**

**Guidelines on Designing and Conducting Applied (Action) Disability Research Projects**

**Which Aim to Bring About Positive Change for Persons With Disabilities**

*Derived from findings of a workshop held at Kyambogo University, Kampala, 2nd March 2016*

The following table of guidelines have been developed from the recommendations of a workshop held at the Faculty of Special Needs and Rehabilitation, Kyambogo University on 2nd March 2016. The workshop was designed to explore the premise that there is a significant and detrimental gap between disability research findings and recommendations and their practical application for positive improvements to the lives of persons living with disabilities. Sixteen participants attended the workshop and included representatives of both research institutions and field stakeholders which have practical experience of responding to the needs of persons with disabilities at community level. Six of the participants were persons with disabilities. Five participants were from Kenya, nine from Uganda and two from UK. Therefore the table of guidelines was devised from contributions informed by the East African context, but they probably have wider application.

As part of the workshop, participants considered the following questions:

* + - How are research topics and teams identified and chosen?
    - What influence do academic institutions and funders have over research decisions?
    - What partnerships and collaborations are made to undertake research (are disabled persons organisations and persons with disabilities involved in the research or in applying research findings)?
    - How are research finding usually disseminated – to which audiences and by which communication media?

During the workshop the participants from academia in East Africa acknowledged that researchers and their universities are often poor at translating their research findings into practical outcomes. They related to the image of a lengthy research report gathering dust on a university bookshelf with the research findings never seeing the light of day, let alone being put to any practical application. In turn the participants with disabilities and those representing disability organisations confirmed that there is a gap between academic researchers and people ‘on the ground’. Seldom were persons with disabilities invited to participate in research projects, and they were even less likely to be the instigators and managers of the projects. However there are notable exceptions to this, and examples of current research were presented at the workshop, which demonstrate how Partnerships between NGOs and universities can be successful in implementing rigorous research projects with practical outcomes.

The reasons for the constraints in taking research into practice were explored in the workshop and it is clear that there are many contributing factors. These include issues around deciding on the focus of the research, membership of teams, accessing funding, publication and dissemination of findings etc (see guidelines table below). However in the context of the UNCRPD all these factors are fundamentally influenced by the underlying principle of inclusion and empowerment. It is self evident that if the end purpose of applied disability research is to somehow improve the lives of persons with disabilities, then they themselves should be central players in instigating, planning, conducting, monitoring and applying their own research. That is not to say that there is no place for expertise and experience of non-disabled people in disability research. Teams which are diverse and multidisciplinary in nature are stronger and can help provide the necessary rigour. However the control and direction of the work must remain focused upon achieving the planned research outcomes and ensuring it has a positive impact.

Three quotes from participants at the workshop illustrate these principles well:

*‘Academic institutions should act as a catalyst or research facilitators in the research process, rather than research managers. This will help spearhead the capacity of the community to undertake their own research’.* Carolyne Maholo, Senior Lecturer, Faculty of Special Needs and Rehabilitation, Kyambogo University.

*‘Academics should stop being selfish, we should come out of our ‘know it all shells’ and start to give away our knowledge’.*

Ephraim Lemmy Nuwagaba, Research Fellow, Faculty of Special Needs and Rehabilitation, Kyambogo University.

*‘The best kind of research asks the right research questions, in order to come up with solutions to real problems identified by communities themselves’.*

Mary Wickenden - Senior Research Fellow, Centre for International Health and Development, University College London.

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| **Table of guidelines on designing and conducting applied (action) disability research projects**  **which aim to bring about positive change for persons with disabilities** | | |
| **WHAT? – the research activity** | **HOW? – good practice** | **RISKS – influencing factors to guard against** |
| **Decision to initiate a disability research project** | **Consider the degree to which new research is needed in the proposed field and why you / your organisation is well placed to conduct the research. Ensure that the decision to initiate the project is based on the need for new knowledge (ie. a research gap) which has potential for application. If considering a range of research topics, prioritise those with genuine potential for application. Ensure that the motivation for the research is not unduly influenced by the ‘risk’ factors (see right hand column)** | **Pressure to advance an individual’s professional career or to meet academic targets such as qualifications or publications**  **Undue influences / biases from academic supervisors , departments, universities or organisations**  **Pressure to raise funds for a department or organisation**  **Responding to funding opportunities without proper analysis of the need for new research** |
| **Selection of a research topic** | **As far as possible the field stakeholders1 (persons with disabilities, their families, and their representative organisations) should identify the research topic or at least be centrally involved in identifying the topic and developing the primary stages of the research concept** | **Research ‘experts’ select a study topic without proper consultation and make assumptions about the views and attitudes of the field stakeholders** |
| **Ensure that the research topic is investigating a clear problem or area of concern to persons with disabilities and has been identified (or at least confirmed) by the field stakeholders.**  **Whilst not predicting the research findings broadly consider whether the possible outcomes are likely to lend themselves to a practical application.** | **External influences / biases distort the judgement of research team members** |
| **Use participatory / inclusive methods to confirm that the research topic is of genuine concern to the field stakeholders** | **Senior team members dilute or modify the inputs from representatives of the field stakeholders** |
| **If the original concept is shown to be weak or less important than other topics, be prepared to change** | **Resources have been invested in the idea and it is deemed as too late to change** |
| **Convening a research team / organisational collaborations** | **Ensure the research team not only has the necessary expertise and knowledge but also includes multiple perspectives from multiple levels, including genuine representation from the field stakeholders** | **The team is made up only of ‘experts’ and lacks the necessary diversity and multiple perspectives** |
|  | **A culture of openness, trust and willingness to share should be nurtured. Clear roles and responsibilities should be assigned with capacity building where necessity. Team members should be mutually accountable** | **Personal or institutional priorities conflict with the requirements of a well functioning team** |
|  | **Ensure the inclusive participation of team members. Consider how different groups communicate and express themselves and facilitate accessible and non-discriminatory use of language** | **Inclusion of people with communication problems is not facilitated**  **Barriers are created by factors such as inaccessible language and jargon** |
|  | **Incorporate an element of capacity building between team members** | **Less experienced and knowledgeable team members are left behind or left out** |
| **Designing and conducting the research** | **Ensure the research design is explicit in showing how the new knowledge might be applied to achieve a practical impact. ie. Show a clear route to change / pathway to impact (many research funding bodies will require applicants to identify this)** | **As the research project develops it loses its focus and commitment to produce results and knowledge suitable for practical application** |
|  | **Monitor the research progress and ensure validation of the process by the field stakeholders at milestones throughout the process** |
| **Dissemination of research findings and recommendations** | **Carefully identify all the various audiences for dissemination of research findings. In addition to the conventional audiences such as peer researchers and academics, include groups that the outcomes of the research are designed to assist / impact** | **Researchers prioritise meeting academic requirements for research publication and overlook other audiences, especially the field stakeholders** |
|  | **Determine the best ways to communicate with different types of audiences. In addition to the usual research reports, and conference papers design other formats such as simple summaries and illustrated, visual and audio versions. Ensure resources are available for these formats** | **Much time and effort is put into research reports and other more accessible materials are not produced.**  **Innovative dissemination materials are not produced because of insufficient funds** |
|  | **Consider enlisting the help of communication specialists such as graphic designers, journalists, cartoonists and video makers to disseminate the research findings in a clear and engaging way** | **The plan for the research did not include time and resources for developing innovative dissemination media** |
|  | **Create dissemination materials in accessible formats such as Braille, large print and symbols, sign language and easy read** | **Persons with disabilities cannot access the research findings and recommendations** |
| **Implementation of practical application of resulting from research** | **Clearly state the explicit actions that are required to take the research recommendations into practice. As far as possible make these SMART2 and locally contextualised** | **Avoid making recommendations that are too broad or vague, or have little chance of being attainable in practice** |

**1Field Stakeholders -** These can include persons with disabilities, their families, and their representative organisations. Any Human Rights organisation working with persons with disabilities. Service providers and other organisations working with Persons with disabilities. Service providers and other organisations working in mainstream that are required to meet the needs of persons with disabilities such as architects, teachers, companies, industries etc. Local, national and international decision makers.

**2SMART –** Specific, Measurable, Attainable, Realistic and Time-bound.