



**Cross-cutting Disability Research Programme
Doing and Using Disability Research –
The Challenges and Opportunities So Far**

Workshop Report

Thursday 8th November 2012
Holiday Inn, Harare

Aims of workshop:

The workshop was an attempt to bring together members of SAFOD and other DPOS, service providers, academics and practitioners to share research experiences, particularly those linked to the DFID-funded SAFOD Research Programme (SRP) and the Cross Cutting Disability Research Programme (CCDRP). It was also an opportunity to road test the DPO Research Manual drafted by the CCDRP team (See Appendix A for an outline of the agenda).

A total of 15 participants from a range of stakeholders, including service providers, disabled people organisations (DPOs) and academia, attended the one day workshop (see Appendix B for list of participants)

Facilitators:

Dr Maria Kett (Leonard Cheshire Disability and Inclusive Development Centre, UCL)
Tecla Butau (Southern African Federation of the Disabled (SAFOD))

Part One

Maria Kett gave an overview and update about the CCDRP. She spoke about the components of the programme, as well as the next steps (see Appendix C for slides of presentation).

This was followed by an update on the SAFOD Research Programme by Tecla Butau, Research Programme Manager (see Appendix D for presentation). This programme is now completed, but Tecla spoke about how the research areas were chosen, and in particular how it intended to influence policy. This is a common area between both the SRP and the CCDRP. Another common issue is that of sustainability – how have both the programmes ensured that disability research has been mainstreamed, and how will these results be maximised?

Following Tecla's presentation, Ms Sibonisiwe Mazula, a graduate of the SRP, reflected on experiences of the programme, and spoke very eloquently about how the process had demystified research for her.

After the presentations, participants broke into smaller groups to discuss the question 'Going from evidence to action in disability research - where are we now?' The results from these discussions are summarised below:

Developing models to use research-based evidence – where are we now? Group Discussion

- 1. Have you used research in your work before?*
- 2. Was it useful?*
- 3. In what way did it help?*
- 4. Were there any problems?*
- 5. Could the research process and outcome have been improved, and if so, in what way?*
- 6. What else needs to be done?*

Group 1:

1. Yes we have done research
2. Yes it was useful
3. It helped improve life
4. Problems: There was resistance
5. Locally done
6. Other requirements: Parts, reassessments, continuous education

Group 2:

1. Yes. Research is on knowledge index on the UN Convention by people with disabilities at all levels (evidence based data):



Research process by DPOs and stakeholders at all levels. Urban, peri-urban and rural

2. It was useful to highlight disability information gaps
3. It helped to educate policy makers and advocate for policy information
4. Problems: funding, human resources, public attitude on disability
5. How to improve the research: Voluntary human resources, increased funding
6. Other requirements: Translation of information; monitoring and implementation; enforcement; advocacy.

Group 3:

1. Yes we have done research on the inclusion of visually impaired in higher learning institutions.
2. It was useful:
 - i) Transcription of exams from print to braille and vice versa
 - ii) Identification of specific issues pertaining visually impaired in higher learning institutions
 - iii) Recommendations for procurement of assistive technology by the institution
3. It helped: Consent of institutions on issues, budgetary allocation for assistive devices, improved awareness of needs of VI in particular.
4. Problems: institutions felt exposed, absence or limited availability of assistive

devices

5. How to improve research: The process is being built upon by involving other institutions; to improve validity, reliability and generalizability of findings.
6. Other requirements: need for more research at a larger scale, commitment by policy makers and all relevant stakeholders, improved funding, and legislation.

Group 4:

1. Yes we have done research at a farm 20km away from the CBD area of Harare. Purpose: We had a high number of people coming to our clinic being referred by a partner organisation working in that area. The purpose was to know and establish the prevalence of epilepsy in that area.
2. The information was useful to establish the prevalence of epilepsy in that area. In every 100 people, 20 people had uncontrolled seizures
3. With the evidence we were able to lobby for more drugs, health personnel, and advocate for free medication and consultation. It also increased our membership.
4. Problems included: language barriers, distance for them to meet at the central point, misconceptions of the condition, limited funds, high illiteracy level of people in that area, people not being cooperative in answering questions.
5. The research could have been improved with more funds, human resources, and technical advice from external researchers.
6. We also need more direct funding of disability research and government commitment. Networking with more research institutions.

Key points highlighted from these discussions were:

1. Issues of generalisation – to what extent can relatively small studies be extrapolated to other contexts, particularly those based on case studies? One solution proposed was stronger partnerships.
2. Need for better baseline studies, and how to ‘translate’ research outputs
3. Need for more knowledge and skills on designing the research question and focus of research
4. Lack of funding and focus on disability issues continues in some regions (but there is a focus on other issues, such as poverty, human rights etc, so disability could be mainstreamed in these approaches
5. There is a need to manage expectations about what ‘research’ can and can’t provide
6. Sustainability – how have both the programmes ensured that disability research has been mainstreamed, and how will these results be maximised?
7. Need to develop stronger partnerships and networks

DPO research manual

In the afternoon, Maria Kett presented an overview of the research manual currently being drafted by the CCDRP team (see Appendix D). This manual will address some of the points raised above, in particular strengthening knowledge about research design, translating research outputs and developing partnerships. There was then a question and answer session about the manual.

Finally, participants were then asked to discuss ways they could go 'from evidence to action in disability research', and to give one example of good practise from the discussions and presentations, as well as one concrete action they could commit to do. The majority the participants stated that the sharing that had taken place at the workshop was in itself an example of good practice, and that they were keen to continue the cross-disciplinary dialogues that had started. Maria Kett and Tecla Batau encouraged them to maintain contact, and continue the conversations. The participant list will be shared as all agreed they would like to participate in on-going dialogues, and were also willing to review the DPO manual once finalised. Though the workshop participants were from Zimbabwe, they have connections and influence across the Southern African region, and crucially, representatives from the DFPOS stated that they would intensify lobbying of the Government of Zimbabwe to ratify the UNCRPD.

The workshop was then formally closed by Mr Chris Manyuke and Mr Robert Mkozho and a vote of thanks was given to the facilitators.

Appendix A: Workshop Agenda

Doing and Using Disability Research – The Challenges and Opportunities So Far

Time	Agenda Item
09.00 – 09.30	Arrival and Introductions
09.30 – 10.15	Update on LCD Cross Cutting Disability Research Programme (Maria Kett, LCD)
10.15 – 11.00	Update on SAFOD research programme (Tecla Butau, SAFOD)
11.00 – 11.30	Coffee break
11.30 – 13.00	Developing models to use research-based evidence – where are we now? Lessons learned, challenges and opportunities. (Discussion groups and feedback)
13.00 – 14.00	Lunch
14.00 – 14.45	Presentation of DPO manual (Maria Kett, LCD)
14.45 – 15.30	DPO manual input (Discussion groups)
15.30 – 16.00	Tea break
16.00 – 16.45	Going from evidence to action in disability research (Facilitated discussion)
16.45 – 17.00	Wrap up of workshop

Appendix B: Workshop Participants

1. Robert Mkozho (SAFOD)
2. Sibonisiwe Mazula (ZDSA/National Disability Board)
3. Fadzai Mundoza (OWID / Young Voice)
4. Jenni Muderedzi (Health Services Board)
5. Taurai Kadzviti (Epilepsy Support Foundation)
6. Oliver Magigwana (SAFOD)
7. Chrispen Manyuke (SAFOD Disability Board/ Federation of Organisations of Disabled people in Zimbabwe (FODPZ)
8. Bigboy Madzivanzira (Health Promotion Clinic)
9. Stewart Kufandirori (Tinokwirira Special School)
10. Emmanuel Munemo (Open University - Zim)
11. Hamida Ismail-Mauto (Disability HIV/AIDS Trust)
12. Zenzo Sibanda (Tose Respite Care Home)
13. Alusi Milasi (LCD Zimbabwe)
14. Daniel Marozva (Mufakose High School)
15. Doreen Mhike (St Giles Medical Rehab Centre)



What will the workshop cover?

- Updates on current or recent DFID-funded disability research
- Lessons learned
- Moving from Evidence to Action
- Developing the manual



The Cross-Cutting Disability Research Programme (CCDRP) Outline

- The Centre is a partnership between Leonard Cheshire Disability and University College London
- It is dedicated to generating a body of knowledge about disability issues that helps to improve the lives of people with disabilities, and their families and their communities, around the world.
- Awarded the DFID-funded CCDRP in November 2009 (approx £1k)
- Three main components:
 - Research
 - Capacity building
 - Research uptake



Research Focus

- Conceptual framework of research on disability and poverty (critical review paper)
- Four research programmes:
 - Maternal and child health in Nepal (MCHA)
 - Mental health and disability in India (MGPI)
 - Urban agriculture in Kenya (RU)
 - Water and sanitation in Uganda and Zambia (SHARE)
- All have the three specific components (capacity building, research and research uptake)



The Cross cutting disability research programme

Uses mixed methods, including:

- Survey based data – allows for quantitative analysis
- Focus groups, key informant interviews and desk-based research for more qualitative outputs
- Outputs include background papers, policy briefs, and peer reviewed academic publications



Capacity building

- Within research programmes
- With partner organisations
- Internship programme



Research Uptake

- Academic audiences
- Practitioners
- Policy makers



Challenges

- Starting up
- Mainstreaming across whole research programme
- Uptake



Opportunities

- What lessons have we learned and how can they be captured and passed onto others?
- The manual
- Research outputs
- Seminars/conferences



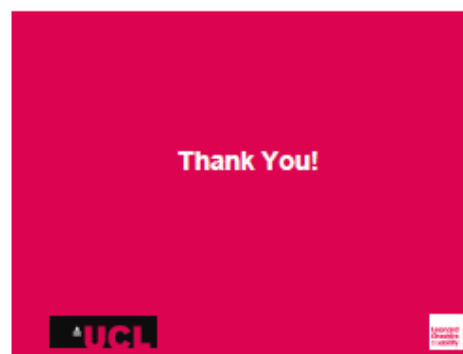
1. Developing models to use research-based evidence – where are we now?

- Have you used research in your work before?
- Was it useful?
- In what way did it help?
- Were there any problems?
- Could the research process and outcome have been improved, and if so, in what way?
- What else needs to be done?



2. Going from evidence to action in disability research

- How does an evidence-based agenda fit in with your work?
- How can we take forward the evidence being developed?
- What are the gaps?
- How can we identify opportunities and build on them?



SAFOD RESEARCH PROGRAMME

UPDATE
8 November 2012
Tecla Butau

Presentation outline


1. Background
2. Framework
3. Implementation strategy
4. Model
5. Project highlights
6. Project status
7. SRP graduate – impressions on status

1. Project background

- Project genesis
- Planning and conceptualization
- Inception phase
- Main phase
 - MIR
 - Close

1a. Project background Planning and conceptualization

- Collaborative approach




1b. Project background Countries



1c. Project background Purpose

- Capacity building of DPOs to:
 - To implement
 - Use research to influence policy



1d. Project background

Key partners

- Stellenbosch University
- Healthlink Worldwide -Inception phase only

2. Framework

- 2 dimensions
 - Training in research
 - Outsourcing research

2a. Training in research

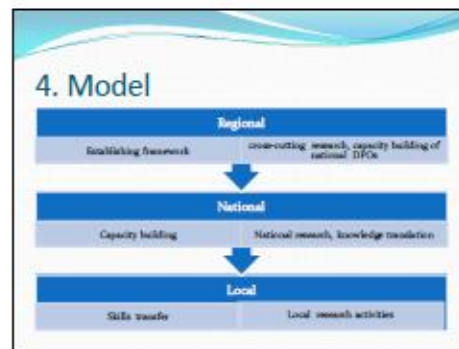
- Building knowledge, skills & confidence
- Developing linkages and partnerships
- Building elements of sustainability/continuity

2b. Outsourcing research

- Cycle One - 5 pilots www.safod.org
- Cycle two - 4 projects (in progress)
- Research component discontinued after MTR.

3. Implementation strategy

- Technical advisory board
- Lead research partner
- Training participants
- Research consultants



5. Project highlights

- FWD influence of research agenda
- Training of PWD in basic research
- Involvement of trainees in SRP supported research
- Involvement of SRP trainees in research outside the SRP
- Accreditation of trainees
- Participation of SRP trainees at AfrinEAD Symposia
- SRP webpage on SAFOD website

5a. Project highlights

Impact on DPOs

- Understanding of value of research in DPO work
- Investing in establishing research structure

6. Project status

- Five pilot projects (cycle 1)
- Four projects (cycle 2 work still in progress)
- Research component discontinued following MTR
- 20 DPO representatives trained in research 2008 - 2011

6a. Project status

Participants:

- 19/20 awarded SU certificates
- 1 pursuing masters programme

Graduation

December 2011



**Doing and Using Disability Research:
A research manual**



SAFOO Workshop
Haringey
8th November 2012

Dr Maria Kell
Leonard Cheshire Disability and Inclusive Development Centre
University College London




What is the purpose of the manual?

- Not intended to duplicate existing publications –not about *how* to do research, rather, *what comes before and after the research is done* – e.g. decisions on type of research, how it can be used and why, what benefits the research could have
- Translating research into action



Process

- Developed in collaboration with DPOs – many of whom have already been involved in research
- Questionnaires sent out – 26 DPOs responded (7 from Asia, 19 from Africa)
- Manual is based on these responses






What will the manual cover?

1. How can research benefit DPOs
2. Using research for advocacy
3. Different types of research
4. The research process
5. What to do with research results

1. How can research benefit DPOs

- Provides evidence base for policy, campaigning and advocacy
- Builds capacity – and visibility - within organisations
- Empowering



2. Using research for advocacy and campaigning

- Facilitates engagement with decision makers
- Can provide rigorous and factual evidence to highlight discriminatory policy or practice to support change
- Can identify and support these change from grassroots to policy level






3. Different types of research

- Helps identify the type of methodologies that could be used, including:
 - Desk-based review/background paper
 - Qualitative data (e.g. surveys, questionnaires)
 - Qualitative (e.g. using focus groups, key informant interviews and case studies)
 - Mixed methods (both quantitative and qualitative)
 - Outputs include background papers, policy briefs, and peer reviewed academic publications





4. The research process

- Provides a guide for the actual process of research – from the type of study to what is to be done with the results
- Support with identifying who will do the research, and/or who the researchers will be collaborating with
- Budgeting and funding advice
- Advice about ethics and IPR



What to do with research results

- How results are presented
- Who is benefiting?
- Who the intended audience is (e.g. academic, practitioners, policy makers, general public)
- Formats
- Can it support a wider change agenda (e.g. UNCRPD)





Challenges

- Funding
- Uptake
- Follow up



Opportunities

- What lessons have we learned and how can they be captured and passed onto others?
- The manual
- Research outputs
- Seminars/conferences
- Others?



Thank You!

