

LONDON  
SCHOOL of  
HYGIENE  
& TROPICAL  
MEDICINE



LSHTM Research Online

Hartley, SD; Yousafzai, AK; Kaahwa, MG; Finkenflügel, H; Wade, A; Bazirake, G; Drachler, ML; Seeley, J; Alavi, Y; Mataze, W; +1 more... Mucuriguzi, E; (2017) Community action research in disability (CARD): An inclusive research programme in Uganda. *Disability, CBR and Inclusive Development*, 28 (1). pp. 5-92. DOI: <https://doi.org/10.5463/DCID.v28i1.630>

Downloaded from: <http://researchonline.lshtm.ac.uk/4650158/>

DOI: <https://doi.org/10.5463/DCID.v28i1.630>

**Usage Guidelines:**

Please refer to usage guidelines at <http://researchonline.lshtm.ac.uk/policies.html> or alternatively contact [researchonline@lshtm.ac.uk](mailto:researchonline@lshtm.ac.uk).

Available under license: <http://creativecommons.org/licenses/by-nc-nd/2.5/>

<https://researchonline.lshtm.ac.uk>

## ORIGINAL RESEARCH

---

# Community Action Research in Disability (CARD): An Inclusive Research Programme in Uganda

Hartley SD<sup>1,2,3\*</sup>, Yousafzai AK<sup>4</sup>, Kaahwa MG<sup>5</sup>, Finkenflügel H<sup>1,6</sup>, Wade A<sup>7</sup>, Bazirake G<sup>5</sup>, Drachler ML<sup>1,8</sup>, Seeley J<sup>2</sup>, Alavi Y<sup>2</sup>, Mataze W<sup>5</sup>, Mucuriguzi E<sup>5</sup>

1. University of East Anglia, Norwich, UK

2. London School of Hygiene and Tropical Medicine, London, UK

3. Faculty of Health Sciences, University of Sydney, Sydney, Australia

4. Department of Global Health and Population, Harvard TH Chan School of Public Health, Harvard University, USA,

Visiting Faculty, Aga Khan University, Karachi, Pakistan

5. Kyambogo University, Kampala, Uganda

6. Institute of Health Policy & Management, Erasmus University, Rotterdam, Netherlands

7. Institute of Child Health, University College London, London, UK

8. Department of Health of the State of Rio Grande do Sul, Brazil

### ABSTRACT

*The ideology of Emancipatory Disability Research (EDR) reflected in the phrase 'Nothing about us without us', was first put forward in the 1990s. Although it aimed to place research control in the hands of the 'researched', i.e., people with disability, this rarely happens even today, 25 years later.*

*The Community Action Research on Disability (CARD) programme in Uganda embraced and modified the EDR approach, recognising the need for including people with disability in the research process from concept to outcome, and nurturing participation and collaboration between all the stakeholders in achieving action-based research. The research teams always included people with disability and staff from Disabled People's Organisations (DPOs) as well as academics and service providers. It endeavoured to generate and carry out research around issues that mattered to people with disability and their families. Leadership roles were assigned by team members. The objectives of the CARD programme were: (1) to fund teams to carry out action-based research on disability in Uganda; (2) to develop research and administrative capacity to manage the initiative within the academic registrar's office at Kyambogo University; (3) to incorporate new knowledge generated from the studies into the ongoing local community-based rehabilitation and special education courses; and, (4) to ensure wide dissemination of research findings to all stakeholder groups.*

---

\* **Corresponding Author:** Sally Hartley, Email:sallydianehartley@gmail.com

*CARD ran for 5 years, commissioning 21 action research studies in the field of disability and community-based services. This paper describes the process, presents the 12 completed studies, examines the extent to which the objectives were achieved and evaluates the experiences of the participating research teams, particularly in relation to the inclusion of its members with disability. It concludes with recommendations for future initiatives designed to promote validity, good value and inclusive approaches in disability research.*

**Keywords:** *Emancipatory disability research, action research, participation, community based action research, disability research, human rights.*

## INTRODUCTION

The basis of the CARD project is rooted in the phrase 'Nothing about us without us'. This phrase was used by Charlton (1998) and Werner (1998) who focussed on human rights for people with disability. They wanted to communicate the idea that no action or policy should be decided by any representative, without the full and direct participation of members affected by that action or policy. Examination of disability research literature at that time indicates that research was mostly led and conducted by people without disability (Barnes and Mercer, 1997). Oliver (1992) was the first to use the term 'emancipatory disability research' (EDR), referring to a new paradigm that emerged from action research, which had the transformative aim of removing barriers and promoting empowerment of people with disability and their engagement in research. Features of this research paradigm included: (1) researchers making themselves accountable to organisations led by people with disability; (2) application of the social model of disability, resulting in an understanding of the social, cultural, environmental and political barriers that lead to disability; (3) ensuring that the voice of people with disability is heard throughout the research process; and, (4) dissemination strategies that reached the end users (Barnes, 2003). It was also argued that EDR should engage individuals with disability at every stage of the research, from concept to outcome, as suggested by Barnes (2003) as this had the potential of influencing the policies and programmes that affected their lives.

Over the last decade, progress towards effective and useful EDR has met with many challenges. Examination of current disability-related research reveals that people with disability are still rarely involved in planning and execution from beginning to end, let alone having ownership of the whole process. For example, examination of a 2015 edition of the 'Journal of Disability, CBR and Inclusive

Development' (vol. 6, No.4) revealed that out of the 8 studies presented, none were led or directly accountable to people with disability. Only 1 study used methods which might reflect an emancipatory ideology as part of the research process. Nevertheless although this study involved disability groups as consultants from the beginning to the end of its programme, none of the final listed authors were people with disability, although acknowledgements were made (Madden et al, 2015). Another 3 of the 8 studies in this journal, collected data from disability groups and incorporated their views into the results presented. The disability status of the authors is not apparent from the information presented in the journal so no conclusion can be drawn about the level of involvement from people with disability, neither is there acknowledgement that such involvement might be desirable. This pattern appears similar in other disability journals.

While there may be multiple factors that lead to the low participation of people with disability in disability research, their presence is only the very beginning of the journey. Mmtali (2009) comments that stakeholders (people with disability and their families), if involved, are usually approached as an after-thought, at the end of a project, rather than being consulted or involved in the development of the research questions from the beginning, and the analysis and interpretation at the end so the crucial emancipatory element can still be lacking even when people with disability appear to be involved.

A wider review of research on disability reveals that a great deal of it tends to focus on the medical or impairment aspects of disability, with less attention to the interactions inherent in the social model or the bio-psychosocial model, as outlined in the World Health Organisation's International Classification of Functioning, Disability and Health framework (ICF) (WHO, 2001). Using the ICF as a research framework enables a wider view of disability than only health conditions, and includes consideration of the environment and personal factors. Despite a resolution adopted by the World Health Assembly in 2001 (WHA54.21) encouraging member states to use the ICF as a research framework, this has also been slow to materialise; although in 2006 the Washington Group on Disability Statistics, in collaboration with the United Nations Statistical Division, made a significant move by developing a population level survey module on disability using an ICF framework ([http://www.cdc.gov/nchs/washington\\_group.htm](http://www.cdc.gov/nchs/washington_group.htm)).

A second challenge is to clarify the role of qualitative methods in disability research. The community of people with disability reportedly have a preference for qualitative research methods (Barnes, 2003; Mmatli, 2009). They see qualitative

methods as particularly important at this time because they ensure that the 'voice' (i.e., feelings, points of view, beliefs) of people with disability and their families are heard. This is considered key to an emancipatory approach, but it overlooks the fact that qualitative methods are obviously not appropriate for collecting demographic data or examining the efficacy and effectiveness of interventions. The limitations of taking a predominantly qualitative or descriptive approach are apparent in reviews of disability literature which identify large amounts of descriptive data (Finkenflügel, 2004; Yousafzai et al, 2014), but show little evidence about which interventions work and which do not. Perhaps it is for this reason that the scientific, policy and planning communities prefer the evidence offered by quantitative approaches. However, a predominantly quantitative approach undoubtedly struggles to reflect the attitudes and concerns of people with disability themselves and may again result in misguided research priorities. A balance between the two approaches is the desirable option, together with research capacity development to choose the correct research method in relation to the question being posed.

In addition to these challenges, the utilisation of disability research findings once secured is reported to be poor (Greenwood and Abbott, 2001). For example, in Kilifi, Kenya, research evidence showed a high association between endemic malaria and delayed language development, with subsequent and considerable limitations in local children (Carter et al, 2003). Despite these findings having emerged more than 12 years ago, the health and education services in this area still do not include any significant support for such children. In addition, results from many of the research studies conducted in the same district emphasise the benefits of community-based participatory practices (Gona et al, 2006), yet existing services are still predominantly centrally located and non-participatory. Of course the challenges of utilising research results are not confined to disability alone. Ways of addressing how research evidence can be used more effectively are needed by all avenues of health and education- related research.

However, in disability research, the authors consider that strategies which explicitly support the capacity development of people with disability to participate are a constructive way forward. They consider that the success of such an approach would involve capacity building for the other stakeholders so that both researchers and service providers learn to value and utilise the input of researchers who have disability, by recognising and respecting them as 'experts' in their field. They consider that such an approach has the potential to inform

the evidence-based development of better policies, services, utilisation and practices. These views form the basis for the development of the 'Community Action Research in Disability' (CARD) programme, which aimed to build on and develop a modified version of the EDR approach in the Ugandan context. The CARD approach facilitated research partnerships between people with disability, service providers and academics, in a continuous process from start to finish, with an appropriate lead person selected by the team. This person was considered to be the best one to fulfil the leadership role, and may or may not be a person with disability.

When CARD began in 2006 there was limited evidence available on issues relating to disability in Uganda; consequently services addressing needs of people with disability were rarely based on sound local information and evidence. Continued delay in investment in research on crucial issues such as Community-Based Rehabilitation (CBR), HIV/AIDS and education appeared to be increasing the social and economic disparities experienced by people with disability, as the Uganda government used resources for strategies that might not be effective in meeting people's needs. Furthermore, the absence of quality research in many higher institutions of learning in Africa had been a major setback that greatly affected local research output. Finally, it was observed that in Uganda the information and research outputs of Disabled People's Organisations (DPOs) and other NGOs were often not shared or disseminated to other groups.

The CARD programme, like EDR, sought to reflect the ideology that 'no action or policy should be decided by any representative without the full and direct participation of members affected by that action or policy' (Werner, 1998), by not only engaging individuals with disability at every stage of the research, from concept to outcome, but also by promoting partnerships with service providers and disability researchers/academics who were also stakeholders in this action. In other words, 'Nothing about us without us all.' The programme sought to promote collaborative, participatory action-based research. It was envisaged that this process would generate research data around issues that mattered to people with disability and their families, and that policy makers and planners (who were also encouraged to be involved in the research) could benefit and act on the information generated.

In order to achieve this aim, four objectives were identified: (1) to fund teams to carry out action-based EDR in Uganda; (2) to develop research and administrative capacity to manage the initiative within the academic registrar's office at



Kyambogo University; (3) to incorporate new knowledge generated from the studies into the ongoing local CBR and special education courses; and, (4) to ensure wide dissemination of research findings.

## METHOD

CARD was a research programme born out of a long association between the University of London and faculty of the former Uganda National Institute for Special Education (UNISE), which is now part of Kyambogo University, Kampala. The original link between these groups began in 1998 when University College London (UCL) transferred a postgraduate training programme in CBR to UNISE. This course and other related courses are now well-established and have subsequently trained over 1000 people in CBR, from Uganda and many other African countries. In 2001, a conference was held with representatives from 9 African countries. The outcome of this conference was to set up a trans-African Network organisation, the CBR Africa Network (CAN) with its secretariat in the CBR Department at Kyambogo University ([www.afri-can.org](http://www.afri-can.org)). Once the CBR courses had been established, members noted that the evidence-base for understanding disability, specifically for the appropriate development of CBR, was limited, especially in terms of local relevance. Therefore, in 2006 the UNISE CBR training programme identified a need to improve their capacity to undertake research and subsequently use the results to inform their teaching. They wanted to be sure that the training they offered was based on local evidence and would therefore be more likely to result in an improved quality of life for people with disability in Uganda.

At this point, funding of £200,000 was secured by the lead author at The University of East Anglia (UEA) from the UK-based charity, 'Ka Tutandike' (in Luganda, the main local language in the area in Uganda, it means 'Let's get started'). UEA, Kyambogo University and Ka Tutandike undertook the development of a 5-year participatory research capacity building programme. This was done as an alternative to funding a specific pre-determined research project, with pre-determined research questions and methodologies. This novel approach was put forward as a research capacity development programme, with no knowledge of what the actual research projects would address as these would be determined later by the individual research teams.

The format of the CARD programme was developed through a participatory process involving visiting academics from the UK, Netherlands and Pakistan,

along with academics from Kyambogo and Makerere Universities in Kampala, and people with disability and service providers from key organisations in Uganda. The latter included staff from Community-based Rehabilitation Alliance (COMBRA), Action for Disability and Development (ADD) and the National Union of Disabled Persons Uganda (NUDIPU). There were also representatives from local Ministries of Health, Education, Gender and Social Services (see full list in the Acknowledgement). An administrator was appointed at Kyambogo University to manage the day-to-day running of the programme. Approximately one-quarter of the participants had limited functioning related to impairment. These included limitations relating to vision, hearing and physical ability. The visiting academics became mentors to the research projects. The mentors had a wide range of research skills including statistics, surveys, trials, evaluation, anthropology and other forms of qualitative enquiry. Their specialisations included disability, community development, public health, child development, social inclusion, participation and protection. An initial workshop established the purpose and ground rules for the programme, and chose the name and acronym of the project (Panel 1).

### **Panel 1: Purpose of the CARD Programme**

It was agreed that the purpose of the CARD programme was to encourage collaboration, participatory action-based research to generate evidence around issues that were seen to matter to people with disability and their families, and to encourage utilisation of the findings. The agreed objectives were to:

1. Fund teams to carry out action-based research on disability in Uganda.
2. Develop research and administration capacity to manage the initiative within the academic registrar's office at Kyambogo University.
3. Incorporate the new knowledge generated from the studies into the on-going local Community-Based Rehabilitation and Special Education courses.
4. Ensure wide dissemination of research findings.

The programme facilitated the formation of research groups and assisted them in making a research application, including a budget. These applications were then evaluated by a panel of international researchers. Each year the panel selected 4-7 research groups, using the criteria shown in Panel 2.



## Panel 2: Research Group Criteria

1. The research groups had to have members representing 3 key stakeholder groups, namely;
  - a. An academic from Kyombogo University or Makerere University whose work focussed on the subject to be investigated and who had theoretical knowledge about this area. For example, for a research project addressing a question such as 'How should community workers be educated to assist the mobility of visually impaired people in the community?', the academic would need to have knowledge and training relating to visual impairment and mobility issues.
  - b. A person who currently provided service or support to the particular group of people with disability who were the focus of the study. For example, in the above example this would need to be a community worker providing mobility support to visually impaired people in the community. If the project was about wheelchair users, then the service provider would need to be someone who provided or designed wheelchairs.
  - c. A person with disability who had personal experience of the issue being investigated. For instance, in the first example this would need to be a blind person who lived in the community. For a study addressing deaf people's sexual education, this would need to be a deaf person who had attended school and had experienced sex education classes.
2. The proposed research questions were seen to be relevant to observed needs and focussed on getting the answers to questions related to improving lives of vulnerable people in Uganda.
3. There was potential for an action element integrated into the study.
4. The group demonstrated an ability to work as a team.

Upon selection, each project team was assigned two mentors. The mentors worked with the teams to finalise a rigorous and ethical protocol for the research, with a detailed budget. After the initial two years of the project, three local mentors were identified from Kyambogo University and appointed to the CARD programme. They brought in local cultural knowledge and expertise in special education, physics and food bio-technology. Once local mentors had been appointed, the mentorship team for each research project comprised an international and a local mentor. Seven international mentors served for different periods of time on the CARD programme over its 5-year life. All staff associated with the CARD programme are listed in Table 1.

**Table 1: Staff Associated with the CARD Programme**

Role in CARD Programme	Period of Association	Name
Administrator	2006-2010	Ms. Nyamutale Winfred Mataze, Kyambogo University, Uganda
International Mentors	2005-2010	Professor Sally Hartley, University of East Anglia, UK Dr. Harry Finkenflügel, University of Rotterdam, The Netherlands Dr. Aisha K Yousafzai, Aga Khan University, Pakistan
	2005-2006	Dr. Keith Sullivan, Institute of Child Health, University College London, UK
	2006-2010	Dr. Angie Wade, Institute of Child Health, University College London, UK
	2006-2010	Dr. Maria de Lourdes Drachler, University of East Anglia, UK
	2007-2009	Dr. Yasmine Alavi, London School of Hygiene and Tropical Medicine, UK
	2009-2010	Dr. Janet Seeley, University of East Anglia, UK
Local Mentors	2008-2010	Dr. George Kaahwa, Kyambogo University, Uganda Dr. Eric Mucunguzi, Kyambogo University, Uganda
	2009-2010	Dr. George Bazirake, Kyambogo University, Uganda

Once the research mentors and the programme director found both the protocol and budget satisfactory, the project teams secured ethical approval through a process created by CARD and began the data collection. On completion of data collection, the mentors assisted them in the processes of analysis and write-up. Each team was required to write a full report and also complete a 2-page summary before the projects were considered complete. Mentorship was managed at a distance through emails and conference calls, with approximately 3-4 mentor site visits per year. On average each international mentor visited twice a year, once as a part of a group and once on an individual basis. Counting each mentor's visit separately, there were a total of 37 international mentor visits throughout the whole 5-year programme.

All members of the project teams had access to a series of research capacity development workshops. During the duration of the project, there were 21 workshops with a total of 773 participants. The workshops were scheduled to address the issues and skills that the teams needed at that particular time (Table 2). Some workshops were repeated according to need. In addition to the workshops, a seminar series was also arranged. This provided project teams with the opportunity to present their research to a large audience such as fellow CARD members, other staff of Kyambogo University and representatives from local organisations. Four seminars were conducted during the CARD programme and attendance ranged from 70 - 160 persons.

**Table 2: The CARD Programme Workshop Series**

#	Workshop Topic	Date	No. of Participants	Mentor
1	How to write a research proposal	October 2005	40	Professor Sally Hartley, Dr. Harry Finkenflügel, Dr. Keith Sullivan, Dr. Aisha K Yousafzai
2	An introduction to research	September 2006	54	Dr. Harry Finkenflügel
3	SPSS data analysis	December 2006	47	Dr. Wilfred Ojok (Kyambogo University)
4	Ethics, Mixed methods, Framework for action research	April 2007	54	Dr. Maria de Lourdes Drachler, Dr. Aisha K Yousafzai, Dr. Adupa Cyprian (Kyambogo University)
5	Ethical considerations for community-action research	April 2007	32	Professor Sally Hartley
6	Introduction to Epi-data	July 2007	40	Dr. Angie Wade
7	An introduction to the sampling of data and data analysis	July 2007	45	Dr. Angie Wade
8	Epi-data analysis	July 2007	40	Dr. Angie Wade
9	Proposal writing	November 2007	58	Dr. Harry Finkenflügel, Dr. Aisha K Yousafzai

10	Literature review	November 2007	40	Dr. Harry Finkenflügel
11	Writing 2-page reports on the research project	February 2008	40	Dr. Angie Wade, Dr. Maria de Lourdes Drachler
12	Analysing qualitative data	February 2008	30	Professor Sally Hartley
13	Making budgets for CARD research projects	July 2008	30	Professor Sally Hartley
14	Developing an interview guide for qualitative research and developing structured questionnaires	September 2008	37	Dr. Aisha K Yousafzai
15	Writing 2-page reports on the research project	January 2009	15	Professor Sally Hartley, Dr. Angie Wade
16	Sampling techniques	January 2009	18	Professor Sally Hartley, Dr. Angie Wade
17	Critical reading skills	April 2009	30	Dr. Aisha K Yousafzai, Dr. Gorreti Kaahwa (Kyambogo University)
18	Analysis and reporting for qualitative data	September 2009	25	Dr. Yasmeen Alavi
19	Referencing techniques	February 2010	35	Professor Sally Hartley, Dr. Harry Finkenflügel
20	Ethics for research	May 2010	25	Dr. Janet Seeley
21	Presentation techniques	June 2010	38	Mr. Fred Wahitu (Kyambogo University)

## RESULTS

### The Outputs of the CARD Programme

Over the 5-year period, 12 action research projects were completed and 9 projects remained ongoing at the end of the programme. Seven of the 21 project leaders were people with disability. Table 3 summarises the completed projects.

**Table 3: Summary of the 12 Completed Action Research Projects**

Number	Title	Researchers	Aim	Methods used
P1-2006	Analysis of perceptions on accessibility to micro-finance services by people with disability in Bushenyi District – Uganda	Ephraim Nuwagaba (Lecturer, Kyambogo University); Edison Ngirabakunzi (Programme Officer, NUDIPU); Imelda Tumukunde (Programme Manager, NUDIPU); Mille Nakabugo (Programme Head, Uganda Adult Education Network)	To investigate the experiences of people with disability in accessing and utilising MF services, in order to highlight gaps in access that could be addressed	Survey, FGDs and IDIs
P2-2006	Employers' perspectives on employment of persons with disability in Uganda	Ali Baguwemu (Lecturer, Kyambogo University); Michael Matovu (Programme Officer, Federation of Employers); Moses Ddamulira, (Lecturer, Kyambogo University)	To find out the views and concerns of employers in the private and public sectors on employing persons with disability in Uganda	IDIs
P3-2006	How can information about disability be effectively disseminated among stakeholders?	Joan Okune (CAN); George William Kutosi (Lecturer, Kyambogo University); Harriet Ntege, (Librarian, Kyambogo University), Francis Kasozi (Programme	1. To know how information is shared, within and between CBR programmes 2. To identify challenges in information sharing 3. To develop strategies on how to improve information sharing based on the data collected	Telephone interviews, workshop documentation analysis

		Officer, Special Needs Children's Sports Organiser); Shepherd Kyagaba (IT Officer, Kyambogo University)		
P4-2006	Disability and injury research among children in Uganda	Alice Nganwa (Director, Injury Control Centre Uganda); Carolyne Maholo (Lecturer, Kyambogo University); Catherine Nansaba (Doctor, Injury and Control Centre); Frederick Sebadduka (Ministry Of Health)	<ol style="list-style-type: none"> <li>1. To determine the common causes of injuries among children with disability in Luwero</li> <li>2. To establish whether children with disability are more prone to injuries than other children</li> <li>3. To identify the specific types of injuries experienced by children with disability</li> <li>4. To determine whether the causes and types of injury among children with disability and</li> <li>5. children without disability differ</li> </ol>	Questionnaire with control group
P5-2006	Mobility and rehabilitation	Asher Bayo (Lecturer, Kyambogo University); Joseph Walugembe (Development Manager, Sense International Uganda); Grace Candiru (Lecturer, Kyambogo University)	To determine how the mobility and orientation training programme has influenced the lives of people with visual impairments in Iganga District	IDIs



P1-2007	Parents' perception of education for their children with disability	Eria Paul Njuki (Lecturer, Kyambogo University); Nakalule Wamala (Assistant Lecturer, Kyambogo University); Josephine Nalego (Training Coordinator, COMBRA); Odette Tumwesigye (Lecturer, Kyambogo University)	To explore parents' perceptions of the education of their children with learning disabilities, in order to generate strategies to improve support for their children's education	IDIs and FGDs
P2-2007	Participation of youth with disabilities in sports in mainstream secondary schools in Uganda	Harriet Ntege (Librarian, Kyambogo University); George William Kutosi, (Lecturer, Kyambogo University), Francis Kasozi (Programme Officer, Special Needs Children's Sports Organiser)	1. To investigate the current situation concerning sports activities for youth with disabilities in mainstream schools 2. To establish the challenges faced in sports programmes for youth with disabilities in mainstream schools 3. To make recommendations or propose solutions for the challenges.	IDIs
P3-2007	Sexuality education in primary schools for the deaf	Maurice Senyonga (Lecturer, Kyambogo University); Harriet Nsereko (Lecturer, Kyambogo University) Rehema Namarome (Programme Officer, NUDIPU)	To establish and document information that can be used in providing better sex education in primary schools for the deaf	IDIs, video recordings and questionnaires

P4-2007	The experiences of people with disabilities in accessing health services in Uganda: A case study of Mbarara district	Christine Kazairwe (Kyambogo University); Edward Obura (Lecturer, Makerere University); Michael Miiro (Officer at District level, Masaka District); Beatrice Kyamazima (Secretary, Kyambogo University)	To increase our understanding of the issues affecting accessibility to health services by people with disabilities in Mbarara District	IDIs
P5-2007	Economic development activities for women with disabilities	Sarah Bunoti (Lecturer, Kyambogo University); Grace Kibirige (Teacher, Kitante Secondary School); Rose Kakai (Programme Officer, Buweda Village); Maggie Katisi, (Teacher, Mpoma Secondary School); Lovis Kabuula (Programme Officer, NAWOU)	<ol style="list-style-type: none"> <li>1. To collect information about economic development activities of women with disabilities</li> <li>2. To identify the challenges they face</li> <li>3. To identify the training needs of the women with disabilities and their leaders</li> </ol>	Questionnaires, FGDs, IDIs, document analysis and observation
P8-2007	An assessment of how mothers with visual, hearing and physical impairments meet the needs of their children	Mary Nabbose Kyagaba (Librarian, Kyambogo University); Andrew Bwogi (IT Officer Kyambogo University); Mbabaali Joseph (Centenary Bank Officer); Mariam Nambooze	To explore how mothers with visual, hearing and physical impairments meet the needs of their children	IDIs

		(Student, Kyambogo University)		
P1-2008	A systematic review of the initiatives to support visually impaired farmers in developing countries	Regina Nakayenga (Lecturer, Kyambogo University); Mathias Sserwadda (Lecturer, Kyambogo University); Fr. Athnadius Mubiru (Catholic Church Priest Socadido); Beatrice Guzu (Programme Officer, NUWODU)	To review the existing literature on the support from development agencies for visually impaired people's agribusinesses in developing countries	Systematic review

**Abbreviations/Acronyms: CBR-Community-Based Rehabilitation, COMBRA-Community-Based Rehabilitation Alliance, FGD-Focus Group Discussion, IDI-In-depth Interview, NAWOU-National Association of Women's Organisations in Uganda, NUDIPU-National Union of Disabled Persons in Uganda, NUWODU-National Union of Women with Disabilities of Uganda, Socadido -Development and Welfare Group of Soroti Diocese, Teso, Uganda**

Brief reports for the 12 completed projects follow.

## **PROJECT 1: ACCESSIBILITY TO MICROFINANCE SERVICES BY PEOPLE WITH DISABILITIES IN BUSHENYI DISTRICT, UGANDA**

### **Background and Justification**

According to the Ugandan population survey (2006)<sup>1</sup>, 4% of the population of 24.7 million Ugandans are people with disabilities. This will be just under 1 million people. Previous studies have shown that people with disabilities face social exclusion and poverty. Microfinance (MF) is one of the Ugandan Government's poverty reduction interventions.

What is already known

- MF services are there to help people (especially the poor) to improve their economic activities
- People with disabilities are among the poor
- It is thought that access to MF services by people with disabilities is low

### **Aim of the Study**

This study aims to investigate the experiences of people with disabilities in accessing and utilising MF services, in order to highlight gaps in access that could be addressed.

### **Objectives**

1. Establish the current status of able-bodied persons and different categories of people with disabilities in regard to accessing MF services
2. Examine and analyse the inherent and external factors determining accessibility to MF services by people with disabilities
3. Examine the involvement of people with disabilities in community-saving initiatives
4. Ascertain whether the general legal MF framework reflects concerns of people with disabilities
5. Propose appropriate interventions for improving access to MF by people with disabilities

### **Methods**

The study was carried out in Bushenyi district, in three counties and two town councils, between June 2006 and June 2007. Documents on the regulation of MF provision, the Constitution of Uganda and the Local Government Act were reviewed to determine the context, challenges and existing legal and economic opportunities available to people with disabilities.

A snowball sampling was used to identify individual respondents. This began with an active person with disability in each county or town council who was asked to identify others. The able-bodied selected were of similar social standing to the people with disabilities interviewed. The following Table shows the categories of respondents that were interviewed for this study.

**Table of Nature of Final Sample**

Population	Able- bodied	People with disabilities			MF providers	Total
		Blind	Deaf	Physical Disability		
<b>Rural</b>						
Male	3	4	1	3	2	13
Female	2	0	1	2	0	05
<b>Urban</b>						
Male	2	1	1	1	0	5
Female	4	1	3	5	3	16
<b>Total</b>	<b>11</b>	<b>6</b>	<b>6</b>	<b>11</b>	<b>5</b>	<b>39</b>

Focus group discussions (FGDs) were held separately for the blind (5 people), those with physical disability (7 people) and able-bodied persons (6 people). Local sign language interpreters helped in communication between the researchers and the deaf. The researchers took notes and also tape-recorded the proceedings.

Before conducting the interviews or FGDs, consent was obtained verbally from respondents after informing them of their rights as participants in the study, and explaining how the results could be used. Although data analysis was done according to the research objectives, the discussion of findings was based on three themes, i.e., accessibility to MF services, perceptions on accessibility to MF services by people with disabilities, and suggestions on improving this.

## Results

- 43% of the people with disabilities interviewed had accessed MF services compared to 45% of the able-bodied
- Some of the people with disabilities who did not access MF had the relevant knowledge and skills to do so
- Of those not accessing MF, there was some evidence of charitable expectation among people with disabilities
- Having collateral was the main criteria used for selection for loans by the MF providers
- Government and MF providers' policies do not specifically target or actively exclude people with disabilities

- Evidence suggests that there may be physical barriers to access, e.g., stairs, high counters
- Those with physical disability (6) accessed more easily, followed by the blind (2) and the deaf (2)
- People with disabilities were fully involved in community-saving initiatives reflecting the international recommendations for inclusion in the UN Convention on the Rights of People with Disability (2006).

## **Conclusions**

Contrary to expectations, disability may not necessarily deny access to MF for those that meet the requirements. There are several factors that could improve usage of MF by people with disabilities. Some of these factors are related to the knowledge and attitude of the people with disabilities; they can control these. However there were also external factors that may limit their ability to boost their chances of success.

## **Recommendations**

- MF government policies and regulations should give special consideration to needs and circumstances of people with disabilities
- Sign language interpretation should be promoted by all stakeholders to ease communication between the deaf and MF service providers
- Provide support for people with disabilities who have successfully used MF to share experiences and thus encourage others

## **Challenges faced during the Study**

- Local MF institutions were sometimes reticent to talk to investigators and referred them to head offices who could not provide the information required on local issues
- Scattered location of participants
- Problems of transporting people with disabilities to the centres where the FGDs were conducted
- Inadequate funding and delays in disbursement



## References

1. Uganda Population and Housing Census: Uganda Bureau of Statistics, Kampala (2006)
2. UN Convention on the Rights of Persons with Disabilities( 2006)

## Researchers:

Nuwagaba Ephraim Lemmy – Lecturer, Kyambogo University elnuwagaba@yahoo.com

M/s Meldah Tumukunde – Programme Manager, National Union of People with Disabilities meldaht@mail.com

Edson Ngirabakunzi –Programme Officer, National Union of People with Disabilities edsonngirabakunzi@yahoo.com

M/s Nakabugo Millie - Uganda Adult Education Network millie22000@yahoo.co.ug

**Mentors:** Professor Sally Hartley, UEA, Norwich, Norfolk, UK S.Hartley@uea.ac.uk

Angie Wade, CICH, ICH, UCL, UK – London awade@ich.ucl.ac.uk

## PROJECT 2: EMPLOYERS' PERSPECTIVES ON EMPLOYMENT OF PERSONS WITH DISABILITY IN UGANDA

### Background and Justification

Bagawemu and Kanya (2001) observed that significant effort had been made by government and development partners towards promoting employment for persons with disability in Uganda. Several vocational rehabilitation centres and sheltered workshops were set up 1960s and 70s respectively, to train people with disabilities in vocational skills and to provide them with convenient and protected employment. Recently, legislative provisions aimed at promoting employment for people with disabilities, such as Persons with Disabilities Act, 2006, have been instigated. Organisations for and of people with disabilities and other agencies like the Federation of Uganda Employers have also been active in lobbying and advocating for the employment of people with disabilities in the formal sector. Nevertheless, it is reported that many people with disabilities, despite possessing the requisite education and training qualifications for certain jobs, find it difficult to obtain employment. Employment in the formal sector is preferable for them because they are assured of regular income and are protected from the disadvantages associated with informal employment which is susceptible to changes in labour market conditions. Research and documentation relating to the problem of employing people with disabilities tend to reflect mainly views of people with disability and viewpoints of policy makers.<sup>1</sup> The

perspectives of employers have not been featured, yet they are key stakeholders in the employment of people with disabilities.

### What is already known

There are many initiatives to promote employment of people with disabilities, yet they still have problems finding employment. It is not known what employers think about employing people with disabilities.

### Aim and Objectives

The study aimed at finding out the views and concerns of employers in the private and public sectors on employing people with disability in Uganda. Its objectives were:

1. To analyse employers' knowledge and opinions on employing persons with disabilities
2. To examine employers' perceptions of the job-related needs of persons with disabilities.
3. To find out the measures organisations take to meet the job-related needs of persons with disabilities
4. To explore the challenges employers encounter in employing persons with disabilities

### Methods

The study employed a qualitative research design, using in-depth interviews with purposively sampled employers selected from private (16) and public (2) employment sectors in the districts of Kampala (9), Mbarara (6) and Arua (3).

### Results

<b>Perspectives on employing persons with disabilities by employers</b>		
<b>Reasons for employing persons with disabilities</b>	<b>Reasons for not employing persons with disabilities</b>	<b>Positive qualities of persons with disabilities as workers</b>
Corporate responsibility	Not many persons with disabilities seeking employment	Reliable and stable
Boosting organisational image	Reluctance to incur extra costs on adapting the workplace	Easy to motivate

Act of philanthropy	Fear that persons with disabilities may not be capable of work	Efficient and committed
Belief in the abilities of persons with disabilities as workers	Ugly physical appearance	
Possession of qualifications	Persons with disabilities may be involved in accidents leading to further disability	
Persons with disabilities having previous relationship with employers		

Perceptions on job related needs of persons with disabilities	Measures taken to meet the job-related needs of persons with disabilities	Challenges encountered in employing persons with disabilities	Suggestions on promoting employment of persons with disabilities
Mobility needs	Placement of persons with disabilities in jobs that suit residual abilities	Lack of knowledge of what to do about the needs of a worker with disability	Government should put more emphasis on employment of persons with disabilities in the formal employment sector
Transport needs	Nothing suggested	Lack of awareness on the employment abilities of persons with disabilities	Sensitisation of employers on potential, abilities and needs of persons with disabilities is needed
Safety needs	Nothing suggested	Lack of organisational policy regarding employment of persons with disabilities	Make employment of persons with disabilities one of the criteria for the prestigious Employer of the Year Award
Communication difficulties	Communicate with deaf through writing and gestures	Communicating with deaf workers	Set up an employment advocacy body

## Conclusions

- Many employers lack information on the potential, abilities and needs of persons with disabilities and how they can be integrated.
- Some employers are eager to take on persons with disabilities provided their philanthropy is recognised. They feel this is necessary considering the possible liability.

- People with mild to moderate disability and those with motor disability stand better chances of getting employed than others.
- The problem of employment is compounded by lack of initiative and ambition to seek employment by persons with disabilities.

### **Recommendations**

- Federation of Uganda Employers should encourage its member organisations to institute disability-sensitive employment policies.
- The Government should respond by instituting policies aimed at encouraging employers to employ persons with disabilities who have qualifications.
- Establish a bureau to specifically address the policy issues pertaining to employment of persons with disabilities.
- Advertise job opportunities widely in various media. Include a specific clause encouraging people with disabilities with qualifications to apply.
- Students with disabilities should be provided with career guidance services early enough during their educational career in order to facilitate their employment prospects.

### **What the Study has added**

Greater awareness of the need to:

- (1) Sensitise employers about how to employ persons with disabilities.
- (2) Encourage more confidence among persons with disabilities in the process of seeking employment.

### **References**

Baguwemu Busulwa A & Kanya J (2001). Perspectives on the employment of persons with disability in Uganda. *African Journal of Special Education*, 6(2).

**Researchers:** Ali Baguwemu (Lecturer Kyambogo University);

Michael Matovu (Programme Officer, Federation of Employers);

Moses Ddamulira (Lecturer, Kyambogo University) ;

**Mentors:** Sally Hartley (University of East Anglia)

Harry Finkenflugel (Erasmus MC Rotterdam, The Netherlands)

## **PROJECT 3: HOW INFORMATION IS SHARED AMONG CBR SERVICE PROVIDERS IN UGANDA**

### **Background and Justification**

CBR Service Providers in the course of their work acquire a wealth of knowledge and experience which, if shared, is likely to benefit policy and practice. However, there are international concerns about whether information is being effectively shared and put to use, as documented in the IRC BUS Handbook. Information sharing and networking is an important part of development programmes. "Publication is motivated by the need for practitioners to share their experiences and perspectives and then to evaluate and learn from them in order to improve practice..." (Hartley, 2001). As noted in the CBR Africa Network Strategic Plan (2006), oral tradition dominates the communication process in Africa (3).

### **Aims and Objectives**

1. To know how information is shared, within and between CBR programmes.
2. To identify challenges in information sharing.
3. To develop strategies on how to improve information sharing based on the data collected.

### **Methods**

Within 19 organisations where the study was carried out in Mbale, Mbarara, Masindi, Lira and Kampala districts, a total of 42 respondents were interviewed. They were Managers, Information Workers and Community Development Workers. Their responses were based on their experiences with information management programmes in their organisations. In addition a workshop, using focus group discussions of the results, developed ideas for improving information sharing. The workshop had 20 participants in total - 11 representatives of organisations, 1 Sighted Guide, 2 Sign Language Interpreters, the 5 Researchers and the CARD Administrator. The informed consent of the individuals and the organisations was acquired, and semi-structured, tape-recorded interviews (face-to-face or telephone interviews) were conducted using a previously prepared framework of questions. Documents shared by organisations were requested and scrutinised to identify the kind of information that organisations share.

## Results

1. Information was shared about programme activities, challenges in implementation, target population, achievements, planned activities and disability- specific information.
2. Information was mainly used by managers in evaluation, development of strategies and avoiding duplication of resources.
3. Information was documented in the form of newsletters, brochures, handouts, periodical reports and financial reports. Small organisations had less documented information, mainly due to financial and human resource limitations; however they often received documented information from larger organisations.
4. Some organisations had a lot of information to be shared, but this was often left unprinted on their computers.
5. Oral modes of sharing were considered most appropriate to share both externally and internally due to low literacy levels. There are many popular FM radio stations operating in local languages and are far reaching within the communities.
6. Some respondents cited email communications as a best practice for sharing information, yet in most rural areas of Uganda there is no internet infrastructure to support it.
7. Limited resources for production of documented materials. The non-existence of well-developed ICT infrastructure, especially in rural areas, also hindered sharing with partners at grass-root levels.
8. Low literacy levels affected the sharing of documented information; it rarely reached the deaf, blind and illiterate audiences.

## Workshop

Suggestions for improving the sharing of information were:

1. Production of a directory of CBR organisations in Uganda, to be led by the Ministry of Labour, Gender and Social Development and CBR Africa Network.
2. Increased research into CBR in Uganda.



3. Integrated work planning.
4. Exchange visits.
5. Carrying out an information needs assessment.
6. Producing materials in Braille, and providing Sign Language interpretation.

### **Challenges faced during the Study**

- It was sometimes found to be difficult to coordinate the research team.
- Scattered respondents – not easy getting them all in one place for dissemination workshops.
- Inaccessibility of some key respondents.

### **Recommendations**

- There is need for development of strategies that support oral means of sharing information, such as community workshops, music, dance and drama, especially when sharing information with beneficiaries at the grass-root level.
- Radio programmes should be used to disseminate information.
- There is need to increase awareness among CBR service providers on cost-effective means of sharing information.
- There is need for use of modes that reach people with special needs, e.g., Braille, sign language interpretation, community theatre, dance, drama, etc.

### **References**

1. CBR- A Participatory Strategy in Africa (Hartley, S Ed. 2001)
2. CBR Africa Network Strategic Plan 2006 – 2011 [www.afri-can.org/reports.html](http://www.afri-can.org/reports.html)
3. IRC BUS Handbook Section 10 Process Documentation and Information Sharing. <http://www.irc.nl/page/27742>

### **Researchers:**

Joan Okune, Coordinator, CBR Africa Network [joan@afri-can.org](mailto:joan@afri-can.org)

Francis Kasozi, Volunteer, Mental Health Uganda [frankasozi@yahoo.co.uk](mailto:frankasozi@yahoo.co.uk)

George Kutosi, Lecturer, Kyambogo University [geowikuts@yahoo.com](mailto:geowikuts@yahoo.com)

Harriet Ntege, Librarian, Kyambogo University harrietnn@yahoo.com

Shepherd Kyagaba, Media Technician, Kyambogo University rskyagaba@yahoo.com

## **Mentors**

Maria de Lourdes Drachler, University of East Anglia <mailto:malu.drachler@uea.ac.uk>  
[malu.drachler@gmail.com](mailto:malu.drachler@gmail.com) Aisha Yousafzai, University of Agha Khan Pakistan [aishayousafzai@  
hotmail.com](mailto:aishayousafzai@hotmail.com)

## **PROJECT 4: INJURIES AMONG CHILDREN WITH DISABILITIES IN LUWERO DISTRICT**

### **Background and Justification**

Injuries are a growing public health and economic problem. Over five million people die annually from injuries; for every person who dies of an injury, several survive with severe disabilities (World Health Organisation, 2000). WHO (2000) reports that many survivors of injury move from secure income to poverty, and that worldwide, 94% of the burden of injury occurs in the developing countries, which severely affects the economies of these struggling regions. In Africa, injuries rank third as a leading cause of death, ahead of diarrhoea, tuberculosis and measles (Injury Control Centre, Uganda). According to Kobusingye et al (2001), in Uganda injuries are among the top ten causes of ill health. The top three causes of severe injuries among young adults less than 20 years in Uganda are traffic (46%), falls (14%) and burns (11%). In order for children with disabilities to realise their potential, the special issues that affect them need to be addressed. One of these is their vulnerability to injury which has received little attention in Sub-Saharan Africa (WHO, 2004). Persons with disabilities are more vulnerable to injuries than their counterparts without disability (Ramirez et al, 2004).

### **Aims and Objectives**

1. To determine the common causes of injuries among children with disabilities in Luwero
2. To establish whether children with disabilities are more prone to injuries than other children
3. To identify the specific types of injuries experienced by children with disabilities

4. To determine whether the causes and types of injury among children with disabilities and children without disabilities differ.

## Methods

A random selection of children with disabilities, aged 1-17 years, was taken from the register of a Community Based Rehabilitation programme in Luwero district, and stratified to ensure proportional representation of all disability groups. At least one control of the same gender and age range of 18 months above or below the child with disabilities was identified. The control was either from the same homestead or, if no child in the homestead was found, two controls were selected from the neighbouring home. Trained nurses used a questionnaire to collect information from the primary carer for each child in the study. Social and demographic information about the child/family, the child's impairment, whether the carer reported frequent injury, and details of the most recent injury, were recorded.

## Results

A total of 51 children with disabilities and 57 controls were recruited into the study. Five children with disabilities were removed because they no longer had a disability due to successful medical intervention. Of the remaining 46 cases: 13 had physical disabilities, 4 had hearing impairment, 4 had visual impairment, 9 had double disabilities, 13 had multiple disability (intellectual disability, epilepsy, and physical disabilities) while 3 were categorised as 'other'. There was no significant difference between the injury rate of children with disabilities and children without disabilities. Similar percentages of children with and children without disabilities were injured frequently (23/42 and 30/55 respectively). The types of causes cited were also similar. Burns were given as a common cause of injury among children with disabilities significantly more often [11% Vs 0%,  $p=0.018$ , 95% confidence interval for the difference (2, 23%)]. All the children with disabilities for whom burns were cited as a common cause (5) had a physical impairment, 2 additionally had intellectual disability, and 1 additionally had both intellectual disability and epilepsy. Injuries in the last 1 month were significantly more common among children with disabilities; 83% (38/46) of children with disabilities were reported to have had an injury in the last one month compared to only 12% (7/57) of the children without disabilities [ $p<0.0005$ , 95% for the difference (53, 81%)]. This was because people could remember recent injuries,

and although memory of the general frequency of the injuries was readily available, not all injuries leave the scars which were used to examine past injuries.

### **During a Training Session for Research Assistants**

Unlike the studies by Injury Control Centre Uganda which show that majority of burns in children occur among toddlers (1-3 years), among children with disabilities these injuries occurred in children above the age of 5 years and at home. The difference could be due to the fact that children with disabilities develop slowly and are not at school even if they are of school-going age. This makes them vulnerable to burns, a vulnerability experienced by children without disabilities at a much younger age. Of the children with disabilities who get injured often (23), 66% (17/23) are not in school. For children with disabilities staying at home seems to be a risk factor for injuries. This could be because the home environment is less safe than school, or the disability which keeps the children at home makes them more prone to injuries, or they stay at home unsupervised.

### **Conclusions**

Children with disabilities were more vulnerable to injury (53, 81%) and more likely to have been injured in the previous month. However burns among children with disabilities were found in older children who stayed at home; this finding is unlike other studies in Uganda where they were more common among toddlers. From this study, staying at home (for children with disabilities) and having multiple disabilities were risk factors for frequent injuries and burns respectively. The study did not find out whether those who stayed at home had more severe disabilities which made them more prone to injuries.

### **Recommendations**

Parents of the children with disabilities need to take precautions to protect their children from injuries, especially burns. Strategies should be put in place to encourage parents to take their children with disabilities to school, especially now that the Universal Primary Education system is in place, as this may help to reduce their vulnerability to injury.

### **Challenges faced during the Study**

The CBR register was not comprehensive. The identification of the children with disabilities was not always accurate. 10% (5/51) who had been included

in the sample were subsequently found to be ineligible. It is not known how biased the register was and whether certain categories of disabilities were under-represented. The data sheets for the children with disabilities and children without disabilities were separate; hence retaining the matching pairs in the analysis was not straightforward. This may have reduced the efficiency of the study. Tracing the children was time-consuming as the study was conducted in a rural area.

### **What the Study has added**

Children with disabilities were more prone to injury than children without disabilities in the previous month. They were also more prone to burn injuries than children without disabilities. Physical and multiple impairments were risk factors for burns. Staying at home increases vulnerability to injury.

### **References**

1. Injury Control Centre Uganda. Safe Schools, Safe Students An Injury Prevention and Control Manual for Schools
2. Kobusingye Olive et al (2001). Injury Patterns in Rural and Urban Uganda Injury Prevention, 7:46-50
3. Ramirez M, Peek-Asa C, Kraus J F (2004). Disability and Risk of School Related Injury. Injury Prevention, 10:21-26
4. World Health Organisation. Injury a Leading cause of Global Burden of Disease. WHO: Geneva; 2000.
5. World Health Organisation. Guidelines for Conducting Community Surveys on Injury and Violence pg 4 WHO: Geneva; 2004. ISBN 92 4 154648 4

### **Researchers**

Alice B Nganwa: Director Injury Control Centre Uganda alicekbn@yahoo.com

Maholo Carolyne: Lecturer, Kyambogo University maholocarol@yahoo.com

Ssebaduka Fred: Ministry of Health

Nansamba Catherine: Epidemiologist: Injury and Control Centre catnsamba@yahoo.com

### **Mentors**

Angie Wade, CICH, ICH, UCL, UK – London awade@ich.ucl.ac.uk

Harry Finkenflugel, Erasmus MC Rotterdam, The Netherlands finkenflugel@bmg.eur.nl

## PROJECT 5: MOBILITY AND REHABILITATION

### Background and Justification

The Mobility and Rehabilitation (MBR) Programme is one of the training programmes offered by Kyambogo University at the Department of Community and Disability Studies in the former Uganda National Institute of Special Education (UNISE). At the time of this study, 82 Mobility Instructors were trained and deployed in 34 districts. The programme was established to empower persons with visual impairment with MBR skills, to enhance their inter-dependence, consequently improving their livelihood capacity. Trainees of MBR, upon completion, were expected to identify and support other persons with visual impairment in their districts. There has never been any follow-up or feedback to establish how the MBR training programme has influenced the lives of persons with visual impairment. The study was designed to explore the experiences of persons with visual impairment in Iganga District by targeting those who had received training in mobility and rehabilitation. The purpose was to gather an evidence base critical for:

- Informing both policy and practice in MBR training
- Reviewing MBR and CBR courses
- Providing rationale and content for replicating best practices of the MBR programme in other districts where the programme has not been introduced.

To guide this study process, the following research question was used: How has the MBR Training Programme influenced the lives of persons with visual impairment in Iganga district?

The sub-questions were:

- What have persons with visual impairment identified as benefits from the MBR training programme?
- What have persons with visual impairment identified as gaps in the MBR training programme?
- How, in their opinion, can the MBR training programme be improved?

### Methodology

The study followed a Qualitative Case Study design with a purposeful sample of

30 adults with visual impairment, aged between 30 –80 years. The criteria used for selection were:

- Persons with visual impairment in Iganga trained by Mobility Instructors from former UNISE
- Persons with visual impairment who were accessible to the Research Team
- Adults with visual impairment, with approximately even numbers of males and females distribution representative of the population of persons with visual impairment. Only 19 adults (10 male and 9 female) were reached, because some relocated to other places, others could not be accessed easily due to the terrain in Iganga District, and some had died.

The main instrument used in the study was Interviews, which were recorded on tape. The tapes were translated and transcribed. Question-led analysis was done, with manual analysis of the data by research group consensus. Data that did not address the research questions was discarded.

## Results

The informants highlighted the following benefits:

**Increased independence in movement:** *“I am now able to move from one place to another with minimal support from sighted counterparts, not only in my own home, but also in our meeting places. I am able to manipulate my environment ... because of the mobility skills, most especially how to use the white cane effectively.”*

**Improved self-esteem:** *“I now participate in all functions of my community.”*

**Ability to own and manage income-generating activities:** *“We also learned how to start and manage income-generating projects, how to make crafts, and so on.”*

Another one said, *“..., I started a brick laying project, I have also been trained in zero grazing ... I was given a Friesian cow which is doing well. I am a small- scale farmer growing both for commercial and subsistence.”*

**Increased participation in leadership:** *“I represent persons with disabilities on Local Council, LC, in my village... LC2, and at LC3... I represent persons with visual impairment.”*

**Involvement in group activities:** *“I have also joined income-generating groups like Idha Obone, Abatulu Kyebakola and Iganga District Association of the Blind, JIDECO, ULA and others.”*



The gaps highlighted were:

**Observed lack of assistive devices and limited training in agriculture, entrepreneurship skills and Braille:** *“Unfortunately the programme did not equip me with commercial skills.”*

The informants suggested the MBR training should include entrepreneurship skills, agriculture, Braille reading and writing, and provision of assistive devices. Some individual differences were also noted among the informants. It was found that those in the age group below 5 years were more active compared to those above 55 years. As far as gender was concerned, the study revealed that an approximately equal percentage of both male and female informants were involved in IGAs, agriculture, leadership and in working in groups.

## Conclusions

Most adults with visual impairment appreciated the programme and found it useful. The programme influenced their lives most by facilitating their ability to move independently from one place to another to carry out activities of interest. It showed that the MBR Programme had a positive influence on the lives of persons with visual impairment, but revealed a need for better training in entrepreneurship, agriculture, Braille reading and writing for the trainees. The data collected can be used to modify the course accordingly.

## Recommendations

There is need to have regular follow-up visits of persons with visual impairment by the MBR Instructors. There is also a need to address the gaps that have been identified in the MBR Training Programme.

## Challenges faced during the Study

- The age group under consideration had a lot of health-related challenges due to the long distances from the health centres in the district
- The scattered location of the participants made data collection problematic.

## References

Bayo Asher (2000) The Impact of Mobility and Rehabilitation Programme on CWVI in Uganda. Master's Thesis. University of Oslo, Norway



**Researchers:**

Asher Bayo, Kyambogo University – ashebayo@yahoo.com

Grace Esther Candiru, Kyambogo University – grccandy@yahoo.co.uk

Joseph Walugembe, Sense International – josephw@senseint-ea.org

**Mentors:**

Harry Finkenflugel, Director, 's Heeren Loo, The Netherlands harry.finkenflugel@sheerenloo.nl

Aisha Yousafzai, University of Aga Khan, Pakistan – aishayousafzai@hotmail.com

Angie Wade, ICH, UCL, London, UK - awade@ich.ucl.ac.uk

## **PROJECT 6: PARENTS' PERCEPTION OF THE GOAL OF EDUCATION FOR THEIR CHILDREN WITH LEARNING DIFFICULTIES**

**Background**

Studies have shown that:

- Parents perception of their children focusses more on their inabilities than their potential (COMBRA, 2006)
- Many parents of children with learning disabilities do not take an active role in the education of their children. This leads to a limited access to basic education and training (Government of Uganda, 1995)
- Girls and children from poorer families are more likely not to attend school (Government of Uganda, 1996).

**Aim**

This study explores parents' perceptions of the education of their children with learning disabilities, in order to generate strategies to improve support for their children's education.

**Research questions**

1. What are the reasons on which parents base their decisions to send or not to send their children with learning disabilities to school?
2. What suggestions are there for addressing parents' understanding and participation in the education of their children?

## Methods

Based on the stratified purposive sampling process, a COMBRA register of 205 persons with disabilities was consulted. All persons with learning difficulties were identified (N=25). Children between 0-20 years were then identified (N=9). Parents of the 9 children were located - 3 were those whose children were going to school, 3 whose children had never been to school, and 3 whose children had dropped out of school. The plan was to have 15 parents, but due to a limited number of children with learning difficulties and the required age range (0-20 years), only 9 were selected and 3 focus group discussions were conducted. Interviews and discussions were conducted in Luganda. Question-led analysis of data was undertaken. The intention was to interview each of the parents using prepared interview guides by the four researchers

## Analysis

The transcripts from each interview and FG were translated and manual analysis was undertaken by each researcher individually, and then by group consensus the main themes were identified.

## Results

Reasons on which parents base their decisions to send their children to school:

- Preparation for self-reliance in adult life
- Socialisation
- Literacy for older children
- Good quality of life
- As a human right
- For children to acquire practical skills

Reasons on which parents base their decisions not to send their children to school:

- Not having enough money
- Inaccessibility to schools
- Lack of information on available schools
- Large classes
- Too much emphasis put on academic achievement
- Prejudices of teachers and parents

Suggestions for increasing parents' participation in the education of their children:

- Parents of children with learning difficulties should be assisted to start income-generating activities such as 'piggery' to help them support their children's specific needs including school fees.
- Government and other stakeholders should build more special schools for children with severe learning difficulties.
- Training and motivating teachers of children in special needs education is needed.
- Sensitisation and training of parents on the goals of education for their children with learning difficulties.
- Curriculum development to suit the needs of children with different learning difficulties.

### **Challenges faced during the Study**

- Tape-recorder failure made it necessary to repeat the data collection
- Small numbers of children with learning difficulties in the COMBRA register.

### **Conclusions**

Parents of children with learning difficulties expect an education that provides their children with practical skills to prepare them for independent living. The current school system that emphasises academic success is not appropriate for their needs.

### **Recommendations**

- Teacher training in special needs
- Income-generating activities
- Curriculum modification to give practical skills
- Boarding facilities which can ease transport costs
- Provision of educational materials/assistive devices to simplify learning
- There is need for education stakeholders to rethink the implementation of inclusive education.

## What the Study has added

- Parents are sceptical about enrolling their children in the inclusive settings provided due to large classes, inadequate training of teachers, negative attitudes and lack of curriculum flexibility.
- General clarification of issues that concern parents of children with learning difficulties.

## References

1. COMBRA Community Support Report 2006
2. Government of Uganda (1995): The Constitution of the Republic of Uganda. Government Printers
3. Government of Uganda (1996): The Children Statute. Kampala: The Law Development Centre.

## Researchers:

Njuki Eria Paul, Lecturer, Kyambogo University njukiep@yahoo.co.uk

Wamala Juliet Nakalule, Asst. Lecturer, Kyambogo University jnakalule@yahoo.com

Nalugo Josephine, Training Coordinator, COMBRA nsago@yahoo.co.uk

Niyisabwa T. Oddette, Asst. Lecturer, Kyambogo University niyisabwa.odette@gmail.com

## Mentors

Harry Finkenflugel, Erasmus MC Rotterdam, The Netherlands, finkenflugel@bmg.eur.nl

Sally Hartley, UEA. Norwich, Norfolk, UK , S. Hartley@uea.ac.uk

## PROJECT 7: PARTICIPATION OF YOUTH WITH DISABILITIES IN MAINSTREAM SECONDARY SCHOOLS' SPORTS ACTIVITIES IN UGANDA

### Background and Justification

The Constitution of the Republic of Uganda (1995), guarantees non-discrimination on grounds of disability, gender, colour, ethnic origin, social economic status or political opinion. A National Sports Policy in Uganda caters for persons with and without disabilities, which is potentially useful to develop a favourable climate for the participation of persons with disabilities in sports activities. However this study was driven by the researchers' notion that

youth with disabilities in the mainstream secondary schools do not actively participate in sports activities.

### **Aims and Objectives**

1. To describe the current situation concerning sports activities for youth with disabilities in mainstream schools.
2. To establish the challenges faced in sports programmes for youth with disabilities in mainstream schools.
3. To make recommendations or propose solutions for the challenges.

### **Methods**

A qualitative study was conducted. Three sources of data were used - interviews, records and archives, and workshop proceedings. Interviews were conducted in two mainstream secondary schools in Eastern Uganda and the National and the District Councils of Sports. A total of 19 individuals who took part in the study were purposively chosen to represent different impairment groups and their teachers: 12 students consisting of youth with disabilities (2 with hearing impairments, 2 visually and 2 physically impaired), 4 youth without disabilities and 2 sports teachers (half of them from each school) and 3 officers (1 from the National Council of Sports and 2 from District Sports offices). An in-depth interview based on agreed topics was conducted with each participant. The interviews were tape-recorded and transcribed. Thematic analysis, using the study objectives and research questions for guidance, was applied to identify the major themes that emerged from the interviews. This was followed by thematic analysis of records and archives of the participant institutions. A workshop was held to validate and disseminate the findings.

### **Results**

#### **1. Current situation concerning sports activities in schools**

**Funding:** No clear specific plans exist on funding sports activities for youth with disabilities at the secondary schools. Efforts were being made to start involvement of youth with disabilities in sports in one of the districts.

**Current level of participation of youth with disabilities:** The schools have some sports and games involving students with visual and motor impairments

(including athletics, cricket, goal ball, sit ball, power lifting and swimming), but the physical environment and equipment are not adapted for the needs of youth with disabilities.

“School activity programmes vary from school to school and from one disability to the other....”

“The playing environment is not adequate and fields are not available, and even if they were, they are not adapted...” ( an Officer).

**The attitudes of youth with disabilities towards sports practices:** They were enthusiastic about participation in various sporting activities like athletics, cricket, goal ball, sit ball, power lifting, swimming and in-door games.

“Even those students with disabilities have expressed interest in participating in sports ....” (a Sports Teacher).

Some youth with disabilities expressed discomfort about participation.

“I feel uncomfortable ...” (a visually impaired student).

**The desires and needs of youth with disabilities:** They wanted to have trained coaches and guides to help them participate better in sports activities in schools.

“... like in running, when you go far in sports, you can lack guides to guide you,” (a youth with disability).

Some of them disliked outdoor games and expressed the need for a variety of games, including indoor games, which made them feel more equal to their peers and gave them more confidence.

“... we feel better with things like Ludo and cards where we can compete better,” (a youth with motor impairment).

## 2. Challenges

- Negative attitudes of other youth such as jealousy (e.g. when a youth with disability is better than a youth without disability in a given sports activity).  
“It’s not that we do not want them to participate. We felt that they’d not be able to compete ...” (a Sports Prefect).
- Poor attitudes of some staff towards the participation of youth with disabilities in sports activities within those schools.

“...the school does not consider them joining sports activities....” (a youth without disability).

- Main focus is on academics to see that students pass exams; in general, sport is not much of an issue.

“Actually games and sports in this school are not so much of an issue ... this is more of an academic than sporting (institution),” (a Sports Teacher).

- Lack of appropriate facilities leads to minimal participation of youth with disabilities, for example, no accessible play ground and equipment.

“...bring in more balls, they’d be made to participate actively and directly, in those sports activities if at all the schools consider them.”

- Inadequate training for both staff and youth with disabilities in the use of specialised equipment and games.

“We lack trained manpower. Sports for the disabled in some areas require technical expertise by its nature and we do not have many of such trained people ...” (the NCS official).

- Poor or inadequate funding from the government towards sports in schools.

“I would say 80% of the funding is through well-wishers and fundraising. Government puts like 40% (20 %?) then we have other supporters....” (an NCS official).

### 3. Recommendations

- Advocacy and lobbying from various stakeholders and pressure groups (government and disability organisations).
- Tailor-made training for existing teachers in sports, and involving universities and national teachers’ colleges.
- Mainstream sports events for youth with disabilities in the national sports calendar.
- Sports training curriculum should have provisions for training both teachers and persons with disabilities at all levels.
- The Department of Special Education, Guidance and Counselling in the MOES should be part of the National Council of Sports for better representation.

## Conclusions

There are policies and structures in place to promote participation of youth with disabilities in sports. The study established that these need to be strengthened at all levels to ensure enhanced participation of the target group.

## Challenges faced during the Study

- Coordinating the different activities in relation to researchers' timetable.
- Results reflect the opinions of respondents from one setting, which are 2 secondary schools. This could be limiting in that other youth with disabilities in other community settings might have varying opinions and experiences.

## What the Study has added

In Uganda, youth with disabilities are interested in participating in sports, regardless of the various challenges limiting them, like lack of adequate sports facilities, trained personnel, inaccessible play grounds, and inappropriate equipment.

## References

1. Government of Uganda. The Constitution of the Republic of Uganda 1995. Government of Uganda: Kampala.

## Researchers

Hariet Ntege, Librarian, Kyambogo University harrietnn@yahoo.com,

George Willy Kutosi, Lecturer, Kyambogo University geowilkuts@gmail.com

Francis Kasozi, Programme Officer, Mental Health Uganda frankasozi@yahoo.co.uk

## Mentors

Aisha Yousafzai, AKU, Pakistan aisha.yousafzai@aku.edu,

Maria de Lourdes Drachler <mailto:alu.drachler@googlemail.com> [alu.drachler@googlemail.com](mailto:alu.drachler@googlemail.com),

Harry Finkenflugel, Erasmus MC Rotterdam, Netherlands, [flnkenflugel@bmg.eur.nl](mailto:flnkenflugel@bmg.eur.nl)



## **PROJECT 8: SEX EDUCATION IN PRIMARY SCHOOLS FOR THE DEAF IN UGANDA**

### **Background and Justification**

Several primary schools/units (PS/U) for deaf children have been established in Uganda since 1958. Sex Education (SE) in all primary schools is contained in the science subject. Several initiatives in relation to the increased prevalence of HIV/AIDS have been introduced into mainstream education, including a government-led campaign like the Presidential Initiative on AIDS Strategy for Communicating to Young People (PIASCY) and non-government interventions like 'Straight Talk, Young Talk' initiated by UNICEF (RHO, 2005). However, these initiatives are hardly available to deaf children. Given the fact that the SE needs of deaf children are quite unique and that the lack of SE makes them doubly vulnerable, there is need to address this issue more purposefully.

### **What is known**

While there have been some sporadic efforts by the Uganda National Association of the Deaf (UNAD) to reach deaf populations, exclusion of deaf children from mainstream interventions in the fight against HIV/AIDS has put them at a higher risk of infection as reported by USDC (2005). SE in primary schools for the deaf is similar to that in the mainstream primary schools (Kisoro Trust). Anecdotal evidence indicates that SE for deaf children is often inadequate.

### **Aim**

To establish and document information that can be used in providing better sex education in PS/U for the deaf.

### **Objectives**

To find out deaf children's views about the sex education they receive in primary schools for the deaf. Specifically, to assess the level of knowledge on sex education, establish strategies that have been used currently to try to create behaviour change and identify potential ways to bridge the information gap among children in PS for the deaf.

### **Methods**

Children were purposefully selected, considering gender balance, age and

ability to communicate well in Uganda sign language (USL). Teachers were purposefully selected to include head teachers, senior women, men and science teachers. 40 self-administered questionnaires were completed by 40 children, 4 Focus Group Discussions (FGDs) were conducted with the same deaf children, 4 video recordings of FGDs were made and 18 questionnaires were completed by the teachers. Data collected was both qualitative and quantitative.

## Results

**Knowledge:** There was evidence that girls were more knowledgeable and articulate than boys, but generally their knowledge on sex education was inadequate.

For example, on ways of avoiding HIV/AIDS, they responded:

‘After condom use, you wash and dry in sun, then use again’.

When asked where and how babies are made, they responded:

‘Mother gets baby from hospital’.

On how they felt when they first experienced signs of puberty:

‘...hair developed in my armpits, I thought it happens to deaf like me’;

‘When I grew small breasts, I thought it was for boys to touch...’;

‘When starting menstruation, I thought I had acquired HIV’.

In the urban school, there was no child who mentioned any another type of Sexually Transmitted Disease (STD) apart from HIV/AIDS. All the children could not define the word puberty. Although the teachers responded that they had taught topics related to sex education such as human reproduction, HIV/AIDS, STDs, among others, the children’s responses showed that they did not or hardly understood the content. Some children had a little knowledge about HIV/AIDS, especially in rural areas. This was partly attributed to UNAD HIV/AIDS sensitisation programmes, as observed during data collection.

**Attitudes/Shame:** Children felt some issues on SE should not to be talked about in public.

‘... I felt so ashamed to tell my sister and mom’, (when she first experienced monthly periods); ‘hair in the armpits...then at the back near the buttocks...’

Others covered their face with their hands and laughed/were ashamed when asked about some of the body changes during puberty.

**Abuse:** All the girls in the urban school had their first sex encounter through rape. They reported that this was done by their neighbours or strangers when left at home alone, or sometimes when sent out alone by their parents/guardians.

**Strategies used by teachers:** The different strategies used by teachers were identified as guidance and counselling, extra co-curricular activities, talking environment, school rules and regulations, and peer counselling. It was noted that these strategies were not working well, primarily due to inadequate Ugandan Sign Language skills. Out of the 10 urban teachers, the most frequently reported challenges were: inadequate communication skills in USL (n8), inadequate teaching/learning aids (n4), lack of parental involvement (n3). Among the 8 rural teachers, frequently reported challenges were: inadequate communication skills in USL (n6), teaching/learning aids (n3), and negative attitude (n3) and slow learners (n3).

**Potential ways to bridge the gap:** Increase Ugandan sign language capacity, provide friendly teaching/learning aids, give routine guidance and counselling, sensitisation, use music/dance and drama, early enrolment of children in school, reorganising sex education in the curriculum, parental involvement and recruiting deaf people in schools.

### **Research challenges**

The age bracket of children was increased in the sample because they are enrolled in school late, the number of teachers was increased and varied in schools after noting that it could enhance the quality of the study, a few sections of the recorded FGDs missed focussing on participants who were signing/giving information.

### **Conclusion**

In primary schools for the deaf, the views of children show that they have inadequate knowledge about sex education and that the girls are sexually abused at home. This calls for better intervention measures so as to promote and protect human rights, including good health and quality education.

### **Recommendations**

(1) Raise awareness on importance of SE for deaf children through discussion with reliable family members. (2) Build teacher capacity to deliver SE to the children

well in Uganda Sign Language. (3) Encourage the development of teaching/learning aids that are friendly to deaf learners/children. (4) Recruit qualified sign language deaf instructors in schools to serve as role models. (5) Forums for teachers of deaf children for information and experience sharing. (6) Involve parents, The AIDS Support Organisation, Reproductive Health Associations, UNAD and National Union of Disabled Persons of Uganda (NUDIPU) and other partners in SE provision.

## References

1. Averting HIV and AIDS: <http://www.avert.org/aids-schools.htm> downloaded 18/03/09
2. RHO: Adolescent Reproductive Health 2005 [www.idrc.ca/acb/showdetl.cfm?&DID=6&Product](http://www.idrc.ca/acb/showdetl.cfm?&DID=6&Product)
3. Uganda Society for the Disabled Children, Ability, Vol. 3 No.4 October 2005
4. The Kisoro Trust Latest News: <http://www.kisoro.org/newsarchive.htm> downloaded 18/03/09

## What the Study adds

Deeper knowledge gained on SE-related issues by the study participants (children and teachers). Giving the information needed to revise the curriculum and pilot this in a new Ka Tutandike Project in Masaka. Teachers do not have enough skills to deliver the content of SE to children. Parental involvement is lacking in SE provision. There is late enrolment of deaf children in school. Teaching/learning materials are not user- friendly.

## Researchers

Senyonga Maurice, Lecturer, Kyambogo University [mauricesenyonga@yahoo.com](mailto:mauricesenyonga@yahoo.com);  
 Namarome Rehema, Programme Officer; NUDIPU [namrh2001@yahoo.co.uk](mailto:namrh2001@yahoo.co.uk);  
 Nsereko Harriet, Lecturer, Kyambogo University, [tabharriet@yahoo.co.uk](mailto:tabharriet@yahoo.co.uk);  
 Mbabaali Joseph, Kyambogo University [mbabaalijoe@yahoo.co.uk](mailto:mbabaalijoe@yahoo.co.uk);

## Mentors

Sally Hartley [S.Hartley@uea.ac.uk](mailto:S.Hartley@uea.ac.uk);  
 Angie Wade [a.wade@ich.ucl.ac.uk](mailto:a.wade@ich.ucl.ac.uk);  
 Aisha Yousafzai, [aisha.yousafzai@aku.edu](mailto:aisha.yousafzai@aku.edu)

## **PROJECT 9: THE EXPERIENCES OF PEOPLE WITH DISABILITIES IN ACCESSING HEALTH SERVICES IN UGANDA: A CASE STUDY OF MBARARA DISTRICT**

### **Background**

According to the Population and Housing Census (2002) an estimated 2.5 million people with disabilities live in Uganda. These include people with impaired hearing, vision, mobility and cognitive functioning. The Universal Declaration of Human Rights states, "Every human being has a right to decent life and equal opportunity in accessing social services (including medical) and so should not be discriminated against regardless of sex, age, race, disability or any other factor"

### **Aim**

To increase the understanding of issues affecting accessibility to health services for persons with disabilities in Mbarara District.

### **What is already known**

- Health facilities in Uganda range from Health Centre I – IV located at county and sub-county levels, with Health Centre I closest at the parish level and a District Referral Hospital which is always within about 30 – 50 Km. The available means of transport used to access these are bus, taxi or motorcycle (Ministry of Health, 1999).
- The services offered in these centres include theatre services, laboratory services, rehabilitation services, special consultant, antenatal services, paediatric services, immunisation, radiotherapy, physiotherapy and other general health care. Medical personnel involved in offering the services are doctors, nurses, midwives, clinical officers and support staff (Ministry of Health, 1999).
- There are problems for people with disabilities in accessing these health facilities (Health Sector Policy Overview Paper 2006; Health Manpower Requirement and Training Priorities in Uganda; 1993)

### **Objectives**

1. Identify health services used by people with disabilities.
2. Establish the challenges faced by people with disabilities in accessing health services.

3. Identify how people with disabilities deal with the limitations in accessing health services.
4. Identify ways of improving accessibility of health services to people with disabilities.

## Methods

A qualitative study was conducted by a team of 4 researchers, in one rural sub-county and one urban municipality. 19 in-depth tape-recorded interviews were conducted with 19 purposively selected persons with disabilities from the hearing, visual, and physical impairments groups identified by the District Rehabilitation Officer and Chairman of People with Disabilities Association, Mbarara district. 10 interviews with medical personnel and 4 focus group discussions with 10 respondents comprising of people with visual, hearing and physical impairments were also conducted. Sixteen photographs were taken of the homes and health centres of people with disabilities. The interview method was used because it brings the researcher in direct contact with the respondents to get first-hand information.

## Results

**Services offered:** It was found that services accessed by people with disabilities at health centres included Outpatients, General medical services, Immunisation, Antenatal, Delivery and Maternity services, PMCTC, Referrals and Paediatric, Laboratory, Ambulance, guidance and counselling services.

### **Challenges people with disabilities face in accessing health services:**

**Distance** – People with disabilities live  $\frac{1}{2}$  - 10 kilometres away from the Health Centres, i.e., a walk of 40 minutes - 4 hours to reach the health centre. These distances are too long for many of them to walk and too expensive for them to secure transport. Transport costs are often doubled as they frequently require a helper to accompany them (2 physically impaired people, 1 blind and 3 hearing impaired people who were interviewed needed helpers to travel). It was observed that there were long queues at the health centres, unfriendly medical staff, difficulty in communicating due to lack of sign language interpreters, lack of wheelchairs so some people with disabilities have to crawl on the dirty floor, and lack of special toilet facilities. High steps, high treatment beds and lack of ramps present difficulties for visually and physically impaired people.

### **Challenges faced by medical workers while providing health services to people with disabilities:**

- (a) **Difficulties with communication** were the biggest reported problem and resulted in not knowing the history of the disease, for example from the deaf clients, because of lack of knowledge of sign language. Other difficulties were work overload because of few staff, very small working spaces and insufficient drugs for dispensing.
- (b) **How people with disabilities deal with the challenges:** Apart from one visually impaired respondent who works with the Education department and earns money to pay for transport, medicines and health services, the rest of the people with disabilities who were interviewed did small jobs which are not well paid. Consequently they could not deal with the challenges of expensive transport and medicine, and depended on local herbs.

### **Ways of improving accessibility as suggested by health workers:**

“This centre should be provided with a wheelchair to help people with disabilities when they are very sick” (Kinoni H.C).

“A special toilet should be built in the ward for people with disabilities” (Senior Nursing Officer, Kinoni Health Centre).

“Provide an eye specialist to every health centre. It will reduce on the number of blind people” (Biharwe H.C).

“Information about the people with disabilities should be established so that they are known and planned for” (Mbarara Mun. H.C).

### **Conclusions and Recommendations**

The researchers concluded that while there are some services available at the health centres that were visited, there are also many challenges that people with disabilities face in accessing mainstream health care in these areas of Uganda. Some of these could be improved through relatively simple means such as: (a) A special desk for people with disabilities could be used so that they do not have to queue up with other people when trying to access services. (b) Sign language could be taught to both people with disabilities and the health workers to enable communication between them. (c) Government could stock medicine required by people with disabilities. (d) Provide equipment such as low treatment beds and



wheelchairs. (e) Special/accessible toilets in the wards. (f) Provide sighted guides so as to ease accessibility to the health services.

### **Challenges faced by researchers during the Study**

There was a communication limitation due to researchers' lack of knowledge of the local language and sign language. The second phase was carried out during heavy rains so people with disabilities who live in the depths of villages could not be reached; as a result, the study did not elicit their responses.

### **What the Study has added**

This study added information about the reasons why people with disabilities do not access health services. It assisted in developing a better local understanding of the issues involved e.g., the rights of people with disabilities to health services. The health service providers also came to know about the special needs of people with disabilities, e.g., as in how to improve their access to health services.

### **References**

1. Health Manpower Requirement and Training Priorities in Uganda; 1993
2. M The Health Sector Policy Overview Paper; 2006
3. Ministry of Health. The Health Policy of Uganda; 1999.
4. Uganda Population and Housing Census (2002), Uganda Bureau of Statistics, Kampala; 2006.
5. Uganda Human Rights Commission. [www.uhrc.org](http://www.uhrc.org); December, 2008

### **Researchers**

Christine Kazairwe, Kyambogo University [kazairwec@yahoo.co.uk](mailto:kazairwec@yahoo.co.uk);  
 Obura Edward, Lecturer, Makerere University [oburnep@yahoo.com](mailto:oburnep@yahoo.com);  
 Beatrice Kyamazima, Secretary Kyambogo University [kyamazimab@yahoo.co.uk](mailto:kyamazimab@yahoo.co.uk);  
 Miuro Michael- Officer at District level, Masaka District [m@yahoo.co.uk](mailto:m@yahoo.co.uk);

### **Mentors**

Sally Hartley, University of East Anglia, Norwich, Norfolk, UK [S.Hartley@uea.ac.uk](mailto:S.Hartley@uea.ac.uk);  
 Harry Finkenflügel, Erasmus MC Rotterdam, The Netherlands [finkenflugel@bmg.eur.nl](mailto:finkenflugel@bmg.eur.nl)



## **PROJECT 10: ECONOMIC DEVELOPMENT ACTIVITIES FOR WOMEN WITH DISABILITIES IN JINJA AND KAMULI DISTRICTS IN UGANDA**

### **Background and Justification**

Women with disabilities in Uganda are assigned a low status because they are women and also because they are disabled (Hans and Patri, 2003). They are marginalised, neglected and are often considered a burden. Economic empowerment is the aim of many NGOs in Uganda but it is not known whether women with disabilities are being reached through them.

### **What is already known**

People with impairment in low income countries are more likely to be poor because of malnutrition, poverty, landmines, lack of services, and poor access to education. This hits the poorest the hardest (Hans and Patri, 2003; Elwan, 1999). The persistence of grossly wide gender gaps in social, economic, political, and civil and health well-being of women and their children has negative economic impacts. Therefore empowering women is emphasised (Schleiter et al, 2003).

### **Aims and Objectives**

- (1) To collect information about economic development activities of women with disabilities.
- (2) To identify the challenges they face.
- (3) To identify the training needs of women with disabilities and their leaders.

### **Methods**

The study was carried out in Jinja and Kamuli districts. Purposive sampling was used to select 8 individuals and 7 groups of women with disabilities (total number of women with disabilities: 38). The sample included representation from a wide age range (16 - 60 years), women from urban and rural locations, and with physical, visual or hearing impairments. Additionally, from each district a Chief Administrative Officer, a Community Development Officer, and a Women with Disability District Chairperson was included in the sample. Questionnaires and Focus Group discussions were carried out to collect information about the projects. Interviews were used to collect data from the district people listed above. Document analysis was done on membership, activities, training, meetings, and

finances of groups of women with disabilities. Observation of the projects was conducted to ascertain the data collected by oral methods.

## Results

**Economic development activities:** Economic development projects for women with disabilities included tailoring, goat rearing, a vocational training school, bakery, poultry, savings and credit, small gardens, small retail businesses such as selling tomatoes, used clothes, making of handicrafts, a photo studio, sweater knitting and a nursery school. Among all these, tailoring is the most popular. While majority of women with disabilities in Jinja operate their projects as individuals, those in Kamuli mainly operate in groups. Only a few groups are registered. All organisations fall under two umbrella associations - JIDAWUD (Jinja Women with Disabilities Association) and KAWIDA (Kamuli Women with Disabilities Association). Most women find out about these organisations or groups through the founders and members. The groups have 15-30 members who either have a disability or are parents of children with disabilities, and pay a membership fee of 2,000-15,000 Ugandan shillings (50p to £3.20). The members meet 1-2 times a month, take down the minutes of the meeting, and all members participate in decision making. They have gained self-confidence through exposure. Some of them have acquired knowledge and skills of management and leadership, and they all feel it is worthwhile for other women with disabilities to join.

## Challenges faced by the economic development projects of women with disabilities:

(a) Their ability is underrated as regards work and leadership and some fail to get tailoring contracts. Their products are bought at lower prices than the farm products. (b) Majority of the women with disabilities are single mothers or widows with large numbers of children and other dependants, and raising them is a challenge in terms of feeding, education, medical care and discipline. (c) HIV/AIDS prevalence among women with disabilities is high, partly because men engage them in casual secretive sex relations with limited opportunity to negotiate for safe sex, and rape cases are quite frequent. (d) Lack of formal education affects their self-esteem and ability to associate freely and compete for jobs. (e) They lack crutches and wheel- chairs due to the cost. Transporters do not like to transport them, claiming they take long to board and require support. Thus women with disabilities have difficulties in attending meetings,

checking on their group projects, and sharing ideas on how to improve and how to look for markets for their produce. (f) Communication is by using pen and paper, and those who can interpret sign language are few and expensive to hire. (g) Limited capital to run their businesses; the groceries that were visited have operational capital ranging from 20,000 to 40,000 Uganda shillings (\$ 10 to \$ 20). (h) Microfinance organisations are sceptical of their ability to repay the money, and ask for sureties in terms of property which the women do not have. This is often coupled with donors' stringent conditions and delayed remittances. (i) There is a lack of proper book-keeping skills, and modern equipment like computers, modern sewing machines, and ovens, which would ease and hasten their work in order to compete with the rest of the world. (j) Lack of market for their products and services, lack of advertisement, involvement in seasonal work and operating in rented premises affect them. (k) Family members assume that women with disabilities get money from donors so they do not need their help.

**Training needs:** As expressed by the women with disabilities, these included project planning and management, proposal writing, basic book-keeping, financial management, environmental conservation, fundraising skills, customer care and creation, human rights education, loan management, credit saving, sign language, HIV/AIDS care and counselling, modern skills in tailoring and modern crafts.

### **What the Study has added**

Important information on the economic development activities of women with disabilities, how they operate and the challenges they face. This information will be used to inform the training which will form the intervention in the second part of the study.

### **Challenges faced during the Study**

Equipment failure was the major challenge. Once, a wrong button of the recorder was pressed so no recording was done. A virus infected the laptop during transcribing and all data was lost. The team failed to work within the programmed schedule due to schools' and university's programmes.

### **Conclusions and Recommendations**

Women with disabilities do engage in various feasible economic development activities which include tailoring, rearing goats and keeping poultry, growing

crops and running of grocery supplies. They identified their training needs in relation to the challenges they face, and these will be used to form the basis of the intervention for the second part of the study. The training will encourage women with disabilities to have projects at home to minimise mobility costs, help them in writing proposals to donors to solicit financial support, and improve their financial management.

## References

1. Hans A and Patri A. *Women, Disability and Identity*. Sage Publications: London; 2003
2. Elwan A. *Poverty and Disability: A Background Paper for the World Development Report*, World Bank, Unpublished; 1999
3. Schleiter M, Reinders T, Stathan A. *Challenges faced by Women with disabilities under Temporary Assistance for Needy Families (TANF)*. Institute for Women Policy Research, University of Wisconsin, Parkerside; 2003

## Researchers

Sarah Bunoti, Lecturer, Kyambogo University sbunot@gmail.com;  
 Lovisa Kabuula, Programme officer NAWOU;  
 Margaret Katisi, Teacher Mpoma Secondary School bntmaggie@yahoo.com ;  
 Grace Nakayiza, Teacher Kitante Secondary School gnk07@yahoo.com;  
 Rose Kakayi, Programme Officer, National Union of Disabled Persons in Uganda

## Mentors

Maria de Lourdes Drachler <mailto:malu.drachler@uea.ac.uk>  
 Aisha Yousafzai [aishayousafzai@hotmail.com](mailto:aishayousafzai@hotmail.com)

## **PROJECT 11: AN ASSESSMENT OF HOW MOTHERS WITH VISUAL, HEARING AND PHYSICAL IMPAIRMENTS MEET THE NEEDS OF THEIR CHILDREN**

### Background

Studies have shown that many mothers in Uganda:

- are not employed; however, some of them do petty work to meet the needs of their children.
- meet the needs of their children through sympathisers.
- take the children to the villages and their parents take care of their children.

## **Aim**

To explore how mothers with visual, hearing and physical impairments meet the needs of their children.

## **Objectives**

1. How do mothers with visual, hearing and physical impairment define the needs of their children? Identify what needs they cannot meet and why.
2. Explore how these mothers meet the needs of their children.
3. Explore the challenges faced by these mothers when trying to meet the needs of their children.
4. Analyse the recommendations from the mothers with visual, hearing and physical impairments.

## **Methods**

Based on the purposive sampling technique, mothers who had impairments (visual, hearing and physical), with children between 0-10 years of age, were identified. The plan was to have 15 mothers from each district (Tororo and Mukono) but due to the fact that the CDOs do not have statistics on these mothers, it was a bit difficult to identify them. Secondly, in Mukono District, the structure of accessing these mothers is not clear unlike Tororo District which is a model CBR District. A total of 23 mothers were located and interviewed - 13 mothers in Mukono District and 10 mothers in Tororo District. In Tororo district the number of mothers with impairments is few because the researchers did not find them at home as some were out running errands.

## **Analysis**

Each of the mothers was interviewed using guidelines prepared by the 3 researchers. A total of 23 interviews were conducted, some in Luganda and some Atesot (local language). The data was transcribed and analysed in the local language, using the research questions as a guide. Data which did not address the research questions was discarded.

## **Results**

1. The mothers defined the needs of their children as: water, food, soap, school fees, medical support, school uniforms, exercise books.

## 2. Reasons these mothers fail to meet the needs of their children:

Unemployment - "I don't have any work."

Accessibility - "The river where I get water is far."

Social attitudes - "I cannot employ you because disabled people are slow."

Rejection - "Their father left me."

Poverty - "I beg in order to buy food for my children."

Lack of access to financial institutions - "At times banks do not give us loans because we cannot pay back."

Low income - "I get little money from frying cassava."

## 3. How mothers meet the needs of their children:

Self-employment - "I weave baskets."

Sympathisers - "Compassion International helps me with school fees."

Grandparents take over the responsibility - "My mother helps me to look after my children."

"When I gave birth I took my kid to the village."

Formal employment - "Am a deaf Instructor."

Support from financial institutions - "I got a loan from the microfinance."

## 4. Challenges faced by these mothers when trying to meet the needs of their children: Harsh conditions - "When it rains I do not work and when it is hot I have to brave the heat."

Communication - "I need an interpreter when I take my child to hospital."

Poverty - "I have no fees for my children."

## 5. Suggestions by mothers on how to meet the needs of their children:

Income-generating projects like poultry, piggery in order to meet the needs of their children - "I can get capital to start my own business."

Government and other stakeholders should involve women with disabilities in mainstream income generating projects - "If I can get money from Government or an NGO and start rearing pigs and chickens."

“I would admire that government could also recognise we mothers with disabilities, because now I married off my 2 kids because I had no money to look after them.”

“If at all I can get capital from an NGO, so that I can start my small business from there I can be getting some little money to support me to take them to better schools.”

“Government should assist me with something like income-generating projects.”

Government should help us mothers with disabilities in other ways - “Government should avail a borehole nearby so that I can fetch water.” “Government should educate my children.”

“Government should give me a job so that I get some money and help my children.” “Help like money for our upkeep and school fees, because next year she is supposed to start school but I do not have money.”

“Financial help from NGOs, individuals, government.”

There is need for more sensitisation and capacity building for mothers with disabilities so as to help them raise their self-esteem - “Government would recognise we mothers with disabilities.”

### **Challenges faced during the Study**

- Noisy environment
- Not enough statistics on disability
- High monetary expectations from researchers

### **Conclusions**

Mothers with disabilities expect aid from the Government and different stakeholders to help them meet the needs of their children. Mothers with disabilities want to meet the needs of their children just like other mothers would, but unfortunately the systems in place do not favour this.

### **Recommendations**

- Income-generating projects
- Capacity building and sensitisation
- Access to financial institutions
- Self-Help Groups/Clubs

## What the Study has added

- It has given an insight into the situation of mothers with disabilities.
- Mothers with disabilities have the passion to see their children go to school and have basic necessities like any other children.
- Mothers with disabilities believe that the Government can do more in supporting them.

## Researchers

Mary Nabbose Kyagaba, Librarian, Kyambogo University mnabbosa@yahoo.com; Andrew Bwogi, Programmer, Kyambogo University andrew.bwogi@gmail.com; Mariam Nambooze, Student, NAWODU marianambooze@yahoo.c.uk;

## Mentors

Harry Finkenflügel harry.finkenflugel@sheerenloo.nl;  
Aisha Yousafzai aisha.yousafzai@aku.edu

## PROJECT 12: A SYSTEMATIC REVIEW OF THE INITIATIVES TO SUPPORT VISUALLY IMPAIRED FARMERS IN DEVELOPING COUNTRIES

### Background and Justification

According to the Human Rights treaties (UN Public Policy on Disabilities), the visually impaired people have a right to economic security commensurate with their capacities, for which the requisite of education and training shall be provided (UNDP). The Population and Housing Census of Uganda (2003) observed that the majority of the visually impaired people live in rural areas where agriculture is their main source of livelihood. By reviewing the existing literature, this study wanted to learn about the initiatives implemented by development agents to support visually impaired people in their agribusinesses.

### What is already known

Uganda has a large agriculture sector which supports many people including the people with visual impairment.

### Aim

To review the existing literature on the support from development agencies for visually impaired people's agribusinesses in developing countries.



## Objectives

1. To establish from the literature the types of support offered by development partners to visually impaired farmers in developing countries.
2. To analyse and learn from the different forms of support offered to the visually impaired people.

## Methodology

The review was carried out between June and December 2008, using two main key search words: “farm” and “disability”. The following questions were used for inclusion/exclusion of documents in the three stages:

1. Is the paper/report an experiential report/primary research?
2. Is the paper/report about initiatives to support people with disability in agrobusiness?
3. Is the initiative in developing countries/blocks?
4. Does the paper present results about blind people?

At Stage 1, 110 titles which had information on disability and farming were sourced from the internet and libraries. At Stage 2, the elimination of documents from developed countries left only 67 titles from developing countries. Then, the review of the abstracts of the 67 documents found that only 23 documents had information on farming activities of people with visual impairment. At Stage 3, the 23 documents were downloaded and scrutinised but only 12 had evidence of implemented interventions in African and Asian countries. The countries represented were Ghana, Kenya, Mali, Malawi, Uganda, Zambia, Bangladesh and China.

## Results

1. 8 developing countries - Ghana, Kenya, Mali, Malawi, Uganda, Zambia, Bangladesh and China - had accessible stories on the internet, written by journalists and researchers.
2. Support to farmers with visual impairment was largely rendered by NGOs in comparison to companies and Governments.
3. When given the opportunity, technical skills and farm inputs, the people with visual impairment ably engage in various farming activities for family food and income; and thus gain community respect.

4. Successful farming empowers the people with visual impairment economically and they cease to be burdens on their families.

Examples of initiatives that worked included: Giving citrus seedlings to farmers with visual impairment, together with farming instructions, in Mali and Ghana ([www.adra.org](http://www.adra.org)). Supplying cassava cuttings with goats and instructions in Uganda improved the food security, and the surplus was sold (Action on Disability and Development, 2008; Nsubuga and Serwaniko, 2003). Coffee farmers learn new planting techniques using lifeline radios in China ([www.sightsavers.org](http://www.sightsavers.org)).

## **Conclusions**

Agribusinesses for the people with visual impairment are not well-reported in the literature; however case studies identified show that when they are supported with assistive devices and agricultural skills, they can improve agricultural yields, food security, family incomes, and general living standards. NGOs, compared with governments, appear to be more supportive of farmers with visual impairment in agribusinesses. Limited literature prompts the need for more research on farmers with visual impairment so that lessons can be learnt and future projects could build on evidence collected.

## **Recommendations**

- There is need for partners to develop more programmes, equipment or technologies to meet the agribusiness demands of people with visual impairment and to document interventions.
- The farmers with visual impairment might benefit from associating collectively to access benefits.
- There is need for further research in developing countries to document and disseminate information about the visually impaired farmers' practices and experiences, for lessons and advocacy.

## **Challenge**

Many papers that were found were of a descriptive nature and did not report evidence in a rigorous manner; the tendency was to relay opinions.

## What the Study has added

- Identified a need to document case studies of visually impaired farmers in Uganda to improve access to information based on experiential learning so that future projects to assist people with visual impairment can build on this information.
- Initiatives that have worked for the visually impaired farmers in Africa and Asia have been identified and described in a detailed report available on request.
- When given the opportunity, technical skills and farm inputs, the people with visual impairment ably engage in various farming activities for family food and income; and thus gain community respect.

## References

1. <http://www.undp.org/governance/docs/humanrights-Pub-policys.htm>
2. The Uganda Population & Housing Census Bureau of Statistics, Kampala 2006
3. Action on Disability and Development (2008). Blind Farmers in Uganda.: [www.miusa.org](http://www.miusa.org); July 2008.
4. Nsubuga M, Serwaniko C (2003). Income Generation Activities for persons with Visual Impairment, Uganda National Institute of Special Education (UNISE).

## Researchers

Regina Nakayenga, Lecturer, Kyambogo University [rsnakayenga@yahoo.co.uk](mailto:rsnakayenga@yahoo.co.uk)

Mathias Sserwadda, Lecturer, Kyambogo University [sserwaddwamathias@yahoo.com](mailto:sserwaddwamathias@yahoo.com)

Beatrice Anguzi, Coordinator, NUWODU [nuwodu@infocom.co.ug](mailto:nuwodu@infocom.co.ug)

Christopher Kaweesi, Coordinator BCDP [kachron001@yahoo.co.uk](mailto:kachron001@yahoo.co.uk)

## Mentors

Maria de Lourdes Drachler [mailto:malu.drachler@uea.ac.uk](mailto:mailto:malu.drachler@uea.ac.uk) [malu.drachler@gmail.com](mailto:malu.drachler@gmail.com);

Aisha Yousafzai, AKU, Karachi, Pakistan [aisha.yousafzai@aku.edu](mailto:aisha.yousafzai@aku.edu)

The 9 partially-completed projects are listed in Table 4. Although these projects did not reach completion, all groups completed a research protocol which was accepted by the project review panel. In the process of formulating the research questions, they engaged in research capacity development workshops: designing the study, doing a literature review and collecting some data. These 9 projects did not however complete the analysis and writing-up stages within the time-frame allowed, so no results are presented. Numerous reasons for the delay were noted. These included illness, delayed access to funding, weather constraints, time issues and change of employment.

**Table 4: Summary of the Nine Incomplete Action Research Projects**

Title	Aim	Team	Reported Project Status by the Research Team (2011)
The challenges, effectiveness and efficiency of persons with disabilities in Ugandan universities	To identify challenges and restrictions in social participation of persons with disabilities in Kyambogo University. Looking at the physical environment, service systems and policies, and the attitude of university colleagues, it is seeking to identify strategies to increase social participation based on the perspectives of persons with disabilities, persons without disabilities, University staff, government and other community bodies.	Angela Nadongo (Kyambogo University); Asaf Adebua (University Planning Director, Kyambogo University); Charlestine Elwange Bob (Lecturer, Kyambogo University).	The project has collected all the data and done some analysis. It is at a report-writing stage.
Vocational rehabilitation programmes and employment of persons with disability	To explore the outcomes of attending vocational rehabilitation, it is seeking to develop a method of doing this in a case study of one vocational centre.	Ali Baguwemu (Lecturer Kyambogo University); Moses Ddamulira, (Lecturer, Kyambogo University); Carolyne Maholo (Lecturer, Kyambogo University)	The team is presently testing the research tools.

<p>Enhancing participation of persons with disabilities in governance: A cost benefit analysis of their participation in selected district and sub-county councils</p>	<p>This study is looking at how people with disabilities are included in governance, what are the challenges and how can they be overcome?</p>	<p>Ephraim Nuwagaba,, (Lecturer, Kyambogo University); Mille Nakabugo (Programme Head, Uganda Adult Education Network); Mutabwire Patrick, (Ministry of Local Government); Christine Nsungu, District Counselor, Jinja District Council).</p>	<p>The team has completed data collection and is at a data analysis stage.</p>
<p>Perspectives of families, extension workers and local leaders on participation of persons with disabilities in agriculture in Uganda</p>	<p>This group is examining how people with disabilities have been included or excluded from Agricultural opportunities offered by the government.</p>	<p>Victor Locoro (Lecturer, Kyambogo University); Vanny Kyobuzaire, (Assistant Lecturer, Bishop Stuart, Mbarara District); Alexander Isiko (Lecturer, Kyambogo University); Africana Habyomugisha (Officer at District level Dept. of Community-Based Services).</p>	<p>The team has completed analysing data and is compiling a report.</p>
<p>Practices and experiences of blind farmers</p>	<p>This is a number of case studies to explore how blind people successfully integrate themselves into farming initiatives.</p>	<p>Regina Nakayenga (Lecturer, Kyambogo University); Mathias Sserwadda (Lecturer, Kyambogo University); Fr. Athnadius Mubiru (Catholic Church Priest Socadido); Beatrice Guzu (Programme Officer, NUWODU).</p>	<p>The team has completed data collection and is now analysing data.</p>
<p>Case studies of children with intellectual disabilities: investigating sexual maturation and development in Tororo and Iganga district, Uganda:</p>	<p>This will explore the experiences of children with cognitive impairments and look at their sexual maturation and what this means to them and to their families.</p>	<p>Christine Kazairwe, (Kyambogo University); Betty Kasavubu (Secretary, Kyambogo University); Juliet Nakalule Wamala (Asst Lecturer, Kyambogo University)</p>	<p>This team has collected and analysed their data and is presently compiling a report.</p>

Piloting a tool for evaluating CBR programmes	This group is taking an evaluation tool that was developed in Tororo, Uganda by researchers from UEA and piloting its use in real CBR programmes to see if it is usable and useful.	Carolyn Maholo, (Lecturer, Kyambogo University); Lucia Kabagere (Deaf Student, Kyambogo University); Asher Bayo (Lecturer, Kyambogo University).	The team is presently collecting data.
A baseline survey proposal on vocational education and deaf people in Uganda	This study is gathering data about deaf children's use and engagement with vocational education in Uganda to see how many access this and what are the challenges.	Rehema Namarome, (Programme Officer, National Union of Disabled Persons of Uganda); Bonnie Busingye (Lecturer, Kyambogo University); Nandelenga Wadada (District Officer, Soronko Local Government).	Data collection exercise was finished and the team is analysing data.
A randomised control trial of Workshop Intervention to improve the economic status of women with disabilities in Kamuli and Jinja districts	This project is building on an earlier project and using information gathered at that time to generate a training intervention for women based on their expressed needs, and evaluates how helpful it is to them.	Sarah Bunoti (Lecturer, Kyambogo University); Grace Kibirige (Teacher, Kitante Secondary School); Rose Kakai, (Programme Officer, Buweda Village); Maggie Katisi (Teacher, Mpoma Secondary School); Lovis Kabuula, Programme Officer, NAWOU).	The team is preparing to go out for training sessions with women with disabilities, which is the data collection stage.

**Abbreviations/Acronyms: CBR-Community-Based Rehabilitation, NAWOU-National Association of Women's Organisations in Uganda, NUDIPU-National Union of Disabled Persons in Uganda, NUWODU-National Union of Women with Disabilities of Uganda, Socadido-Development and Welfare Group of Soroti Diocese, Teso, Uganda**

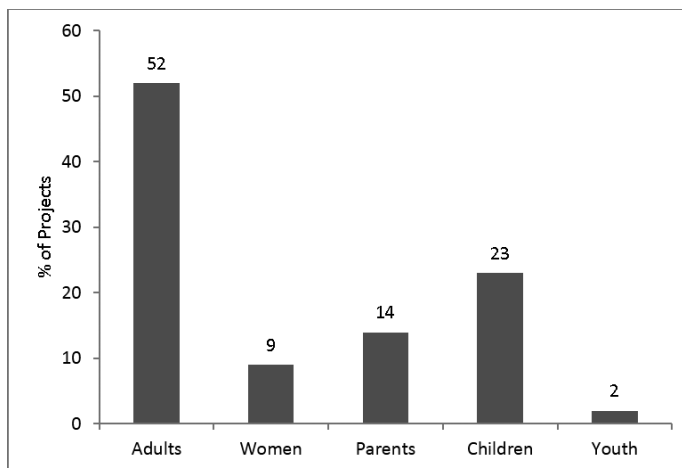
After the duration of the CARD programme came to an end, some meetings were held with selected CARD members and suggestions were made to register CARD as an organisation in Uganda. Funding was required, as well as a Memorandum of Understanding (MOU) with the University, but to date these have not been achieved. In a recent development, this group has approached 'Advantage Africa' seeking to revive the CARD action research programme.

## EVALUATION AND ANALYSIS OF CARD RESEARCH PROJECTS

### The Research Topics Chosen by the CARD Research Projects

Unlike most research programmes, the local teams had the freedom to choose the focus of their studies, and as seen from the preceding lists, the range of topics was wide and varied. Analysis of these topics showed that 75% of the projects targeted adults and only 32% looked at children or youth (Figure 1).

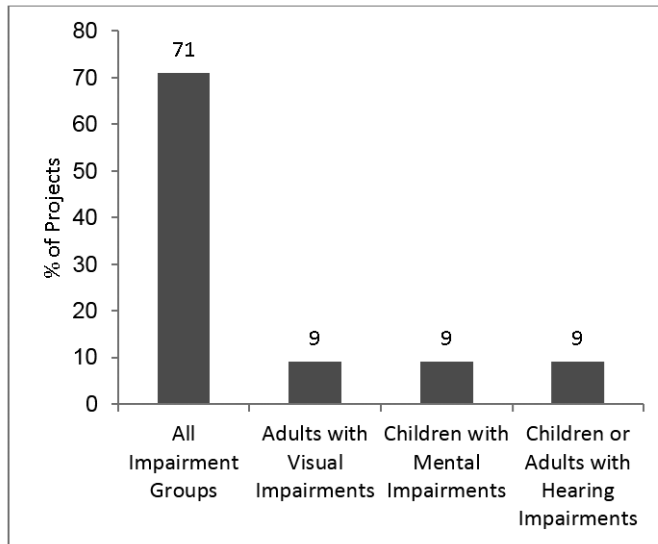
**Figure 1: Target Populations Selected in Projects of the CARD Programme**



**Note: Some projects focussed on more than one target population**

With regard to the different impairments, some projects focussed on people with specific impairments, but most (n=15, 71%) wanted to examine the situation for all impairment groups (Figure 2). Evidence of this more inclusive approach by the community members is in harmony with the philosophy promoted by the WHO in the CBR guidelines (WHO, 2010) and the values of the UN Convention on the Rights of Persons with Disabilities (UN, 2006).

**Figure 2: Types of Impairments in Project Population**



There was a wide variety of subjects chosen for investigation, but the descriptive analysis shown in Figure 3 indicates that the majority of projects related to economic and employment issues, followed by access and inclusion of people with disabilities in mainstream services. Together these two groups made up 66% of the projects, indicating that these areas of investigation were the priorities in this Ugandan context. This provides evidence to support the inclusion and the importance of the Livelihood pillar of the CBR Guidelines.

**Figure 3: Issues Addressed in Projects**

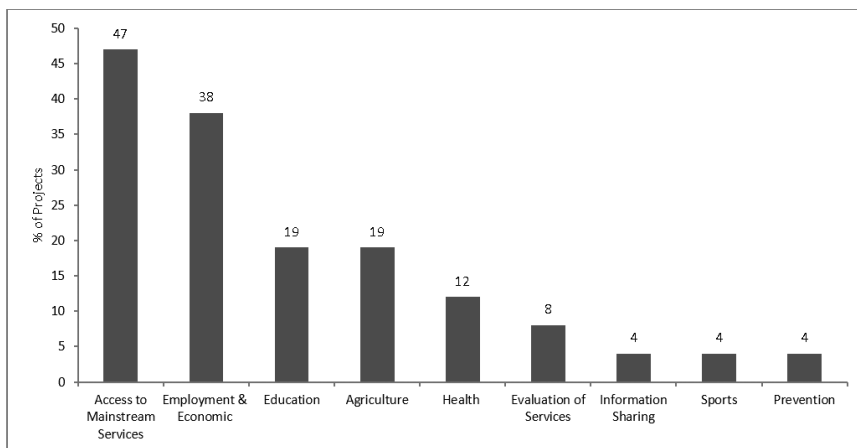
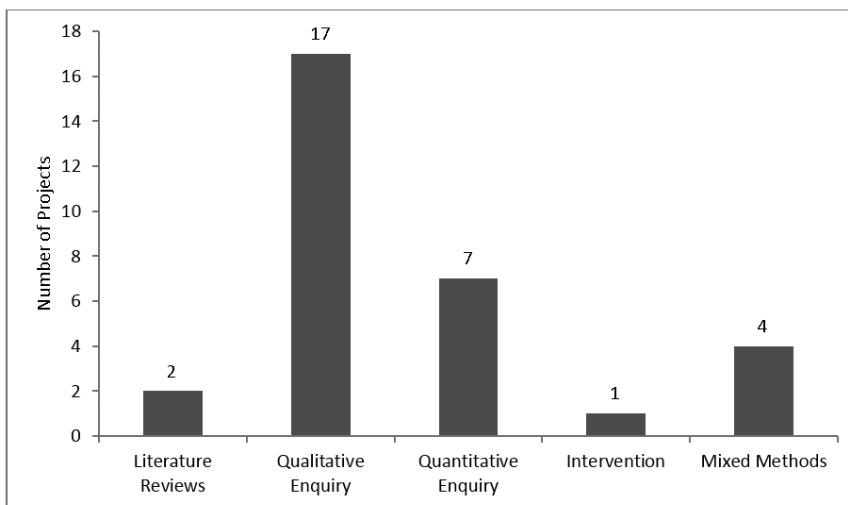




Figure 4 shows that the most common research methods used were qualitative. Although this was linked to the type of questions that the groups posed, the teams found that dearth of previous research on the topics chosen often made it difficult to formulate a hypothesis for quantitative examination. Also, the qualitative approach did not require as large a study sample as its quantitative equivalent, and consequently was sometimes more feasible given the available resources and time. The focus on qualitative enquiry might also have been related to, as Mtali (2009) suggests, serving as a vehicle for 'hearing the voice' of the people. The need for making this voice heard is more important when local realities may also not tally with the ideas about disability and service provision from the West. In addition, the participants came from an oral tradition, and it is likely that they find it more meaningful to relate to qualitative data which uses words as currency, than the numerical equivalents. Given this background, it is possible that qualitative enquiry provides a better introduction for research capacity development in this particular context.

**Figure 4: Research Methods employed in Projects**



## Dissemination

As specified in the agreed objectives of the CARD programme, completed research was disseminated in a wide variety of ways with the aim of reaching all of the relevant stakeholders. Findings from 2 research projects have been published in peer-reviewed scientific journals (Panel 3).

### Panel 3: Peer-reviewed Articles from the CARD Projects

Nuwagaba Ephraim Lemmy, Meldah Tumukunde, Edson Ngirabakunzi, Nakabugo Millie, Angie Wade, Sally Hartley. Accessibility to Micro-finance Services by People with Disabilities in Bushenyi *Disability and Society*; 2012; 27(2): 175-190.

Christine Kazairwe, Beatrice Kyamazima, Edward Obura, Michael Miro, Yasmine Alavi. People with Disabilities and Barriers to Health Services in Uganda: Community Action Research on Disability. in *Access to Services for Persons with Disabilities in Challenging Environments*, pp.44-46, Handicap International; 2011.

Findings from several research projects were disseminated through newspapers, newsletters, radio and websites, making everything accessible to a wide audience. Some were presented in conferences or seminars (Panel 4).

### Panel 4: Project Dissemination Platforms

#### Newsletters

- Reproductive Health Education for Deaf Youth. *Katutandike Newsletter Article*;2010; pp 18-23
- CARD Bi-Annual Newsletter

#### Newspapers

- Newspaper articles on a range of CARD supported projects were published in spreadsheets 2008 and 2010 in the *Daily Monitor*, Uganda's leading independent daily newspaper. Both publications talked about the CARD projects and achievements.

#### World Wide Web

Completed research projects produced a summary report that was disseminated online: <http://afri-can.org/cbr-projects/Conferences and Seminars>

- Five Uganda Seminars were held in total, one at the beginning of each year, with a final seminar at the end of the project in July 2010. In total 401 participants attended (ranging from 70-160 in each seminar).

- Presentations were given about CARD at the University of East Anglia in the Faculty of Health in 2009 with an audience of approximately 40 health professionals, covering CARD's aims, structure, progress and outcomes. Similarly, dissemination about the CARD programme was presented at the University of Sydney, Australia, in 2011, to an audience of approximately 60 disability activists and health professionals, examining how people with disability could become more involved with research.
- A presentation and workshop were made by a CARD team at the 4th Pan-African CAN conference in Abuja, Nigeria, 'Linking CBR disability and rehabilitation.' This was done by 4 members of the CARD group in October 2010 to around 500 people. This conference was run by the CBR Africa Network and the World Health Organisation. It provided an opportunity to share the CARD programme approach with many disability and rehabilitation experts, including people with disability, from all over the world and from all the United Nations agencies involved with people with disability and rehabilitation. The CARD team's work was well received, with non-government organisations such as CBM (formally known as the Christian Blind Mission) indicating interest in adopting a similar research process. Universities such as University College London, UK, and the WHO/CBR guidelines researchers also indicated interest in adopting a CARD programme approach to research.

### **Radio**

- A total of 11 radio programmes transmitted about 8 of the studies. The last talk show in 2010 was held at Star FM in Kampala and provided an opportunity to share information about CARD project activities, the success stories and to advertise the forthcoming local seminars.

### **Action Outcomes of the Research Projects**

A further objective of the CARD programme was to promote tangible action outcomes that would make a positive difference to the lives of community members in the location of the research project. Achieving action outcomes proved challenging to the project teams within the constraints of the budgets and frameworks of the CARD programme. However, it was anecdotally noted

that many projects appeared to have a positive effect on the individuals who participated. Some examples of outcomes are listed in Table 5.

**Table 5: Action Outcomes emerging from the Projects of the CARD Programme**

Research Project	Action Outcomes
Information sharing	The CARD programme responded to the finding from this study that many people in community development preferred to access information orally. In response to this, CARD modified its dissemination strategies to include radio programmes. Extra funding was identified to do this and, as described in Panel 4, eleven radio programmes were transmitted. It is worth noting that there is other research evidence indicating that radio is a more effective means of communicating with rural populations in Africa than written or online material but this modality is still not regularly adopted (Hill et al, 2007).
Sex education for deaf children	The results of this project were used to inform a new project, (Reliable Health Education for Deaf Youth) funded by Ka Tutandike to introduce sex education in Deaf Schools. This project is an intervention on reproductive health education for deaf youth, based on the evidence collected in the project supported by the CARD programme.
Economic development activities for women with disabilities	An interested donor from the CRAM Foundation (Care, Recreation, Accommodation and Management for People with Disabilities) read the 2-page report on the findings from this study, and subsequently met the team. This resulted in the provision of support for women with disabilities to start income- generating projects in Jinja District, Uganda.
Evaluation of mobility and orientation courses for blind people	The results of this project were used to modify the curriculum of the 2-year course in mobility and orientation at Kyambogo University; for example, giving more attention to developing skills and strategies on how to share the information they had acquired.
Accessibility of people with disabilities to health services	Anecdotal feedback indicated that the health staff interviewed about access for people with disabilities to their clinics changed certain practices to accommodate them. These included a new examination trolley which was easier for people with physical disability to use, and ramps for better external access to buildings.
Parents' perspectives on their children's education. Experiences of adolescents with intellectual disability and their parents.	Parents of children with disabilities were reported to be more proactive in encouraging and accepting their children after exposure to these projects. For example, a group of parents set up play groups and respite care sharing initiatives.

In addition to the actions outlined in Table 5, at the programme level research capacity of the participants made progress, and a number of CARD project leaders went on to acquire further qualifications (Panel 5).

### **Panel 5: CARD Research Project Team Members who successfully completed research degrees**

- Ali Baguwemu, PhD at Makerere University, Uganda.
- Ephraim Lemmy Nuwagaba, PhD at University of KwaZulu Natal, Durban in South Africa.
- Paul Ojwang, PhD at Kenyatta University, Kenya.
- Paul Njuki, PhD in Oslo. Norway
- Carol Maholo, Master's degree at Bugema University and now pursuing a PhD with the University of Central Luzon, Philippines
- Harriet Ntege, Master's degree at Makerere University.

At the teaching level, many participants described how they had changed their way of teaching as a result of their experiences in the CARD programme; for example, having more people with disabilities to give presentations to their students, being more realistic about what can be achieved in the community, and being more aware and sharing with their students the challenges and limitations they are likely to encounter in the community.

### **Challenges and Limitations of the CARD Programme**

While the overall objectives of the CARD programme were achieved, the implementation faced several unexpected management challenges.

#### **1. Underestimation of Travel Budget**

The travel budget was underestimated as the programme required more mentor visits than were originally envisaged. This was partly because of concern regarding under-utilisation of email and remote communication mechanisms by the Ugandan teams. The Ugandan team members sometimes found it difficult to engage through email, not because of access or availability, but because such forms of communication were slightly at odds with their

oral cultural base. Most groups were slow to respond to email support and much preferred (and responded much better) to face-to-face sessions. In addition to this, there were unforeseen and considerable increases in air fares during the term of the study. Fortunately, in the 4th and 5th years the funders increased the budget to cover some of this extra cost.

## **2. Payment of Research Mentors**

During the project there were many requests from the local Ugandan mentors for extra payment for their efforts. The project met all costs incurred by the mentors, but gave them no additional payment. This issue was discussed with both of Kyambogo University's Vice-Chancellors and they both felt that research activity was part of an academic's job and hence did not necessitate extra payment. However, the monetary aspect remained an issue for the individuals concerned, who felt they deserved payment for CARD work over and above their salary. One local mentor pulled out of the study over this specific issue. It was also generally felt that there was a need for more Ugandan mentors and, in particular, those with a disability.

## **3. Activities and engagement of Local Mentors**

Aside from the financial issues, locating local mentors with the necessary research skills, time and willingness to engage with the project was problematic. Efforts to develop the Ugandan mentors as a local team were sometimes limited, and feedback from the research teams on the support that local mentors were able to give, between international mentors' visits, was not always positive. The reasons for this included lack of time, low priority, limited research skills and experience, difficulties responding to advice and some competitiveness between staff.

## **4. Ethical Process**

Kyambogo University did not have its own ethical procedures for research but operated under blanket permission from the ethics committee of the Ugandan National Council for Science and Technology. Without more specific ethical procedures in place, CARD undertook to develop one for its own use and to offer this to the University as a starting point for developing one of their own. A draft ethical protocol (see Appendix 1) was supplied to them for consideration as a guideline. This was accepted with enthusiasm by the researchers and by the University officials. However, no change in

practice took place during the time- frame of the project, the guidelines remained un-ratified and the process of ethical approval for research projects at the University continued to be unclear. Through the duration of the project, CARD undertook to monitor its own ethical procedures by not allowing groups to begin collecting data until they had addressed all the ethical considerations for their study. It is recognised and accepted that it is not best practice for an organisation to perform its own ethical check, and this was a limitation of this project.

## **5. Record and File Management**

Although a system of file management was set up and several training sessions were given, this did not always appear to be effective, with many files being misplaced or irretrievable because of inconsistencies in the computer filing system. An alternative tactic was developed about half-way through the project whereby a more structured template was provided. All previous files were entered into this system, but there were still problems of maintaining this effectively. In the final event, most of the file management was undertaken in the UK. The production of the CARD Folder and the 2-pagers were also completed in the UK.

## **6. Field Trips**

Some travel was an essential and integral part of most data collection. The costs for this travel were covered by the grant. Over and above that, it could be beneficial for mentors to visit data collection sites, to gain a better insight into the data collected. Unfortunately, the costs for project visits by the local mentors and the administrator had not been budgeted for at the start of the programme. Given this situation, and at the request of the Ugandan staff, it was decided to include this expenditure in the research budgets. However, securing documentation about the aims and objectives of the trips, and securing an evaluation of the outcomes were problematic. It was therefore not possible to draw any conclusions about the value of these visits.

## **7. 2-page Reports**

The 2-page summaries provided a big technical challenge to the group who, on the whole, found the task of summarising the main points of their projects very challenging. However the results, in the form of the 2- pagers, formed



one of the programme's strongest outputs. They have been useful when visiting funders, of interest to other researchers on the web, and intrinsically helpful to the researchers in formulating their research work into a language and of a length that other groups can read, follow and understand.

## **8. University Financial Situation**

The bureaucracy of Kyambogo University posed many challenges during this project. At the beginning, a memorandum of understanding was signed by the then Vice-Chancellor, stating that the funding would be managed through the graduate and financial offices of the University, with a committee to oversee this, consisting of the Vice-Chancellor, the research registrar, the university secretary and the CARD administrator. Half-way through the project the Vice-Chancellor left and there was a period of temporary management. When the new Vice-Chancellor took office, the procedure for securing the funding through the University was changed. Requests made for funds which belonged to CARD were repeatedly delayed or declined for reasons that were difficult to understand. The CARD administrator became very depressed by these obstacles and found it difficult to keep reverting with requests, thereby delaying the process from both ends. Many of the research teams became disheartened. This situation delayed the activities of many of the CARD projects. During the latter part of the project, a temporary arrangement was made with Ka tutandike Uganda, whereby the money was sent to them and they supplied it to the administrator on approved request. These financial delays contributed significantly to the non-completion of the 9 projects.

## **Summary of Results in relation to achieving the Objectives of the CARD Programme**

### **1. Fund teams to carry out action-based research on disability in Uganda**

As mentioned, 12 research projects were completed and 9 others reached various stages of completion. The projects chosen were in harmony with the international focus on equality, inclusion and mainstream access for people with disability and their families. Appropriate workshops and seminars were carried out to facilitate learning for the team participants.



## 2. **Develop research and administrative capacity to manage the initiative within the academic registrar's office at Kyambogo University**

This proved to be the most challenging objective and while the project was set up with central governance within the University, factors outside the remit of the project served to confound its management. These contributed significantly to 9 of the projects failing to complete.

## 3. **Incorporate the new knowledge generated from the studies into the ongoing local CBR and Special Education courses**

This was achieved to some degree and the positive nature of this relationship may have been associated with the participatory nature of the programme. However, in future programmes more attention needs to be given to evaluating this relationship so that better evidence becomes available about the nature of this process.

## 4. **Ensure wide dissemination of research findings**

Newsletters, journal articles, newspapers, community meetings, seminars and radio programmes served to disseminate the findings to a wide audience base. These audiences included the people who had participated in the data collection, local service providers, Government officials, NGO organisations, academics and politicians.

### **Individual Experiences of CARD members**

In addition to addressing the overall objectives of the CARD programme, ongoing discussions with all the research teams agreed that the CARD programme should be evaluated in terms of 2 further research questions: **What changes did the participants experience during the programme?** What role did people with disabilities play?

To address these questions, both qualitative and quantitative data were collected through interviews and a survey questionnaire.

Interviews by the administrator were used to evaluate the programme with all 58 registered Ugandan programme participants, 17 of whom were people with disabilities. They were interviewed at least once. Data was collected using 2 simple interview questions:

- What difference has the CARD programme made to you and your work? What is changing /has changed?

- As a person with impairment, what particular contribution do you think you have made to your research team? Or, if able-bodied: What particular contribution did the member with disability on your team make?

This data was recorded in note form. A small group of CARD members met three times to discuss the data and, using question-led analysis, the recurring themes were identified by consensus. The main areas of change are shown in Table 6. The particular contribution from having a team member with disability can be seen in Table 7.

**Table 6: Themes concerning General Changes attributed to Participation in the CARD programme**

Area of change	Change	Supporting quotes
Teaching	Increased knowledge	<p>‘The CARD programme has given me confidence when teaching my students. I feel more knowledgeable and authoritative’ (Kyambogo lecturer with disability).</p> <p>‘Because I have met and talked with more people with impairments, I pay more attention to my students who have a disability’ (Kyambogo lecturer).</p> <p>‘So I can say that what is now different is that teaching is filled with illustrations from experiences through the research studies’ (Kyambogo lecturer).</p>
Teamwork	Appreciating the value of different people as members of a team	<p>‘Teamwork is what I emphasise these days because CARD is where I have learnt to appreciate other people, their knowledge and contributions, especially those with disabilities’ (Programme Manager).</p>
Prejudice/awareness	Less prejudice, more respect for people with disabilities	<p>‘It has made me aware that even those with disabilities are capable of doing all things that normal people do e.g., running a school, monitoring a photo studio, farming and many others’ (Kyambogo University lecturer).</p> <p>‘I have come to appreciate persons with disability because they give me a lot of information during research’ (NGO community worker).</p> <p>‘I have come to know that deaf people are able, they have the potential to participate in many things’ (District Officer).</p>
Research potential	Increased awareness about the potential for future research	<p>‘CARD has been mind opening....I am discovering that there are many more areas that are not handled in research.... it is this CARD work that has prompted me’ (Kyambogo lecturer with disability).</p>

		'When you have a DP as a member of your team you are challenged to re-think your perceptions' (Kyambogo University lecturer).
Influencing more learning	Encouraging (others) to study disability and community-based action	'I will even encourage my wife... I picked for her to do a diploma in community-based rehabilitation' (Kyambogo lecturer with disability). 'After going through CARD workshops, I felt more confident. I really feel it was one of the reasons why my PhD proposal was successful' (Kyambogo University lecturer).
Community action	Increased awareness of different ways of management	'It has really opened my mind more widely than before in relation to the management of disability issues and on managing programmes in the community' (Community worker with disability). 'I had not understood that there was something that ordinary people can do about persons with disability' (Kyambogo administrator with disability). 'Let's go to the villages and let's go to different communities' (Centrally located Service provider).
Publishing	The importance of publishing	'We need to get them (research projects) published and make them available' (Kyambogo lecturer).
Practice	Change of practice	'I now know that these types of people (blind) also need information... and I am going to purchase some special books for them' (Female librarian). 'We are now changing the curriculum because of what we learnt from CARD' (Kyambogo University lecturer).

**Table 7: Themes concerning the specific contribution of People with Disability in the research project teams**

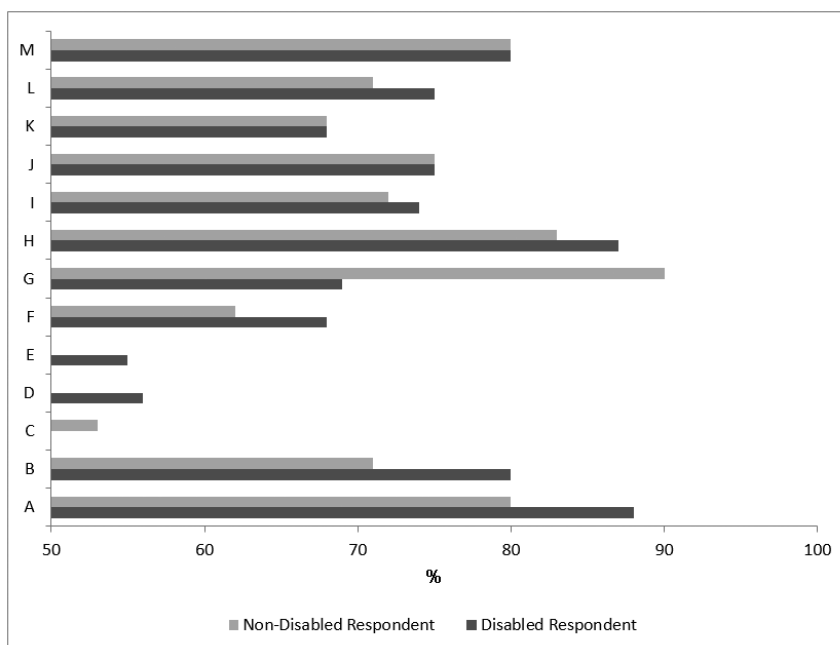
Theme	Role	Quote
Access	Improving access to relevant population Facilitating access to better quality data	'People who are more resourceful in providing relevant information may be left out if persons with disabilities are not involved' (Service provider with disability). 'The person with disability in our team was a great help, she had some contact with resourceful people and this enabled us to gather our data effectively' (Librarian). 'I am also aware of the cultures of people with impairments (the dos and the don'ts). Hence while collecting data from the field I inform my team members to be sensitive to such issues, so as to get relevant data that can make the research credible' (Service provider with disability).

		'(DP) get information which is more touching and more relevant to the needs of persons with disability' (District Officer).
Trust	Improving trust	'The fact that one (of our team) was disabled, meant they (community members) knew we were not getting this information for our own gain, so they knew this information would help them achieve what they want.' '(DP) increase the respondents' trust in the team, when they learn that a member is also impaired' (Academic and service planner with disability). 'Having someone with an impairment is very important, the researcher and the respondent together feel that they are really in the same boat' (Administrative secretary).
Awareness	Raising awareness of able-bodied people about persons with disability	'Because of CARD our perceptions of the blind people have really changed, we are not sympathising but we are empathising' (Kyombogo University lecturer). 'Without a DP in the research team they would lack the experience of a person who has lived through what they are trying to investigate' (Community worker with disability).
Ethics	Increased sensitivity to the relevant issues	'My personal experiences guide the team in determining what is ethically acceptable, what could be offensive and what could trigger emotions' (Researcher and service user with disability)
Relevant research topic and direction	Formulation of research questions	'(DPs) contribute significantly in the formulation of research questions that can probe certain aspects of life of fellow visually impaired persons' (Academic and service planner with disability).
Inspiration	Giving confidence to others with impairments	'DP as researchers provide inspiration to other people with disability that they meet, many of whom are experiencing low esteem' (Programme Manager).
Time	DP can supply knowledge and guidance that saves time	'DP have vital information that saves the team time' (District Councillor).
Avoiding dangers	Reporting inaccurate information	'Some myths about impairment would be written as facts' (Kyombogo University lecturer). 'Issues that do not carry much weight in the lives of persons with disability might be included in research documents' (Kyombogo University lecturer).

In addition, quantitative data was collected using a survey questionnaire at the end of the programme. 48 of the 57 participants completed this survey, including

16 people with disabilities. The respondent could rate the strength of agreement with a statement from -5 (disagree) through to +5 (agree). The findings are summarised in Figure 5 below. Participation of people with disability is seen as very positive by most, with the exception of 1 respondent. The results are presented in Table 5.

**Figure 5: Participants' Rating of Strong Agreement on Working in Inclusive Project Teams**



**Note:** For all statements apart from C and D, 'agreement' (either strong or not) is a positive response. For C and D the most favourable response (for the study having positively influenced attitudes towards people with disability) would be 'strong disagreement'.

#### Statement Key:

- A Having/being a member with disability of the project team was a good experience
- B The member with disability of the project team made a unique contribution to the project

- C Having the project team member with disability was inconvenient at times
- D The project team became impatient with the project team member with disability at times
- E The project team would have found collecting data difficult without a project team member with disability
- F The other project team members have learnt from the team member with disability on the project
- G Being on the team has given me a more positive attitude towards people with disability/without disability
- H I would recommend to other project teams to include a team member with disability, or other people with disability to join such teams if asked
- I The project team member with disability made the research more sensitive to people with disability
- J The presence of a project team member with disability improved the capacity of the team to show respect for other people with disability
- K The presence of a project team member with disability increased the respondents' trust in the project team
- L The project team member with disability contributed to the research design
- M I would want to work with people with disability/without disability again

The survey results showed strong agreement that members with disability on the research team were appreciated by the able-bodied members of the group and that working with them served to facilitate more positive attitudes and appreciation for their unique contribution; so much so, that many of the team members would also recommend to other groups that people with disability should be included. However it is important to note that the biggest discrepancy between people with and without disability is shown in response to statement G. It seems the respondents with disability were far less likely to have given a more positive attitude to working with people without disability (70% versus 90% for without disability), a difference that is only just non-significant at 5% (95% ci for difference (-47%, 0.8%).

However, overall it can be seen that these results triangulated well with the qualitative data and illustrated that members with disability had an overall positive influence on the research process. This was in addition to the perceptions that

participants benefited in a number of constructive ways from their engagement with the CARD programme, as illustrated in Table 6.

Both the qualitative and quantitative data illustrate positive changes in the lecturers' understanding of the lives of people with disabilities, and show how this affected their teaching, for example, in increased confidence, increased understanding of ethical issues, increased understanding of the advantages of working in teams, better capacity to undertake literature searches, higher levels of sensitivity, better appreciation of people with disabilities as people with abilities, and an improved understanding of management issues.

## DISCUSSION

The CARD programme contributed positively to achieving 7 out of the 9 recommendations of the World Report on Disability (WR, 2011). For example, nearly half of the research projects (47%) addressed the first WR recommendation (enabling access to all mainstream policies, systems and services), and looked at the challenges of accessing employment, health and education while revealing possible strategies to overcome these challenges. This came about by letting the research teams identify the issues that they saw as important to them and to the communities in which they lived and worked. WR recommendation 2 (providing specific programmes and services for people with disabilities) was also addressed by 47% of the research projects. This served to increase local knowledge about microfinance, sports, education of children with intellectual disabilities, sex education for deaf children, community-based rehabilitation and injury prevention. All this information was fed back into the education system of the Faculty of Special Education. The strategy of having people with disability as key members of every CARD research team was in harmony with recommendation 4 of the World Report (involving people with disabilities). Their unique insight not only influenced the choice of topics investigated, but also the manner in which the research was carried out, as well as the level of trust and respect the teams were able to develop within the communities in which they worked. Recommendation 5 of the World Report (improving human resource capacity) was addressed through the many seminars and workshops held by the CARD programme, and by the individual mentoring structure. This improved participants' understanding of the research process and their knowledge of previous research. It also, anecdotally, contributed to a better understanding by the international researchers (mentors) of the realities faced by people



with disability and by local researchers within their Ugandan communities. This knowledge and understanding informed teaching and lecturing in their respective academic institutions at an international level. The radio programmes, newspaper articles and seminars to which many public figures were invited, contributed to addressing recommendation 7 of the World Report (increasing public awareness and understanding of disability). Great care was taken not only to inform the academic community but also to get the messages out into the community through newspapers and radio programmes. While Recommendation 8 (improving disability data collection) and recommendation 9 (strengthening research on disability) were key tenets to the whole CARD research programme.

The 'action element' to the programme was challenging and ambitious. Possible strategies to strengthen it might include improving the research project selection criteria and making stronger links with service providers, with appropriate funding attached. Where meaningful relationships developed between people who had specific and often personal but rather isolated interest in disability issues, positive outcomes emerged. For example, the investigation into sexual education for deaf children established strong relationships with the schools where data was collected. This resulted in information sharing which assisted in changing how sex education was carried out in a number of schools for deaf children in the local district.

The programme also appeared very good value for money, as the two other research grants held by the lead author at the time had values between £150,000 - £200,000 and each focussed on one piece of research, whereas this research programme achieved 12 completed projects for a comparable amount. There was also the added value of producing a team of developing researchers, a few of whom went on to acquire PhDs at the same time as yielding a positive influence on local CBR and special education teaching. Such outcomes were not forthcoming in the other research projects held by the lead author.

## CONCLUSION

The CARD programme in Uganda demonstrated that a multi-stakeholder, action-oriented emancipatory research programme is a practical option and can have many positive outcomes at a reasonable cost. It is therefore a desirable alternative to the more conventional approach to disability research.

Benefits were demonstrated for all those involved. The funders had good value for their money, the international academics had exposure to what really mattered to



people with disability in Uganda, the local academics learnt many new research skills, and people with disability were involved and increased their confidence and skills. They felt ownership and, although they might not always have been leading the research, there was evidence that they exercised empowerment over the research agenda. This feeling of ownership seemed to increase participation and enthusiasm. The project focus was not determined by the international mentors or the funding agency, and the leadership for each project was local.

### **Limitations**

This document seeks to inform the reader about how to undertake such a community action research programme; therefore it is important to minimise its limitations. This could be done by:

1. Putting more strategies in place to achieve more action elements to the outcomes of the projects.
2. Establishing independent ethical procedures. Pay more attention to ethical procedures with the utilisation of the guidelines included here as a starting point.
3. Paying attention as to how best to develop research and administrative capacity to manage such initiatives within the academic system of a University. Any future project would need to support and nurture: the capacity to keep files in an ordered and retrievable fashion, responding to email communication accurately within an acceptable timeframe, structures for ethical considerations in the research, and adhering to timelines.
4. Paying even more attention to incorporating the new knowledge generated from the studies into the ongoing local CBR and Special Education and/or health courses, accompanied by an evaluation structure.
5. Ensuring wider dissemination of research findings. Future dissemination strategies might seek to include tape-recorded information, Braille, large print and 'daisy' compatible electronic files.

### **ACKNOWLEDGEMENT**

Thanks go to Ka-tutandike that funded the programme and to the 57 Ugandan participants whose hard work and participation made this programme possible. Thanks also to the many Ugandan Organisations that engaged with and supported

the programme. These include: ADD Action for Disability and Development; Bishop Stuart, Mbarara District; CBR Africa Network (CAN); Community-based rehabilitation Alliance (COMBRA); Department of Community-Based Services, Ugandan Government; Federation of Employers Uganda; Uganda Adult Education Network; Federation of Employers Uganda; Injury Control Centre, Kampala; Jinja District Council; Kitante Secondary School; Kyambogo University, Kampala; National Association of Women's Organisations in Uganda (NAWOU); National Union of Disabled Persons in Uganda (NUDIPU); National Union of Women with Disabilities of Uganda (NUWODU); Masaka District Council; Ministry of Health, Kampala; Mpoma Secondary School; Sense International; Socadido, Development and Welfare Group of Soroti Diocese, Teso, Uganda; ; Ugandan Ministry of local Government; Soronko local Government.

## REFERENCES

- Barnes C, Mercer G (1997). *Doing disability research*. The Disability Press: 236.
- Barnes C (2003). What a difference a decade makes: Reflections on doing 'Emancipatory' disability research. *Disability & Society*; 18(1): 3-7. <https://doi.org/10.1080/713662197>
- Carter JA, Murira GM, Ross AJ, Mun' Ala-Odera V, Newton CRJC (2003). Speech and language sequelae of severe malaria in Kenyan Children. *Brain Injury*; 17: 217-224. <https://doi.org/10.1080/0269905021000038447>. PMID:12623498
- Charlton JL (1998). *Nothing about us without us: Disability, oppression and Empowerment*. University of California Press: Berkeley and Los Angeles, California. <https://doi.org/10.1525/california/9780520207950.001.0001>
- Finkenflügel H (2004). *Empowered to differ: Stakeholders' influences in community-based rehabilitation*. Vrije Universiteit: Netherlands
- Gona JK, Hartley S, Newton C (2006). Using participatory rural appraisal (PRA) in the identification of children with disabilities. *Rural and Remote Health*; 6(3): 553 PMID:16956314
- Greenwood CR, Abbot M (2001). The research to practice gap in special education. *Teacher Education and Special Education*; 24(4): 276-289. <https://doi.org/10.1177/088840640102400402>. <https://doi.org/10.1177/088840640102400403>
- Hill Z, Kirkwood B, Kendall C, Adjei E, Arthur P, Agyemang C (2007). Factors that affect the adoption and maintenance of weekly vitamin A supplementation among women in Ghana. *Public Health Nutrition*; 10(9): 827-833. <https://doi.org/10.1017/s1368980007382554>
- Madden RH, Lukersmith S, Millington MJ, Scarf C, Fortune N, Hartley S, Llewellyn G (2015). Participatory monitoring of community-based rehabilitation and other disability-inclusive development programmes: The development of a manual and menu. *Disability, CBR and Inclusive Development*; 26(4): 26-52 <https://doi.org/10.5463/dcid.v26i4.472>

- Mmatli TO (2009). Translating disability-related research into evidence-based advocacy: The role of people with disabilities. *Disability and Rehabilitation*; 31(1): 14-22. <https://doi.org/10.1080/09638280802280387>. PMID:18946807
- Oliver M (1992). Changing the social relations of research production? *Disability, Handicap and Society*; 7(2): 101-114. <https://doi.org/10.1080/02674649266780141>
- United Nations (2006). UN Convention on the Rights of Persons with Disabilities Available from: <http://www.un.org/disabilities/convention/conventionalfull.shtml> [Accessed on 22 January 2016].
- Werner D (1998). *Nothing about us without us: Developing technologies for, by, and with disabled persons*. Health Wrights Press: Palo Alto, California
- World Health Organisation (2011). *International classification of functioning, disability and health*. Available from: [www.who.int/classification/icf/en/](http://www.who.int/classification/icf/en/) [Accessed on 21 January 2016]
- World Health Organisation (2011). *World report on disability*. WHO: Geneva
- Yousafzai AK, Lynch P, Gladstone M (2014). Moving beyond prevalence studies: Screening and interventions for children with disabilities in low- and middle-income countries. *Archive of Disease in Childhood*; 99: 840-848. <https://doi.org/10.1136/archdischild-2012-302066>. PMID:24647995

## Appendix 1

### **CARD Programme and Kyambogo University Checklist for Ethical Aspects of Research Projects**

Ethical approval is required from the CARD programme and Kyambogo University Ethics Research Committee before data collection can commence. The following checklist is a guide for the development of research projects which will follow the ethical practice required by this Ethics Committee and the CARD programme.

#### **The research project MUST:**

- ❖ Demonstrate that the researchers understand and respect the cultural viewpoints of research participants.
- ❖ Explain how the subjects will be identified and describe what procedures will be made to avoid any harm when recruiting the subjects. If recruitment involves clinicians, managers or administrators for subject access, the reasons for this must be justified and the procedures to avoid harm to participants described.
- ❖ Specify who will collect the data and how fieldwork training and supervision will be provided to guarantee high quality of technical and ethical procedures.
- ❖ Specify how the data will be analysed, reported and disseminated so that it will protect the participant individuals and institutions from harm, and will promote benefits to them and the population
- ❖ Demonstrate that the study has a good chance of answering the research question(s) posed. The sample size should be justified. The timescale of the study must be shown to be adequate to achieve the aims and have sufficient funding to sustain.
- ❖ State that No information about the individuals or institutions will be collected for pilot studies or the main study without their previous informed consent. Only the information that the subject agrees to provide can be collected. The term information refers to any data from individual records, questionnaires, interviews, photographs, videos, specimens (e.g., blood, urine) and other information about the individuals or institutions being studied.

- ❖ Specify how the informed consent will be sought. Witnessed written consent is normally preferred, but verbal informed consent can be also accepted if clearly justified by the researchers in the research project. Where the subject is in a vulnerable position (such as a client in a hospital), witnessed written consent is essential. In cases where research subjects might be deemed not capable of giving informed consent (e.g., people with severe mental impairments; young children) the research proposal should describe and justify the procedures to be followed to protect their interests.

**The project will include a section named ETHICAL ISSUES (usually less than 400 words)**

This section must summarise evidence of the following:

- ❖ The research is socially relevant: Explain why the research questions (specific objectives) are relevant to improve the lives of persons with disabilities in Uganda and show in the literature review that these questions were not totally answered by previous studies. The project must also explain how the research procedures and results are expected to improve the lives of persons with disabilities and the overall society.
- ❖ The research is scientifically sound: The research design is scientifically strong to answer the proposed research questions.
- ❖ The research procedures are organised to protect the subjects and institutions being studied from harm, to protect their rights and welfare. The project must demonstrate that the researchers understand the culture of the participants and respect their views. This section must describe which procedures will be used for recruiting subjects and institutions, collecting information, analysing and disseminating the research findings, and whether these have potential to produce physical, emotional, social or economical harm to the institutions and subjects being studied. Then it describes how the research team will identify and handle these situations.
- ❖ The dissemination of the results is likely to promote improvement in the lives of persons with disabilities and their communities. Show evidence that the dissemination will be carried out by various organisations and will use various forms of dissemination. Examples are radio, television programmes, workshops, publication on the internet and in newspapers, presentation in congresses and scientific journals. The different forms of dissemination

are likely to reach: the community of people with disabilities and their families, health, educational and social workers, policymakers, NGOs and governmental organisations which directly or indirectly provide services which may benefit people with disabilities and also reach the scientific community of researchers and lecturers.

### **The research project must be accompanied by**

- ❖ All questionnaires and framework of topics for in-depth interviews
- ❖ A copy of the information sheet to the participants
- ❖ A copy of the consent forms which will be read to the participants if verbal consent will be asked or signed by them if written informed consent will be used.
- ❖ There should be an explanation of what happens to individuals refusing to consent to the trial. It should be made clear that neither will refusal affect the standard of their care, nor will a withdrawal at any point. In the case of a randomised controlled trial, the information sheet should state what treatment the client will receive if they do not take part in the trial.

### **Guidelines for the information sheet**

- ❖ The heading of the information sheet and consent form must contain the title of the research, the name and contact details of both the lead researcher and the person responsible for obtaining information from that subject or institution.
- ❖ The information sheet must be written in the language used by the subjects (translations carefully checked) and in English. The text must be simple and use expressions commonly applied by the age group of the subjects in the region. (Technical jargon must be avoided.)
- ❖ The text usually begins by stating that the subject or institution is being invited to take part in a research project. The fieldworker asks permission to give or read to the person a text containing information about this research for the person to decide whether or not he or she would accept the invitation.
- ❖ Then the text responds to the following questions that a person needs to know before deciding whether or not he/she will consent to participate in the study:

1. What is the purpose of the project?
2. Why have I been chosen? Or why my institution/organisation has been chosen?
3. Do I have to take part? (freedom to refuse to participate or to withdraw at any stage)
4. What will happen to me and what will I have to do if I agree to take part?
5. What are the problems that may happen to me if I participate in this research? Describe possible problems and how the researchers will identify and deal with those problems.
6. What are the possible benefits of my participation? Describe likely benefits for the participant individuals and institutions, and for the society. Make sure not to raise expectations which cannot be fulfilled directly by the research procedures.
7. How can I be sure that only the research team will know about my participation in this study and that the information I provide will be treated with respect? Describe how participation in the project will be kept anonymous and confidential, i.e., which procedures will guarantee that the identities of the participant subjects and institutions will not be disclosed to any person other than the research staff, either during the development of the research project, the recruitment of the subjects, data collection, analysis and reports of the research findings. Specify that any information that may identify the participant subjects and institutions are NOT presented in the research project, and will be deleted from the transcripts of the interviews, notes of observations, any documentary evidence and will NOT be presented in the reports or publications. Furthermore, personal data of the participants will be stored in a locked cabinet under the responsibility of the lead researcher for years after the end of the study, at which time it will be physically destroyed. During that period the participant can access his or her own data.
8. What will happen to the results of the project? Describe how the results will be disseminated and how the results are expected to promote improvement for persons with disabilities and their communities (for example, organisations which have agreed to use the information and how).
9. Who is organising and funding the project? (Names of the researcher, his/her institution and point of contact.)