peer-to-peer), that they are able to validate any public representation of their views, and that they can generate ideas for addressing the issues they identify through analysis. In this regard the research is resonant with the longstanding rallying cry of the disability movement 'nothing about us without us'.

## 1.3 Peer researchers

This project involved two peer research groups – one based in urban Kawempe (situated on the outskirts of Kampala) and the other in the northern rural Gulu district, Odek sub-county. By 'peer researchers' we mean persons with disabilities working together with other persons with disabilities. Those collecting the stories of persons with disabilities were themselves persons with disabilities; and they then analysed the stories collectively with other persons with disabilities.

We have not sought to achieve representativeness or to determine the frequency of the specific issues identified. This would be impossible in research of this sort. The aim of the research has been to understand the complex dynamics that face persons with disabilities in their everyday lives as they try to make a living. So the focus is on *how* and *why* things

happen, on what constrains the ability of persons with disabilities to act, and on what opens up meaningful pathways for them.

We started by identifying our urban and rural localities. They were two areas where ADD International had a track record of work and could mobilise effective support. We set a series of selection criteria. All the peer researchers should be persons with disabilities; we should ensure a mix of different impairment types and a good mix of men and women; peer researchers should reflect the educational and income level of most persons with disabilities living in the research sites (e.g. most should not be able to read). As many as possible of the peer researchers should not already be known to ADD International. In the category of those known to ADD International we should identify people who have a positive story to tell (we wanted to be able to learn from positive deviance) as well as negative ones. While the sample size was too small to draw generalisable conclusions, we noted that certain highly stigmatised impairment types – including deaf-blindness and albinism – were not represented among the positive deviants.

One limitation of the research was that we did not gather the experiences of persons with intellectual and psychosocial disabilities, nor did the peer research group include people with these impairment types (please refer to [Annex A](#) for reasons). The research cannot therefore be taken as being representative of these groups' experiences. For instance, persons with intellectual and psychosocial disabilities are at risk of particularly extreme marginalisation. Livelihood interventions have the potential to mitigate – or to exacerbate – this marginalisation, depending on their approach. This would be a fruitful area for further investigation in future.

## 1.4 Research design

The core method involves the collection and analysis of life stories. The aim of the life stories is to understand the different experiences and livelihood choices faced by persons with disabilities. The process involved a story collection workshop; a story collection process; and a collective story analysis workshop. The story collection training was carried out in January 2016. The stories were collected between January and March 2016. The collective analysis workshop took place at the end of March 2016. The workshop was then written up by Danny Burns and Erika Lopez Franco. The two groups met again for a full day workshop to validate – amend and add to – the write-up. On the basis of those meetings this report has been validated by the peer researchers as an accurate reflection of their analysis.

In total, 91 stories were collected which are anonymous and will not be published due to ethical and confidentiality matters. These stories are essentially open-ended life stories but they do have a focus on work and livelihoods. Peer researchers were taught how to ask open prompt questions; how to solicit causal accounts; and how – without framing them – to deepen and probe the narratives that the participants themselves have generated. The researchers were taught, for example, how to ask probing questions, deepening questions, and clarification questions, and to ask questions like 'what happened next?' and 'what happened as a result of that?' to ensure that the stories contained strong causal connections.

Once the researchers had practised this process in the story collection workshop they piloted story collection in their respective localities. ADD International organised for literate recorders (i.e. research assistants) to accompany them so that they could get an accurate account of the story, using the relevant local language, Luganda (in Kawempe) and Acholi (in Gulu). The recorders were instructed to take as verbatim a record as possible and that they could not actively engage in the questioning as this was the role of the peer researcher. In the first instance each group collected a few stories which were translated into English so that the IDS could give feedback. Once we were confident that the stories were strong the peer research teams collected all of the stories. In total, 41 stories were collected and analysed from Kawempe and 50 from Gulu. All of the stories were translated into English for the workshop so that IDS and Coady researchers could engage with the content.

The next stage of the process was a week-long collective analysis workshop. The idea of such a process is for small groups to analyse together the whole of the data. This means that no one analyses all of the data, but by putting the collective analysis together we can see all of the underlying patterns. What is powerful about this sort of analysis is that it:

- enables a group of people to see the patterns and relationships within the whole even though each pair only sees the detail of a part of the whole
- is rooted in the perspective of persons with disabilities themselves and is therefore owned by them
- can be done quickly (in a week) in such a way as to be useable.

We divided the participants into pairs. Each pair had 11 or 12 stories to analyse. ADD International organised strong support for the duration of the workshop which included two Acholi translators; two Luganda translators; two sign language translators; five focal points (resource people who could provide logistical and administrative support as well as help with reading text) and five support researchers who had helped to record the stories.

Before analysing the stories the groups did some more work together on causes and consequences and practised drawing system maps which linked the key factors in the stories. Important to note is that special attention had to be provided to the visually impaired people in order for them to keep up and be able to contribute. Once this was done, the small groups were given 24 hours to analyse their stories. Some groups were a little slower and others a little faster so stories were redistributed from the slower to the faster groups as necessary. The participants were asked to write two sticky notes: one with a negative factor highlighted by the story and another with any positive factor; all sticky notes were identified with a code so that we could track which story they came from. These sticky notes were clustered on two large paper sheets (see Figures 1 and 2). This gave us a strong sense of what was important in the stories.

We then asked the groups to draw on their causal maps to show how the clusters that they had identified were interlinked. This helped us to identify some of the key causal connections. Finally, we asked participants to look at the maps and reflect on their analysis and choose eight topics for more detailed discussion. The rest of the workshop comprised dialogues on the key issues chosen. The write-up that follows in this report reflects:

- a. the peer researchers' discussion on the linkages between the issues identified by their mapping – see [Section 2](#)
- b. the peer researchers' more detailed discussions about the key issues – see [Section 3](#).

These discussions firstly focused on drawing out the evidence from the stories about the issue; participants then went on to discuss the implications of this evidence, and finally they brainstormed possible solutions.

In all of this work the 'data' comes from two sources. The first is the stories from the ground, and the second is the life experiences of the peer researchers themselves. It is not possible for all of the story givers to analyse all of the stories so this analysis is carried out by the peer researchers to ensure the analysis is as close to the ground as possible. Peer researchers also reflected on their own experiences and used that knowledge to help build an understanding of the issues.

## 2 Collective analysis – whole group discussions

Authored by Danny Burns and Erika Lopez Franco based on the peer researchers' analysis

In this part of the analysis the peer researchers made observations on the whole, noticed what surprised them, and talked through the linkages between the clusters of sticky notes representing groups of stories. As we have seen in the methodology section, the group produced two maps. One showed the linkages between the 'positive pathways' and one showed the linkages between the 'negative pathways'. This section of the report is a write-up of the conversations about the clustering and the maps. Firstly, we can see from Figures 1 and 2 below the positive and negative issues identified.

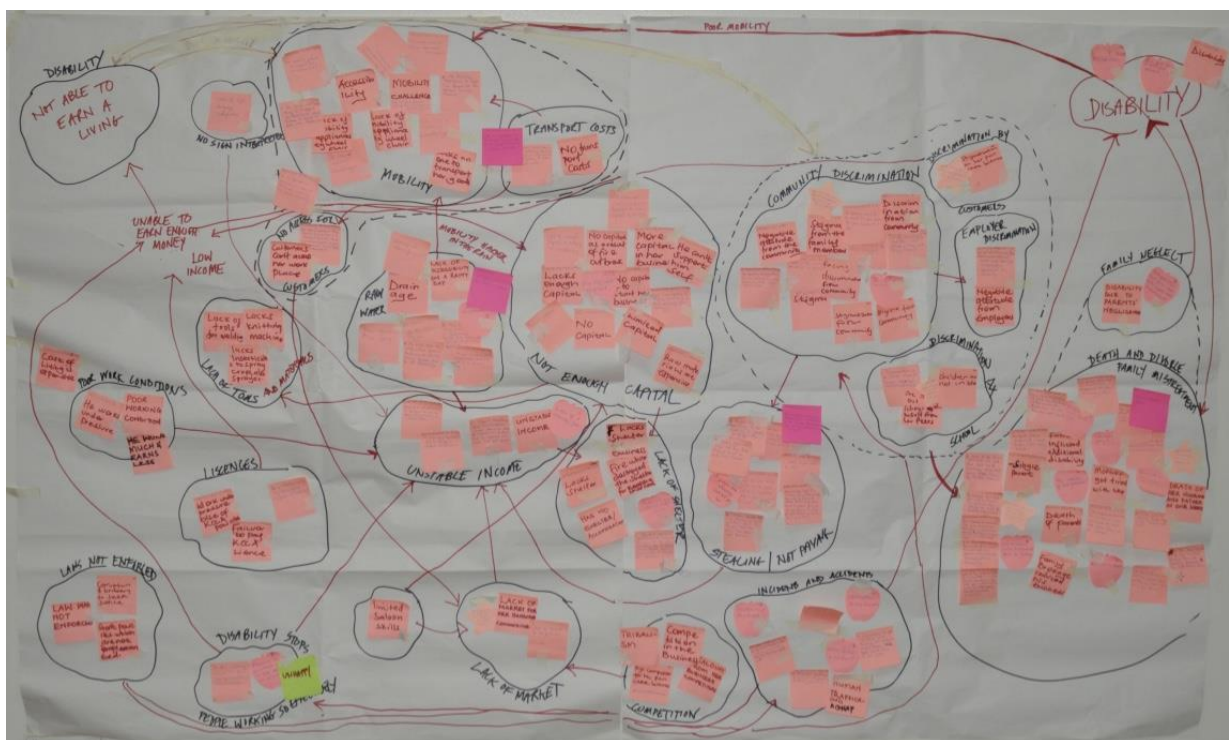


Figure 1: The main negative issues identified

The negative issues identified by the clustered sticky notes in Figure 1 are as follows:

1. Discrimination
  - 1.1. Community/neighbours discrimination
  - 1.2. Discrimination at school
  - 1.3. Discrimination at the work place
2. Death, divorce and family mistreatment
  - 2.1. Family neglect
3. People stealing or not paying for their merchandise/service
4. Incidents and accidents
5. Lack of shelter and land
6. Accessibility to markets and from customers
  - 6.1. Mobility: access to wheelchairs, etc.
  - 6.2. Transport costs for people and for their products to the market
  - 6.3. Customers' inability to reach them
7. Lack of sufficient capital to start businesses
8. Seasonality: rainy season complicates livelihoods
9. Lack of licences
10. Lack of market
11. Competition
12. Erratic/unreliable law enforcement
13. Poor working conditions
14. Lack of tools
15. Disability prevents people from working effectively

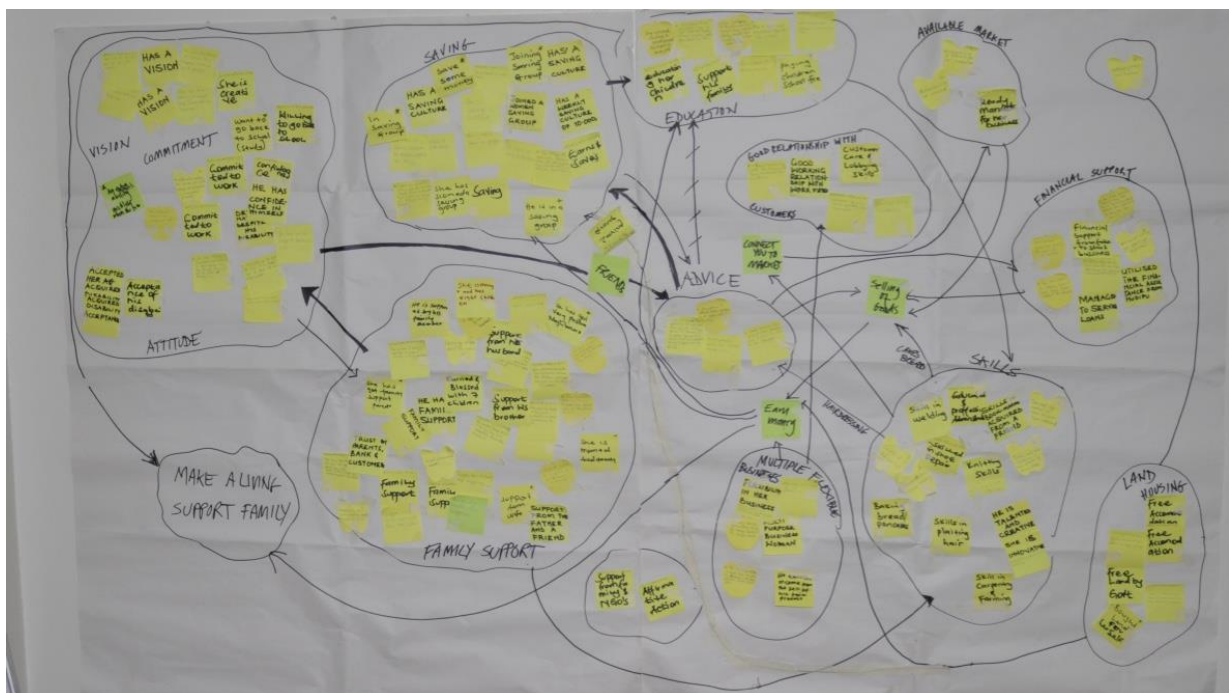


Figure 2: The main positive issues identified



The positive issues identified by the clustered sticky notes in Figure 2 are:

1. Support from family, friends and other helpful people (e.g. neighbours, etc.)
2. Commitment, determination, vision and self-esteem
3. Saving culture and availability of community saving schemes
4. Access to skills, training, education
5. Loans and access to some capital
6. Different sources of income through multiple businesses undertaken simultaneously
7. Ability for customer care, good work relationship
8. Land, free space to work or stay without renting
9. Advice and mentoring for business
10. Availability of market opportunities
11. Government and NGO support
12. Working from home
13. Respect for rights of persons with disabilities among some people

The maps help us to see the big picture. These are some of the issues that the group noted. It was surprising that government and NGOs were only prominent in two out of 91 stories.

## 2.1 Analysis of the maps

One of the things that was very clear from the maps is that almost all persons with disabilities are self-employed (growing or making things or providing a service, e.g. hairdressing – and then selling that locally). Few persons with disabilities are formally employed. Also almost all persons with disabilities are engaged in two or three different enterprises. This is because the types of work they can do are unreliable and their disabilities amplify that insecurity (e.g. they are cheated, they cannot sell in the rainy season, etc.). Persons with disabilities have to engage in multiple income-generating activities to ensure that when one fails they have the possibility of income from another. Overall, this was seen as a positive rather than a negative factor by the peer researchers.

We looked at the number of sticky notes for each issue and the linkages. What was very clear was that the largest number of sticky notes on the positive map related to support from family and friends, followed by issues of confidence and self-esteem. In many stories, bad family relationships frequently led to a spiral of decline amplifying difficulties for persons with disabilities. More generally the map highlighted the fact that family neglect leads to disability, as well as disability leading to family neglect; a few stories mentioned that people got an impairment in their childhood because their parents did not take proper care of them.

It was striking that the largest number of sticky notes on the negative map related to death and divorce, situations which can significantly reduce the income and the ability to access land of those spouses (mainly women) who have been abandoned. Women with disabilities felt that men approach them only for casual sex rather than for marriage. They felt that persons with disabilities should marry amongst themselves to stop being exploited. Children with disabilities suffer in the same way when the family income is reduced as a result of divorce. Once again this leads us to focus on family issues as a foundation for any work on disability.

Family relationships also featured as the strongest factor on the positive map. Good family relationships can lead to a significant upward spiral enabling persons with disabilities to create positive pathways which lead to livelihoods. Family support fosters confidence, self-esteem, a positive attitude, and a vision for the future. These in turn lead directly to the ability to create relationships and networks, and these relationships give access to external support and advice. This point was stressed by the peer researchers who felt that those persons with disabilities who were able to be positive received far stronger family support so this becomes a positive upward spiral, which the peer researchers thought was crucial for starting and sustaining an economic activity. Another important aspect of confidence is that it enables persons with disabilities to forge good customer relationships. This is crucial because they are already battling against people's prejudice.

Peer researchers were surprised at how strong the culture of saving was amongst people who had such low incomes. One participant said that he had assumed that because people had so little it would be impossible for them to save but this proved not to be the case. It is important because there are a lot of sticky notes on the 'positive map' which show positive outcomes where people save. The culture of saving enables persons with disabilities to pay for children's education, for example.

This is linked to confidence. Confidence often results in making friends who give you good advice, and one of the most important pieces of advice is to save. Good advice also leads to the ability to sell goods, because even though persons with disabilities can craft or cultivate produce, they often don't have access to information on how best to sell them. Advice did not appear as a major issue in the stories but the peer researchers felt that it was a crucial factor and talked a lot about it.

Education is seen as a short-term expense but also an investment for persons with disabilities because their children will look after them later. However, for persons with disabilities there is a lot of discrimination at schools and in the workplace for , which leads to either dropping out or completing school and still not being able to make a living. The acquisition of skills is also seen to be very important and these are currently gained mostly through family and friends. Whilst analysing the maps, there were few accounts of formal skills training; although a few stories did mention short training courses such as welding, catering and tailoring.

Unstable incomes and not enough capital lead to a lack of shelter. This in turn leads to an inability to generate income as you do not have a stable place in which to run your business. Land and accommodation are seen to be crucial. If you have these then you can save because you don't have to spend your money on rent. This is also why a lot of persons with disabilities work from home but this comes with a whole set of other problems. For example, customer access is a problem when it rains and the roads are blocked. In that sense, it becomes evident that improving the roads and overall infrastructure would also be important but this was seen by the peer researchers as overly ambitious and too long-term an idea for which people cannot afford to wait.

### 3 Collective analysis – thematic discussions

Authored by the Gulu and Kawempe peer research groups – written up by Danny Burns and Erika Lopez Franco

This section records the peer researchers’ discussion of each of the main issues they raised. As much as possible, the voices of the peer researchers are preserved. Erika and Danny have provided an initial summary paragraph presenting the main message for each of the themes.

It is important to note the different ‘voices’ within this section, as set out in the table below.

<b>Voice</b>	<b>How presented</b>
Peer researchers’ description and analysis of stories	Ordinary text
Peer researchers’ own stories and direct quotes	Text with quotation marks italics
Quotations from the stories gathered in the field	Within a box
Section summaries by Erika and Danny	Bold
Interpretations/interpolations/observations by Erika and Danny	[ordinary text in square brackets]

The text refers to both ‘we’ and ‘they’ as sometimes the peer researchers are talking about themselves and the wider community of persons with disabilities (we) and sometimes they are talking about the people who have told their stories (they)

#### 3.1 Family support

**Family support gives persons with disabilities an underlying stability that makes it easier to develop a livelihood; the absence of this support substantially increases the challenges they face. Family support builds confidence and a sense of self-worth which in turn makes an individual more likely to undertake and succeed in skills training or education. In most stories, family members provided the capital and/or land needed to develop a business. However, people who were rejected by their families (due to their disability or women who were abandoned/abused by their partners, etc.) were often found to be at much higher risk of poverty – unless a friend or other community member provided support instead.**

The family support is very important because if a person with disability is in a good family where they are supported, they are happy; with even the little money they get from their family they can save and start planning to think about the future. Also, when you are a person with disability living in a supportive family, you will not have a lot of trauma, you will rest well at night, ready to wake up in the morning to do your work. In contrast, not having this support can make you very sad/inactive.

For example, in one story a woman using a wheelchair was crying when she told her story because her husband divorced her, the house she was staying in was in an awful condition, and it was in a very isolated place away from the village. At one point, she even thought about committing suicide, until a friend gave her a little money and she began to sell fruit with her

children who push around the wheelchair. Another story, in Kawempe, was about a girl who was paralysed, except for her hands, but her family have helped her in many ways. They provided her with jewellery making skills and some initial materials, and her sister and mother have been able to sell her jewellery. In this case, it was important that she develop some record keeping skills because it was the mother who was taking sole responsibility for this.

One story allowed us to see that despite the fact that the parents had died, the siblings were sharing and considerate so the family member with disability was able to actually develop his business, pay school fees and gain some income. In a few other stories, supportive families gave land to persons with disabilities so this allowed them to set up a business, and in other cases families paid for the loans. However, for others it was the opposite: family members were not caring for those with disabilities; in fact, some family members frustrated the activities of persons with disabilities, especially when they noticed that the person with disability was progressing and doing well.

The worst consequence of family neglect is self-isolation, lack of confidence, low self-esteem and lack of determination. Some persons with disabilities consequently end up as street beggars. The wider implication is that persons with disabilities who are neglected by their families often end up facing greater social exclusion.

In the stories where there was absence of family support, friends, close community and neighbours were sometimes those providing support to persons with disabilities. In one story in Gulu, a woman had no support from her family despite the fact that she had skills in hairdressing, and her friends were helping her with that. In Kawempe, too, a woman had no love from the family, but at least neighbours and other community members helped her.

Having good relationships with other people is also another good thing for us to survive in communities. I am not rich but I have the friends who have greatly assisted me – woman with disability, Kampala

In a few stories, persons with disabilities had been able to marry and have children and this was seen as a motivation to keep searching for a livelihood. However, marriage of persons with disabilities is a point of contention. Some interviewees and peer researchers considered that marriage amongst persons with disabilities was not ideal in terms of the level of support required [implying that both parties will struggle finding a stable livelihood] but it is approved socially; as such, some persons with disabilities have ended up marrying spouses with disabilities against their will.

Others felt that marriages between persons with disabilities and persons *without* disabilities can lead to many problems. For example, some families of persons without disabilities own children fathered in such marriages (a peer researcher shared a personal experience). In Kampala, there were about five stories of persons with disabilities who married spouses without disabilities. Three of the marriages did not last due to lack of support from the spouse's family. Often, these men without disabilities abandoned women with disabilities because their families put pressure on them; even if they initially get married the in-laws push for the union to end. As a result, the peer researchers felt strongly that persons with disabilities should marry amongst themselves.

I was challenged in that [after my accident] my former girlfriends distanced themselves from me during the day. They used to come to my place at night. Whenever I requested them to go with me to different ceremonies, they always gave regrets. Two of them got pregnant and they had to abort because they could not stand giving birth to a child whose father was a person with disability – man with disability, Kampala

[My husband's] sister ... came back home and found me staying with her brother, then she started abusing me that I wasn't fit to stay in their home. That I am a woman with disability, ugly, I am not supposed to be alive, I am not fit to be seen in their compound. She then advised the brother to leave me, so that I go back to our home, and she will find for the brother another healthy able woman who can stay with him. Her brother who is my husband after hearing that, he then went to the centre and got drunk then came back home and started abusing me – woman with disability, Gulu

I don't have a loud voice over my husband, the other two [wives] have a loud voice and can be heard because they don't have any disability... My co-wives don't look at me as a human being and they call me with bad words. For instance they say I am a useless woman with disability and I am not fit to share a man with them – woman with disability, Gulu

Many stories spoke about women with disabilities being abused, abandoned with children, and in one particular case infected with HIV by men without disabilities. This situation made these women even poorer as they now had to care and provide for their children as well as take care of an illness.

I used to pay school fees for my children – my husband ran away, so I was the only one to support them. As you know, most men when they impregnate a woman with disability, they always run away – woman with disability, Kampala

My children are staying at home without going to school because I cannot raise school fees. People who used to come to me have disappeared and my husband abandoned me with all the three children. This simply has happened because I am a person with disability – woman with disability, Gulu

How can these issues be addressed?

**The peer researchers provided some ideas for overcoming the challenges arising from the life stories.**

- 'I would recommend training for the family members of persons with disabilities because some of them don't value their children.'
- It makes a huge difference if the family takes their children to school and vocational training. So families must be made aware that it's not enough to just provide food

because then when you're alone you do not have the means to earn a living. But if parents provide you with education then it's possible to fend for yourself.

- This training should be centred on the rights of persons with disabilities and how they can be inclusive of them within their families. It can even relate to the importance of integrating persons with disabilities into social dynamics. For example, involving persons with disabilities in all family and community celebrations within and outside the home – 'It is common to find families leaving behind family members with disabilities when going out for celebrations on festive days such as Christmas'.
- NGOs should train parents of children with hearing impairment in sign language to ease communication within the family.
- This training can be done by different organisations of persons with disabilities, who can organise community training with the families and once they are trained they will be able to extend it to the rest of the neighbours.
- Also the peer researchers can support other persons with disabilities: 'We could conduct these trainings, most of us are confident to do so, but we can also develop further skills to do it better'. The training content should include counselling, family planning, and HIV/AIDS.
- Use of role models with disabilities – to advise parents and create awareness and appreciation of persons with disabilities.
- Because in Kawempe everyone is busy, the way to do this training has to be in markets or other places where people gather
- Parents also should be advised not to marry off their daughters to men without disabilities because it is risky.
- In rural contexts such as Gulu, the local leaders will also need to be involved in training as they could also be obstacles if they are not included from the beginning.
- In these rural areas, it would help to have the government and NGOs sensitise and mobilise communities to provide communal labour for digging and cultivation of the lands of persons with disabilities [see below section on Land]
- We, as a research group, some being part of various different organisations, should come out to highlight the role that persons with disabilities have as business people in order to raise awareness within their families and the community
- In relation to abuse by men, we can organise a group of women with disabilities for training on sexual and reproductive health to be aware of these dangers. In Kawempe there are groups already doing this but they target those who are better educated, not those most poor and excluded. In Gulu, there was one group working on sexual and reproductive health but it stopped.
- There is definitely a need for working more with women but also men must be trained on these issues
- Your attitude has a big bearing on whether people will support you: 'If you have a positive attitude you will get more support from your family and neighbours, friends and relatives'. Some are willing. The problem is that the majority are also poor, so they think first of what they can get to eat.

### 3.2 Access to capital

**Capital is important for developing stable businesses. Persons with disabilities face not only physical but also hidden barriers to access the capital and financial support needed to start or grow a business. Overall, the research participants' stories showed that persons with disabilities, if given some basic opportunities, develop a 'savings culture'. However, there are many reasons why persons with disabilities are unable to access capital; these go beyond the actual physical barriers to reach financial services.**

In some circumstances, persons with disabilities don't have the capacity to work as productively as persons without disabilities, so the money they are able to make and the support they can get from friends and family is not substantial enough to save or use for growing their business.

Lack of capital leads to lack of shelter and also tools to conduct a business. Also, jobs that generate high salaries are for skilled and very strong people so not for persons with disabilities, hence it is hard to acquire capital. So, the bottom line is that persons with disabilities cannot accumulate enough capital.- man with disability, Gulu

Persons with disabilities fail to get money because there is a need for training in order to access capital. There is also an element of fear. Persons with disabilities are afraid to ask for a loan – bank loans have many terms and conditions associated such as collateral and inspection of the applicant's house. They also fear bank loans because their businesses are largely small scale and unreliable which means that they are uncertain about their capacity to repay. Because of this they prefer to borrow from friends.

I stopped taking loans in 2000 because when I started falling sick I was not all that strong. I could not even service the loan from BRAC – man with disability, Kampala

There is also a fear from the people who provide loans who don't want to take the risk of giving a loan to persons with disabilities. In Kawempe, a group of persons with disabilities wanted to connect tap (piped) water for commercial purposes. One requirement was to have the landlord as a guarantor, but the owner of the land declined to guarantee the application and the initiative failed. Another obstacle comes from the fact that certain microfinance schemes ask for a guarantor and most persons with disabilities who go to microfinance institutions don't have one. Also, there are some places not accessible for wheelchairs, and for blind and deaf people the communication barrier is huge because there is no provision of sign language and Braille.

'Persons with disabilities are not able to access this credit because we are not seen as having the capacity to generate income. For example, once I went to the market and wanted to borrow from this local group but I noticed people murmuring: How will she be able to pay back? She doesn't have tools in her house, she won't be able to pay back the loan. So I didn't borrow in the end.'

In Gulu, people's ability to save and build capital becomes worse when crisis hits – for example, when poor and unpredictable weather destroys crops or suddenly there is an increase in regular expenditure because of treating malaria or any other illness.

'For both urban and rural, the community saving groups are a more viable option. When persons with disabilities are saving it is because the village saving groups are near them. There is a positive story where there was a woman who repeatedly got loans from the saving scheme. Because she always repaid them she was able to get bigger loans which allowed her to become more stable. A key feature of these groups is that they are formed by people in the village who know you, know what you do for a living and don't require a guarantor for joining.'

They are accessible, near people and in the case of Gulu, there is no need to go into the city as it is the case with banks.

'Persons with disabilities save in those small groups because members of the group are your neighbours, people you work with, so when you take that money home you are encouraged to save in order to pay back. So, every day after work you separate a little amount.'

Another advantage of the group being nearby is that in emergency situations you can easily run to the group and request this money. An element of trust is also relevant. Persons with disabilities who are in a village saving group (VSG) cannot be cheated because they are all part of the community so it's easy to know and trust the others. Moreover, there are some groups which are only for persons with disabilities and others which are mixed; so if you see others (i.e. persons without disabilities) joining these groups you get the idea that you are also able to do it.

However, it is true that persons with disabilities often can only contribute to one saving group whereas some persons without disabilities can contribute to all the groups that exist in the village/locality. Also, persons with disabilities make friends in those saving groups. So, if a person has a problem with a family member or health issues then they are supportive and feel they can rely on the group.

Now even I am in the saving group as a member. I keep taking my money on a weekly basis and it is gaining interest. The saving group is also helping me to borrow some small loan that I am using to develop my business and at the same time I borrow for school fees. Thanks to the group in my village they do accept to include persons with disabilities among them. This has helped many persons with disabilities like me not to commit suicide – woman with disability, Gulu

However, while there are examples of VSGs which have been made more accessible and friendly to persons with disabilities, their reach is limited and they are not as useful in the city as in a rural context [in the conversations it was noted that those most marginalised people ignore their existence in both settings]. Persons with disabilities who are part of these savings associations usually save less and they cannot increase the amount of their loans because they do not have the capacity to pay back. Most saving groups hold weekly meetings at



trading centres or meeting venues distant from the homes of persons with disabilities; this limits participation of persons with disabilities in the savings groups, especially during the rainy season.

Because of my disability, which doesn't allow me to walk very fast, I am always reaching the saving group late, where I pay fine for my late coming – woman with disability, Gulu

Not all persons with disabilities participate in saving groups; some save with trusted family members:

'The only other way for persons with disabilities to access capital is to borrow money from friends and relatives. So parents and guardians should guarantee loans for persons with disabilities'.

Also in a cash box and secret places:

'In one of the stories collected, a person with disability who sells fruits (bananas and mangoes) ...was reported to be saving in a hole she dug in the ground in a spot only known to her. She wraps the savings in a polythene bag and buries it in the ground.'

How can access to capital and other financial services be improved for persons with disabilities?

- Have inclusive microfinance/banks with disability friendly terms and environments such as low interest rates and arrangements to guarantee loans. Promote trust of persons with disabilities.
- These microfinance institutions should offer training to persons with disabilities on enterprises and managing finances.
- In Kawempe, as most of the information on the existence of these savings schemes comes by word of mouth, there is a need to have more publicity on their existence.
- In Odek, a sub county of Gulu district, publicity comes from the community members of the village, but there is also information coming from the radio stations and the churches/mosques. This is not useful for deaf people: they can only know through friends as there are no posters or visual materials advertising the VSGs. So, there is a need for putting posters which are very graphic (also understandable for those who cannot read) in key places where people gather for example to watch football or trade their produce.
- Also face-to-face communication is needed, so if there is a training or workshop it must include *all* persons with disabilities and here you would provide this information about VSGs.
- Having the capital, and the knowledge on what is best to produce is important but this is not useful without access to the market to sell the goods. An idea that works is to access a bigger amount of capital if people ask for a loan as a group, not only as individuals. This has happened and there are documented cases in Kampala, not in Gulu. ASSA and Deaf Link are the microfinance institutions that have provided group loans and have supported persons with disabilities to access capital. Deaf Link, however, has now stopped operations.

- NGOs might be able to give support. For instance, currently in Gulu rain is not there so they could help with start-up capital. In the context of a place similar to Odek sub-county:

‘A grant of 300,000 shillings [US\$83]<sup>1</sup> is a good amount for cultivating crops for sale. However, 300,000 it is not adequate to start a produce business and meet associated costs of transport, rent and feeding. A person requires 400,000–500,000 shillings [US\$111–139] to start a produce business. Whereas 100,000 shillings [US\$28] can suffice as start-up capital for a basin full of silver fish obtainable from Barrio market (a distant but big auction market where prices are fair), otherwise for a bigger quantity, a person would require 250,000 shillings [US\$70]’.

- In Kawempe this is different as other many factors are at stake and the type of business you can start is more varied:

‘If working from home, as little as 30,000 shillings [US\$8] is useful. But then this substantially increases if you’re renting a space, to approximately 500,000 shillings [US\$111]. From the stories, one man who needs a small shelter for his shoe business for 100,000 shillings [US\$28] and another man who sells tomatoes can have a stall for 50,000 shillings [US\$14]. However, this grows a lot more if you are aiming to set a well-established business which for example, requires you to buy a sewing machine for being a tailor or other expensive tools for other occupations.’

- There is work to be done in changing the misperception that persons with disabilities are not hard-working people, who are not trustworthy and have no discipline; perhaps the peer researchers of this project could inspire others through their personal stories.

### 3.3 Land, housing and shelter

**Having land, housing and shelter makes a significant difference to the way persons with disabilities can develop a livelihood. The stories show that the few persons with disabilities who owned land, a house and/or a shelter from which to trade were much better off than those who didn’t have access to these assets. However, in Uganda buying a piece of land is impossible for the vast majority of persons with disabilities: it is only through inheritance or communal ownership that you can own land and prejudices from parents and clan leaders often obstruct access to persons with disabilities. A few government schemes exist but there is minimum knowledge about them and requirements are so complicated that few access the schemes or remain throughout the whole process.**

When people have land it multiplies their opportunities of attaining a more stable livelihood. Those who have land will be better off because they will save money, and rather than paying rent they are able to save to improve and grow their business. Also, if a person with disability has got a piece of land then he/she is able to get a loan more easily because it is a guarantee for the lenders – some sort of security. People who have shelter or land have their hearts at

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<sup>1</sup> Conversion rate as at 23 January 2017, to the nearest dollar, [www.xe.com/currencyconverter/convert/?Amount=1&From=UGX&To=USD](http://www.xe.com/currencyconverter/convert/?Amount=1&From=UGX&To=USD)

rest and they can concentrate on working and growing their businesses. A story was recalled of a deaf man in Kawempe who did have land and even had a plan to get more land and buy a car. He has been able to get to this point because through his business he has saved and takes his savings to the bank.

In most of the stories land/housing was acquired through family, but this was often more difficult for persons with disabilities because of discrimination within the family. The most common situation for persons with disabilities is to have access to land denied because people believe that it is not possible for us to make the best use of it. In one of the stories a man was denied land by his family due to his disability. [The area] where he is renting now is expensive so a lot of money goes to pay for this. In some other stories, women with disabilities were not given land by their family members because they were seen as of little value. However, discrimination in matters of land and shelter affects all women; not just women with disabilities.

My elder brother has sold off the land of my parents, he says I am a person with disability and can't cultivate the land – man with disability, Gulu

One time our husband went [away for work]...and he never came back. After some years, my co-wives came for the property. I tried to resist but I failed and they were saying that it is impossible for a person with disability to take and own property. I was overpowered and I had to come back to my father with my children – woman with disability, Kampala

The situation is particularly challenging when there is communal land like in Gulu. If you are a person with disability they sometimes deny you access to this communal land because they think you won't be able to use it properly. It is not your family but the authority of this communal land, the clan leaders, who will decide on any issues of the communal land. For many Ugandan people land has been inherited from our ancestors so we do not know how they acquired it. But when it comes to children and persons with disabilities the clan members will despise you and not let you have access. It's even worse if you are a woman, you are never allowed.

There were a couple of stories which spoke about Kampala City Capital Authority (KCCA) putting up some shelters where persons with disabilities could trade. But the truth is that the majority of the space was misused and mostly occupied by persons without disabilities, making KCCA reclaim the offer.

I got a place in the city where they had allocated the businesses of persons with disabilities. .... The space became small because persons without disabilities also came in this same market. One time they took my place when I was absent – woman with disability, Kampala

There have also been cases of persons with disabilities who come together as a collective to ask for this space to the KCCA. It is a requirement that they put a plan together for this space, what they will trade, what economic activity they will do. But because of the time it takes the

district to start the whole development, the deals tend to be forgotten. Persons with disabilities are able to mobilise and fundraise in order to get these spaces. For example, ADD International supported the fundraising for one of the organisations of persons with disabilities and now they have got a space. Sometimes they are able to get this land but then if they don't comply [with] paying taxes (i.e. licences) they are then chucked out as it is not ownership but a lease. In Gulu town there was a space for persons with disabilities to trade before. Today, in the town market a certain percentage of the space can be allocated to persons with disabilities, but in the case of Kampala this is only given to those who comply with a series of requirements; if you don't meet these by a certain point then you lose the space. Moreover, persons without disabilities easily take advantage of the situation.

A personal experience was shared:

'There is land gazetted for persons with disabilities which persons without disabilities have snatched. Having got financial capacity, the person without disability has established a washing bay and is using the earnings to acquire land elsewhere. There are even rumours that this land has been sold off and the matter is in court.'

Most persons with disabilities are not aware of the existence of these spaces. It's true, only very few people in the urban setting would know about these schemes. Rarely would anyone in the rural area have heard about them.

This is a market for persons with disabilities so we do not rent. However, we are worried because we can leave it any time when the KCCA decide to develop the area – man with disability, Kampala

It is technically possible to buy land, but it is extremely expensive and, for the great majority of persons with disabilities, impossible to buy as you have to pay all in cash; there are no schemes to pay in instalments. Some formal jobs have certain social housing schemes but certainly not those which are accessible to most persons with disabilities. In sum, persons with disabilities cannot even buy the land available at cheaper prices in rural areas, 'so, those who are born poor stay poor'.

What can be done to solve this problem?

- NGOs need to act on behalf of persons with disabilities to talk to the government to develop better saving schemes which allow for larger quantities of money to be saved in order to acquire land, and not only small amounts as it is now.
- Raising the awareness of parents is important: to treat all their children equally and to distribute the same amount of land to all of their children; it should not matter if they are a person with disability.
  - Persons with disabilities can also be encouraged to have a plan for the future: 'You can have a plan to save even small amounts, because you know that in the future you might acquire land, perhaps in the villages because in town it is very expensive'.
  - Persons with disabilities can form a group and save money collectively in order to acquire land: 'It is true; each of us in isolation won't be able to get very far; we must come together. But also some training is key to boost us on how to work together, how best to organise, seek for resources, etc.'

- Government should train persons with disabilities and their families on land laws and in so doing empower them to participate in resolving land conflict and protect their land.
- Persons with disabilities should form groups and develop ideas/proposals on a joint project in order to access land from government.
- For people who have severe impairments it is true that they will have a hard time, so other approaches are needed. However, there are many others who are still able to undertake farming. So, it is important to have much more involvement of the cultural leaders in the issues of land distribution and ownership amongst persons with disabilities.

### 3.4 Good advice on livelihoods

**Peer-to-peer advice and business advice can make a difference to the way persons with disabilities approach their livelihoods. Advice from experts and others who have managed to set up successful businesses is also useful. While this was not a major issue in the stories it was seen to be very important by the peer researchers and key to providing good services or sustaining a business**

It is easy to see from the stories what type of business a person with disability can undertake in order to thrive; thinking of questions such as: What is the business? Who is already doing it? How is that happening? Where is it located? What are the challenges of that particular business? So, if you as a person with disability have access to this information then you can start a business activity much better informed and with more possibilities for developing that livelihood activity for a larger period of time. From the stories, it was clear that people were jumping from one thing to another without proper knowledge behind their decisions.

Advice is important for selling goods because even if you have the skills (i.e. formal training) it is difficult to know what to do if you do not have advice on how to sell them:

‘With some skills you can directly start using them to buy products for the market. For example, [with] cakes and bread you don’t need further support; but, if it is something like hairdressing, then you have to get advice and people who connect you to the sector. People should make sure they seek advice and then start selling their goods and services.’

Another type of good advice is to help fellow persons with disabilities to learn from their peers. So, those who have been deaf or blind for longer can support you to live with your disability better. Peer-to-peer works well when there is cooperation:

‘For example, when peers dealing in the same business such as tailoring agree to make African wear and in the process share different ideas and advice on how to make [tailor] the fabric, they end up making a better product compared to working as separate individuals.’

Co-operation between peers in the same business can further widen the market, as peers refer customers to each other.

‘Also, your friends and personal networks can tell you: sell this secondhand clothing, there is a space where you won’t get evicted to trade, don’t come to South Sudan because things are dangerous, etc. This is another type of informal but valuable advice.’

If you are a person with disability you can advise your fellow persons with disabilities to join certain activities, which would encourage him/her to accept this disability and stay with our people. In the villages there are some people who have no idea about the existence of support, so it is important to let them know about it. For example, to get someone to dig their land, so at least they can cultivate basic crops to eat. Finally, when you give persons with disabilities good advice you take away the psychological trauma that many confront as a consequence of stigma and isolation. A type of advice that is very useful is telling us that we are 'one', that we all are united as persons with disabilities. We are left behind because we are on our own. If we worked more on pulling the others, telling our fellow persons with disabilities about workshops, training, etc., this would help us to grow together as persons with disabilities.

This saving group has helped me to gain more courage because there are many persons with disabilities who are the members. They became my counsellor of how to live in the community with my disability – woman with disability, Gulu

How can we increase the advice to persons with disabilities?

- Exchange visits with other persons with disabilities to learn how they are doing businesses in other parts of the country/world; we can learn from them.
- Exchanges [by means of] group meetings where persons with disabilities can share ideas and think about new enterprises.
- External advisers: there is value for external people to approach persons with disabilities to advise them on how to do business, for example how to attract more customers. But this should be done through good training like the [sessions] that have been part of this research: 'For those of us who are older, looking at our disabilities and our age, this type of training keep us going and gives us hope to be able to learn from experts'.
- Persons with disabilities should get business advice pertaining to commodity prices, record keeping, basic foods on demand, etc. from friends operating similar business.
- Dealing with competition: there were reports of witchcraft arising from jealousy (competition) among persons who engage in similar [types of] business, except when they worked together as a group and accessed capital from the same source. To address this, persons with disabilities should work in groups; apply for a group loan and implement agreed projects. People who have experience in a particular business should provide mentoring and coaching support to peers who are new in the business rather than look at them as competitors.
- Since persons with disabilities experience challenges with mobility, peer-to-peer/business advice through meetings is not a practical solution. So, there needs to be thought about innovative ways of providing this advice. For example, government and NGOs should regularly announce (create awareness) on market prices through radio and advise farmers against selling their produce cheaply.

### 3.5 Stealing, taking advantage and discrimination that affects people's ability to work

**The main focus of this group was on people who were cheated by their customers, middlemen and others in the community. The impact that this wrong behaviour has on the businesses of persons with disabilities was seen as far greater than for other businesses.**

Because of discrimination, as a person with disability it is almost impossible to be employed in the formal sector. For example a man did a catering course; he made applications and got interviews. On the form he didn't say he had an impairment but as soon as he came to interview he was rejected. They told him directly that this was because of his disability.

Another woman did a course and looked for jobs. She failed because 'you are just too short' [she is a person of short stature]. So she started self-employment with her friend. Because of her size her friend wanted to be the boss, but she had put more capital into the business. So they separated, and her business succeeded but in less than six months her friend's business had failed.

Insults are common. Nearly all of the other persons with disabilities reported being laughed at, insulted and cheated by middlemen and others. But discrimination also directly affects their ability to trade. Some people discriminate against persons with disabilities by refusing to associate with them or buy from them because they fear of contracting the impairment which they believe is contagious. Several cases were recalled.

One woman told of how other traders in the market discouraged customers from buying from her because of her disability.

In another case, a man who planted and sold sugar cane had some of the crop stolen from his fields and another time burned down – it was the local community members who did this.

A shoemaker reported that in many instances customers wouldn't come directly to him and went instead to persons without disabilities. Customers treated him badly and wanted to beat him, so that in the end he chose to trade through a middleman].

One woman, a mother with her own children, lived with her uncle, as her parents were dead. She grew and harvested crops, but her uncle sold them and used this money to drink alcohol. Her uncle claimed that the land was not hers so he was entitled to the profit from the produce. The woman reported this to the elders but nothing changed.

Another woman cultivated soya beans, but because she didn't have the capacity to carry the soya beans to the market, she sold them at a much lower price [she is cheated because she doesn't know the prices].

In another story, a deaf person who was engaged in farming green vegetables was not aware of the market price. Some people came in false pretence to help him, but they were in collusion with the customers. This is the problem of the middleman.

Some people despised me and they said, 'how can a person without legs design our clothes?– woman with disability, Kampala

People started saying, 'look at that woman with disability, she is crawling and then selling'. They think since I crawl I am dirty so my product will also be dirty. So there I started losing the customers because I am a person with disability – woman with disability, Gulu

When people are borrowing and not paying their debts then you do not want to sell to them anymore, so you start losing customers.

Other people borrow my products but they don't pay and when I try to ask for my money then that is the source of conflict... I will not do anything because they know for sure that I am a person with disability and have no voice. Sometime I think of taking them to the local leaders but I stop because I fear that I might lose my customers – woman with disability, Gulu

Participants also shared personal experiences of how having mobility challenges provides opportunities for persons without disabilities to snatch customers from them. For instance, a person with disability may be struggling to serve the customer, and the neighbouring trader without disability quickly renders the service; a practice locally called '*okuyiribya* customer' ('snatching the customer').

In one story, a lady who sold Chinese herbal medicine within Mulago hospital reported that whenever one of her customers comes when she is not there and asks for her, colleagues without disabilities in the same business snatch the customer. By doing this they take away her wage, as the work is on commission.

In another instance, a participant narrated a story of a man without disability who snatched a customer from a person with disability, by saying that the latter's brain was as impaired as his body. Hearing this, other persons with disabilities in their vicinity came together to protect their fellow friend. The man fled and has since changed his attitude.

Another story spoke about a person with disability in Nakulabye-Kiwunya zone who also faced the challenge of other persons without disabilities snatching his customers who were on the way to his shop. Due to this experience, he relocated his business and is now happy with its progress.

'Competition affects all traders, not only persons with disabilities. But we have more obstacles to manage this competitive environment of the street trade.'

How can this problem be resolved?

- NGOs need to support people to stop being cheated. They should sensitise the community and families on the potential of persons with disabilities to compete favourably in business if given the opportunity.
- Establish a law at sub county level to stop people being cheated. We at the village and parish level can make a bylaw to address cheating and stealing from marginalised



persons, including persons with disabilities. We need to mobilise and present a united voice to the authorities.

- Government should sensitise the community
- [Self-respect:] ‘You need to update yourself. To know that you are the owner. It all goes back to the self. If there is a middleman, you can use sign language to demand a number.’
- Those who give [sell] goods must learn to take cash and not give credit.

### 3.6 Unreliable incomes

**The incomes of persons with disabilities are often less reliable and stable than those of persons without disabilities. This of course increases their vulnerability to shocks such as unexpected illness. There are many reasons why persons with disabilities have unstable incomes, e.g. weather patterns and the fact that you cannot communicate with customers (i.e. no sign language).**

Unpredictable climate and poor weather cause unreliable income, particularly in rural areas such as Gulu. One example given was of a banana farmer who failed to make an income in a given period due to poor weather which destroyed his banana production. At the other end of the scale, when there is a big harvest [large supply in compared to the demand] then prices go down and this also leads to unstable incomes.

What I want to start doing is other business, as farming has lots of risk related to weather hazards. Besides, I have to rent land from other people for the farming. This is really a challenge when the harvest is poor – woman with disability, Gulu

In Kampala, the rainy season results in severe mobility issues for persons with disabilities (see section below) because the river streams flood and the roads that have a lot of potholes also become flooded. So, people with crutches fear movement because the crutches slide down. In addition, the footpaths become [impassable] because the grass grows and this stops the wheelchairs being able to move. Customers fail to come when it floods. This automatically leads to no or low income.

Income is dependent on the support that is available. Persons with disabilities can only produce when they can get the materials they need, and can only sell when they can get the goods to a market. If they cannot do these things themselves then they depend on others who are unlikely to be available all of the time.

‘There was a woman. When it rains she cannot get to the market. Her daughter helps her to move her wheelchair, but if her daughter is at school she cannot earn money.’

‘There is a beekeeper. She has a number of beehives. Because of the weight of the honey she has to sell from home, her income is lower. Her son takes it to the market where he can get a higher price. Sometimes she can get people to take her goods to

market and sometimes she cannot. Sometimes people in the community steal her honey [see section above]. The stealing creates an unreliable income.'

'A woman makes necklaces and bangles. She has to work from home. She has no limbs but she does have hands. She has to lie down to work. She can only get her materials and take the goods to market when her mother goes to Kampala. She has to wait for her mother to be around in case someone wants to buy, even being at home. She can only sell if her mother is available.'

'Waiting upon the supplier to deliver supplies for your business results in unreliable incomes, especially when the suppliers fail to deliver over a longer period of time.'

Stealing and cheating as described [by the honey seller] above means that persons with disabilities cannot rely on their incomes because they don't know how much of it they will actually get. [In addition], beekeeping is seasonal resulting into the lady's failure to have income when honey was scarce.

Another reason why persons with disabilities do not have stable income is because they keep changing business and therefore do not get to understand a particular trade:

In some way this multiplicity of incomes is also what makes them more secure. People have more than one job in order to manage the difficulties of getting income with one job. It cushions the livelihood of persons with disabilities better:

'It is good to have two jobs. One person has a job in a salon when it is raining and concentrates on farming when it is not.'

'There is a story of a man who started loading bricks, then he started car washing. When he had collected enough he was able to clean shoes. This business was successful but all of this work was making him have to move left right and centre which was difficult because of his disability.'

Some aspects of unreliability are the same for persons without disabilities also. You are selling some products which fluctuate in price. When you can, you wait until the prices are higher and let others sell at the local price. But during that time you are not eating.

What are the solutions to unreliable incomes?

- Join a savings group so that during a time when there is lower income you can borrow and boost your business.
- Form groups of people in a business. When we come together we can link up with others who have bigger markets. Those making the same products can link up with the big companies because there is more volume on the production.
- Establish a joint storage facility to store produce in bulk. This will enable the sub county to advocate for better prices for their produce.
- Say to persons with disabilities you should not go by the wind. Someone says milk, then fish, then... They should consult people they trust [the implication is that people's income is unreliable because they often fail with their new enterprises and so are constantly moving from business to business].

- Having access to proper information [about prices, weather conditions for certain crops, etc.] is needed in order to diversify, because when one commodity/business does not thrive, persons with disabilities can rely on income from the other business.
- In Gulu, persons with disabilities can focus on trading goods which are readily available and non-seasonal, such as paraffin, soap and salt, etc.
- One way to boost business for persons with disabilities is to start selling wholesale. In the retail business there is a tendency for goods to be taken on credit.
- Persons with disabilities need to be patient. Some goods you can keep for some time, e.g. honey, and then connect to market and sell at a higher price.
- Where possible, persons with disabilities should be supported to do a feasibility study before establishing a business: determining if there is demand and market for their product; research on the community and the clients to ensure that the enterprise is wanted/needed; for instance, it would be a mistake to open up a pork joint in the Muslim community. Also, check if the roads are accessible, and that the distance is manageable by the person intending to establish the business considering the severity and type of disability.
- The place should be made accessible in all aspects. It is required to strike a balance between finding a trading place only for persons with disabilities and integrating these spaces into bigger markets. Whereas persons with disabilities need protection of their rights and affirmative action, they also need to be integrated among other people so that they can learn new business ideas from others, share information and establish other networks.

### 3.7 Mobility

**Mobility is a big issue. Persons with disabilities have to pay additional costs for transport. They also have to pay middlemen to get materials and sell goods, which often results in a low quality of materials and lower prices for the goods. Peer researchers offered many examples from the stories:**

‘There is the case of one man. He has double crutches and has to move a long way to Kampala to get materials. Unfortunately, he has to climb to the second or third floor and this is very hard. Sometimes he fails and has to pay someone to buy what he wants, but this means he doesn’t get the colours he wants or the best quality.’

‘There is a man who is a shoe maker. He has problems with transport. It is too far from his house to a road with *boda bodas* (motorcycle taxis), so he has to take a motorbike which is twice as expensive. The problems are the inaccessibility of the road, the delays in public transport and then the expenses of the motorbike.’

‘A lady sells small fish. She lacks transport. So she sends people to get the fish but they bring back bad quality which she sells for lower prices or is not able to sell.’

‘There is a man with both of his legs paralysed. He uses crutches and his workplace is far. He is often late. He wants a wheelchair to reach his workplace more easily.’

‘There is a man who is a tailor but he does not have a mobility device. He uses a stick to get to his workplace, but the stick gives him greater pain. This causes another

problem and he has to rest for two days because of the pain [this is also relevant to unreliable incomes].’

‘A man who sells spare parts for bicycles has no means to buy the parts so he uses someone to buy the parts but often he comes back with the wrong parts.’

‘There is a cultivator of bananas. People want ripe bananas. He uses a motorcycle, but the driver charges him an excessive fee. This driver then sells the bananas to the market but makes less money.’

‘A child going to school has no wheelchair. He reaches school, but his hands are dirty because he has had to crawl in the dirt. The teacher complains that his book is dirty, so he has to get a friend to copy for him.’

‘A man who sells fish has a challenge in movement. When he travels long distance he has a pain in his hip and has to take days off.’

The rainy season also is strongly linked to mobility because it makes much harder to move to the workplace. The market places are inaccessible and get flooded. There are no places that persons with disabilities can sit comfortably.

What would make a difference?

- Those who have responsibilities for the road should take into account the disability issues. Roads must be constructed in a way that persons with disabilities can use them.
- NGOs like ADD International should lobby government for tax reduction or exemption on assistive mobility devices. Persons with disabilities have to buy the same things to do business but we have more costs due to the need for these devices.
- At the sub county level, groups of persons with disabilities should present to the local government their mobility needs.
- Families should take persons with disabilities to health centres so as to assess their health and mobility needs.
- Different impairment types require different assistive devices (hearing aids, wheelchairs, crutches, etc.), so the government should be responsible for providing these to the persons with disabilities who need them most and cannot afford them.
- Persons with disabilities should be provided with a bicycle and if they cannot ride the family member or neighbour can use it to help
- Accessible places should be constructed by government in the markets. In addition, authorities should enforce and ensure implementation of laws and policies; especially those on accessibility of buildings
- ADD International should lobby the Ugandan government on behalf of persons with disabilities who are engaged in trading in the rest of the world for tax reduction or exemption on their imported mobility devices
- Government departments in charge of road infrastructure should construct roads that accommodate people with visual impairments and guides.

### 3.8 Skills and education

**This was a shorter discussion which focused mainly on how people could get informal training while still working, as persons with disabilities do not have the time to attend formal education because they need to keep working to cover their basic needs.**

Inadequate or a limited level of education among persons with disabilities limits their employability and affects their ability to manage their business effectively. But not all skills are gained through school: 'Skills can be gained through formal education, but others are natural, we are born with some skills we gain through family support'.

Training in communication and basic literacy skills is needed. Deaf people experience challenges communicating with customers/community members and vice versa, so they need the skills to communicate. It is true that lots of persons with disabilities have not gone to primary school so they need to learn to read and write. Some people need training in counting. They need to know how much they have spent and saved [because fewer persons with disabilities have primary education this is a real problem].

[Discussions above highlighted the problem that people with no counting skills don't know the prices that they should be charging or even how much money they are actually getting. Moreover, the importance placed on savings across many stories as well as personal experiences of the peer researchers highlighted how essential it is to provide financial training to persons with disabilities.]

Persons with disabilities continue to keep their money in their houses because many of them not only find it difficult to understand and interpret the bank papers but also find it difficult to fill the bank forms.

A friend based in Juba sent me money with a request for me to open a bank account and deposit her money in it. Not knowing bank processes, nor how to read and write, I requested a friend to fill the bank form. This friend filled wrong information which I did not realise until I submitted the forms to the banker who supported us to fill a new bank form. Had it not been for the banker, I was finished. – woman with disability, Kawempe

Also, persons with disabilities prefer saving at home simply because it is physically easy to count the money rather than reading the bank statements. In Kampala, the majority of persons with disabilities keep money in their houses because of the failure of the community-based saving groups. They need to be taught the culture of saving in the banks, which are seen as more reliable.

The group discussed if it is possible to manage skills training workshops at the same time as work and how to do so. Someone suggested that the skills training needs to not be the whole day, because we need to work: 'It cannot be continuous. Maybe 3 or 4 times a week so we can work at the same time.' One peer researcher gives an example of herself. She weaves mats but when she was learning different styles and designs she trained daily for two or three hours. This allowed her to work while she was training.

What needs to be done?

- Organisations of persons with disabilities should sensitise teachers and schools about the needs and how to care for and support the learning of children with disabilities.
- The Gulu sub county local government should establish an adult literacy education centre in Odek to enable persons with disabilities to learn how to read and write and manage their business better. Training should include Braille language for the blind.
- Some researchers acknowledged that [there are] ‘skills we can get without having to go through the formal system’. So, organisations of persons with disabilities can also at least provide basic training in reading and writing to persons with disabilities. Moreover, persons with disabilities with experience in business should train other young entrepreneurs with disabilities
- Persons with disabilities need short, bespoke training sessions because skill issues are more complex if you have to do multiple jobs.
- Gulu Disabled Persons Union could identify a sign language trainer to conduct community based training for deaf people and other community members for the duration of one month within the community.
- Persons with disabilities should advocate for government to open up more schools that can benefit children with disabilities.
- Where banks are available, organisations of persons with disabilities should lobby various banks to create awareness and train persons with disabilities on savings and the banking systems. Persons with disabilities on the other hand should commit to learning the banking systems – how they work and how to take advantage of available and suitable products, including mobile banking.
- Some participants felt that persons with disabilities should be encouraged to only do one job and specialise; others disagreed and felt that persons with disabilities needed the security of multiple jobs and that training and education should take this into account [this remained a point of contention and no consensus was reached].

## Conclusions

Authored by Danny Burns

We want to highlight a few conclusions from this research. Firstly, persons with disabilities are the experts and disability research that does not put them at the centre is in our opinion likely to deliver a very inaccurate analysis and generate inappropriate solutions. Secondly, it is crucial to understand the systemic context that persons with disabilities live within. If we were to highlight just a few overarching points they would be these:

A focus on training, capital, loans and transport etc. is likely to miss the point: it is only when there are strong family and friendship bonds that give people self-esteem and confidence – and changes in the structural inequalities and discrimination that hold people back – that any of these [other] solutions are likely to work.

Most persons with disabilities are doing multiple jobs in the informal economy. In the short term this is likely to continue to be their reality so it is really important that solutions focus on the informal economy, not the formal economy.

Any solutions to the problems faced by persons with disabilities need to take these factors into account.

## **Annex A: intellectual and psychosocial disability**

One limitation in the participatory process was that we were not able to engage persons with intellectual or psychosocial disabilities as researchers, nor to collect their stories. In principle, ADD International and its partners seek to work with persons with any impairment type, in line with the UN Convention on the Rights of Persons with Disabilities. However, meaningful inclusion of persons with intellectual and psychosocial disabilities in participatory research is an area that requires specialist skills. We did not have these skills on the research team, and did not consider it feasible to train the peer researchers in such skills within the timeframe of the project. Undertaking the research without appropriate training risked leading to meaningless, tokenistic and potentially unethical participation – and for this reason we reluctantly concluded that we could not include persons with intellectual and psychosocial disabilities in the project in this instance.

We will be clear about this in all reporting of our findings, noting that that the experiences of persons with physical and sensory impairments may not be generalizable to persons with intellectual and psychosocial disabilities (who are likely, for instance, to experience particularly extreme stigma). This would be a fruitful area for further research in future.



## Annex B: Examples of positive deviance

### Example 1 (Kampala)

I am a widow, the father of my children died. I have four children and have a number of dependants. I met my late husband in 19XX. He was a neighbour. I am a bar maid, my mother was also a bar maid and we used to work together selling local brew. I did not stay in school for long. In that case, I decided to start this business because it makes me stay in one place. I did not have enough capital and my friends informed me that there was an organisation [MCDT] which was a microfinance organisation. I got the loan and bought a fridge and I started selling drinks.

I added the little money and the business moved on...

[After the death of my husband], I had to take another loan and my mother-in-law also assisted me with some money. Since then, my business has been moving on. I even paid school fees for my children.

I inherited my mother's customers, so they knew me and did not despise me. I am challenged with the way I get the beer to sell because I get it from a far place yet my mobility is not all that good since I have an impairment. I cannot lift heavy things. Another challenge is movement at the place of work when I am serving my customers, it gives me problems. It was the reason why I left the business of roasting meat because I could not move sufficiently to manage the two businesses.

I am not renting where I am working from. I normally get 3,000 shillings [US\$0.83] daily as profit. We have a SACCO [savings and credit cooperative organisation] for persons with disabilities we save and borrow money.

All my children are persons without disability and the oldest is working in one of the schools as cook. I have also managed to support the three young ones. I look at my future as promising in that my children have grown up and I intend to have a depot for beer so that I can stay in one place. This is because my problem is mobility.

I think that my life is very important since I look after so many people despite my situation.

## Example 2 (Kampala)

I am a man with physical disability and I am married with children. I came to the city to look for work but I did not go to school. I first worked as a banana porter from the lorry to the customers. I used to get 500 shillings [US\$0.14] per bunch and we used to fight because we were many on the job.

When I realised that this was not paying enough money, I joined an organisation of persons with disabilities which belonged to NUDIPU [the National Union of Disabled People of Uganda]. It gave us 20,000 shillings [US\$6] and I started selling pens and padlocks and books. I used to sell them at the taxi park. I used 20,000 shillings [US\$6] only. I used to put the money back in order to promote my business.

I got another chance because the government representative gave us a space in the new park and we were not paying rent. I then shifted from the old park to the new. I got more 20,000s and injected it in the business. I got it from our organisation.

This group belonged to us, the persons with disabilities, but it had no permanent name. We were 20 members and every member used to collect 1,000 shillings [US\$0.28] every day. I was the first to get and I got 20,000 shillings [US\$6]. My business started growing and at this time I could get a profit of 300,000 shillings [US\$83] per month.

I then started another stall of men's shoes. I buy them from [a certain district] and I buy one pair each time I go there. This is because I do not have enough capital...

[Later in the conversation, this interviewee added] I have a challenge of buying in the shoes in bulk because of capital. I have therefore to buy very few and the people are always many and they normally push us and as a person with disability, I get affected.

I get a profit of 30,000 shillings [US\$8] from five pairs. I put the profits back to boost my capital.

I am a poet and a musician. This has also promoted me. I have managed to get some little money to support myself. I also assist my fellow persons with disabilities. I compose my music and write my poems. I have managed to sustain my music group.... I have managed to record a number of songs and poems through this group. These are played on different radio stations....

I do not put in a lot of money to these radio stations but the managers give me some little air space and I display my talents. I want to tell you that ever since I started singing, I have never regretted why I am a person with disability. I have through this music group tried to promote other persons with disabilities with talents and we are supporting ourselves.

I now survive on my talent because I organise shows in different places and we perform. In a good show, we can get a total of 400,000 shillings [US\$111], since they pay 2,000 shillings [US\$0.56] as entry fee. I am proud because I have uplifted my fellow persons with disabilities. There was one person with disability who had no arm and he had one leg. During the show, a gentleman from Japan gave us 300,000 shillings [US\$83]. We bought music machines and we no longer hire them.

Although I have a stall where I am working from I have another one which I rent out ... to boost my income. One might think that I have a lot of money but I have a family and children like any other man.

I normally take my CDs when there are some music performances and I sell them I get some money from them. I sell each CD at 5,000 shillings [US\$1]. I leave my friend at the place of work and he assists me to sell the items.

Although I do not rent where I am working from, I cannot say that the place is mine because I do not have any document to that effect. In this case, KCCA [Kampala City Council Authority] can easily remove us. However, I am not discouraged because I do my work effectively.

### **Example 3 (Gulu)**

I am blind, being a blind person it is very difficult. I have nothing and I cannot even pay school fees for my children. I don't have any means of raising money. My disability has made many people neglect me. They abuse me and think that I cannot do anything. I really don't know what I can do to them. I don't have any freedom, even if I think of staying with my colleagues I cannot stay freely. I keep imagining how am living.

To make it worse, the issue of land is disturbing me a lot. I don't have any piece of land. If I want I must go and rent from the owners, who overcharge me. When I grow crops and it gives a good yield, the land owners even want me to give some to their family, although I already I completed the rent payment... I do some casual work in my neighbours' home and they pay me some little money. I save a little and use it to pay school fees for my children, use part of it for feeding, paying for land rent, and I keep the rest for any emergency like sickness. I would hire one acre of land and divide it into two. Half for planting sim-sim [sesame] and half for other crops.

After some time I saved some money but it was not gaining interest. So I decided to join the village savings and loan association. I started realising some interest on my savings. I also borrow money and it boosts my farming. In the savings group my colleague advised me to start farming in the wet land, because even during the dry season I will be producing. So I started growing tomatoes, cabbages, dodo [amaranth – a type of seeds] and egg plants. I have now many customers during the harvesting period and they come and buy right from home. So I started getting some positive change in my life because I am earning a little.

I have added to my business by buying and selling soap and paraffin.

I keep records of all the business separately. The amount I am taking to the savings group is written in a different book and the amount I am selling with the paraffin and soap is also done in the same way.

This business has brought great change in my life. I have friends who used not to be there. I am also forgetting about my blindness and the problems that I used to face.

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