

Title:

A comparative overview of baseline studies on CBR documentation commissioned by the Norwegian Association of Disabled in Palestine, Uganda and Malawi¹

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Background

The Norwegian Association of Disabled (NAD) promotes equal rights and social participation and inclusion of persons with disabilities in Norway and abroad. It targets organizational development of disabled persons' organizations (DPOs) and inclusive development through Community Based Rehabilitation (CBR). Currently NAD supports CBR programs in Palestine (since 1992), Malawi (2002), Lesotho (2003) and Zambia (2010). Support to the Uganda CBR program phased out in 2008.

In response to the apparent lack of and need for better documentation and dissemination of CBR good practices, NAD, in 2010 embarked on a five-year plan for introducing documentation and research as an integral part of CBR programs it supports in Africa. This is being done to promote evidence based documentation of CBR outcomes and processes and sharing of good practices among CBR programs.

¹ Paper presented at the 1st CBR World Congress, Agra, India, 26th -28th November 2012.

The Documentation and Research project is supporting CBR programs to use documentation and research to: generate databases of CBR documentation to facilitate sharing of good practices; identify CBR thematic areas which may require further documentation; and identify themes for action research with a view to getting a more in-depth understanding of certain themes for the purpose of identifying best possible interventions. Overall, documentation and research in CBR is progressively proving to be a significant tool for disseminating good CBR practices within and across CBR programs, as well as to inform CBR policy and practice.

This paper provides a comparative overview of baseline studies on CBR documentation and research commissioned by NAD in Palestine, Malawi and Uganda. It highlights strengths and challenges in existing CBR documentation systems and practices. Based on available evidence, the paper promotes the need to use evidence based documentation in planning and reporting in CBR programs for better quality and targeting of interventions and to effectively measure the benefits of CBR on the lives of persons with disabilities and their families, inform policy development, and demonstrate CBR's achievements to development partners and donors.

Methods

Baseline studies on existing CBR documentation were conducted in Palestine (2010), Malawi (2010/11) and Uganda (2011/12) CBR programs. These consisted of a desk study of available documents and interviews with key CBR stakeholders. This was followed by an analysis and comparison of results among the CBR programs.

Results

A comparative analysis of baseline studies in the three countries has brought to light a number of well-intentioned initiatives to document and research CBR themes and interventions, though in most cases not done systematically. The study revealed that documentation of CBR programs and activities is varied in terms of quantity, quality, and applicability, and generally is of limited access

to professionals and project staff across projects in the three countries. Following are the study's specific findings:

1. Availability and accessibility of CBR documentation

Considerable information has been documented on CBR and related topics (59 documents in Palestine, 90 in Malawi, 76 in Uganda). These include reports on baseline surveys, thematic studies, assessments and evaluations, films, brochures and newsletters. The last three, which largely target the public, are least in number, supporting the impression that most of the documentation is intended for in-house and donor consumption. In Malawi and Uganda, much has been documented on health and education components of the CBR Matrix with the social component ranking fourth and the empowerment component, least². This finding highlights the need to undertake more documentation and action research on the social and empowerment components for better targeting of interventions and advocacy activities.

2. CBR program monitoring and documentation: tools, systems and practices

In Malawi and Uganda, monthly, quarterly and annual field reports constitute the main tool for monitoring and reporting on national CBR programs. In Palestine³, CBR indicators and narrative reports are submitted every six months. Whereas tools for monitoring results (against indicators) exist in all three programs, the tools vary and have been used with varying degrees of success with the Palestine program using them more consistently and effectively than Uganda and Malawi. Involvement of line ministries in monitoring is not mandatory or routine in Malawi and Uganda.

CBR management information systems (CMIS) are not fully developed (Uganda, Malawi) compared to Palestine. Malawi is currently developing a

² Information on documentation by CBR Matrix component is not available from the Palestine CBR program, as the WHO CBR Matrix had not been finalized at the time of the baseline study.

³ Unlike Malawi and Uganda CBR programs, which are implemented by government, the CBR program in Palestine is implemented by consortiums of local NGOs; handover of CBR projects to local government entities is gradually taking place in some areas of Palestine.

CMIS which promises to be more user friendly than its previous system, and the revised CMIS for Uganda requires further piloting across the national CBR program. In Malawi and Uganda there is need for consensus among CBR stakeholders to adopt a standard CMIS.

In line with decentralisation (delegation of power for planning and implementation of programs to local governments), findings of baseline studies in Uganda and Malawi would imply that reporting of CBR program outcomes would need to be integrated within reporting formats at local government level. Adoption of CMIS as a disability specific reporting format by local governments would lead to parallel reporting. This may have its own challenges.

3. Existence of systems for storage of documentation

Although CBR programs in the three countries have developed and or adopted various systems for planning, monitoring and reporting on results and outcomes of CBR programs, most of the CBR stakeholders have not established systems for archiving soft and hard copies of their documents.

4. Extent of dissemination of existing CBR documentation

In Palestine, the NAD/Diakonia Rehabilitation Program office is the main location for CBR documentation. In Malawi and Uganda, there is no single repository point for CBR documentation. As a result, hard and soft copies of documentation are not easily accessible in one organized space. These are scattered all over with different stakeholders keeping different documents. Save for the Palestine program, there is very little sharing among stakeholders and almost no sharing across countries.

There has been very limited effort to disseminate CBR documentation even among the staff of key stakeholder organizations in Uganda and Malawi and for public consumption in all countries. This is largely due to lack of deliberate effort to make dissemination an integral part of CBR activities. Notable efforts

in this area have been through the CAN website⁴ (for Uganda), FEDOMA website⁵ (for Malawi) and external repositories of CBR documentation⁶.

Government websites in Malawi and Uganda do not feature documentation on disability. There is thus need for stakeholders to partner with reputable, locally maintained internet websites (e.g. the CAN website and websites of the respective national bureau of statistics) for dissemination of CBR documentation.

Of a few organizations that produce hard copies and do have a resource room, MACOHA⁷ (Malawi) provides an example of good practice. Its resource room has dedicated staff, with systems in place for cataloging and accessing documents by both MACOHA staff as well as the general public. Similarly, the Palestine program has a system for distributing documentation to key CBR stakeholders. The Palestine program also organizes workshops for dissemination of research findings and other reports to CBR stakeholders.

In Palestine, reports and documents on CBR and DPOs are available both in English and Arabic. However, language is a barrier to dissemination of CBR documentation in Uganda and Malawi where most documentation is produced and disseminated in the English language – a medium that is not accessible to the majority of the population. In Uganda, none of the 76 documents reviewed was accessible in any other language but English and little effort was made to provide for translations into Braille and large print for the visually impaired. Similarly, in Malawi, only 7 of the 90 documents analyzed were either translated into or produced in local languages and one document (newsletter) was produced in both English and Norwegian.

⁴ CAN (CBR African Network): www.afri-can.org

⁵ FEDOMA (Federation of Disability Organizations in Malawi) is the DPO umbrella in Malawi: <http://www.fedomamw.net/>

⁶ see www.asksource.info; <http://www.safod.org/Images/LCMalawi.pdf>; <http://www.docstoc.com/docs/49686779/DISABLED-PEOPLES-ORGANISATIONS-DENMARK>; <http://www.atlas-alliansen.no/Publikasjoner>; <http://www.norad.no/en/evaluation>

⁷ MACOHA (Malawi Council for the Handicapped) is the parastatal agency that implements CBR in Malawi.

5. Extent of use of existing CBR documentation

The study revealed that existing baseline studies, project evaluations, action research and other forms of documentation have in all the three countries been used to inform CBR programming and lobbying and advocacy activities, as well as used as part of reporting / accountability to donors. Documentation and research in Palestine has been done more in response to the needs felt by the program and its partners than in Malawi and Uganda. Accordingly, the majority of existing documentation in Palestine has been in the form of action research to inform the planning process and decision making, to explore new thematic areas, to identify concrete problems and achievements, and to develop strategies. The program has had a specific budget item for research and documentation which has provided financial flexibility to undertake studies as needed. The Palestine experience is an example of good practice that could be emulated in CBR programs elsewhere.

6. Level of DPO participation in documentation and research assignments

DPOs in Uganda and Malawi have over time and to varying degrees developed their capacity and profile such that it is difficult for anyone interested in research and documentation about disability to ignore them. The majority of DPOs in Uganda have been actively involved in documentation, especially through initiating and participating in research albeit not necessarily always CBR specific. Their research projects have largely intended to generate information for their own programming interests as well as lobbying and advocacy. Of the 76 documents analyzed, 22 (29%) have been authored or co-authored by DPOs. The areas of interest for DPOs have largely been empowerment, livelihood and health. Out of the 22 documents published or co-published by DPOs, 8 (36%) focused on empowerment, with 4 (16%) focused on health and livelihood, respectively. The active involvement has emanated from the fact that the disability movement, as one of the primary end users of research, has over the years lobbied for active involvement of persons with disabilities in research.

On the other hand, there has not been any DPO initiated research in Malawi. Their role has been limited to participating as research

assistants/enumerators and supervisors. This is, however, a notable development considering that, until the last ten years, persons with disabilities had been involved solely as respondents. In Palestine, a major CBR evaluation from the perspective of persons with disabilities undertaken in 2005 informed program planning. The active participation of persons with disabilities in undertaking research is a new and limited development which post-dates the documentation study.

7. Capacity to document and undertake research in CBR: strengths and challenges

In Uganda, some efforts have been made under the Community Action Research in Disability (CARD), a project through which seasoned researchers and academicians have mentored academics/researchers at Kyambogo University. The Uganda Bureau of Statistics (UBOS) is also taking progressive interest to integrate disability in national surveys. Similarly, the Centre for Social Research of the University of Malawi has done a number of studies on disability. The university plans to introduce post graduate disability studies with a strong research component to groom more researchers in this field. In Palestine, the CBR program adopted a strategy of evidence-based planning from the start due to the pressing need for information to inform practice. The program's cooperation with Birzeit University allowed for designing and conducting action-oriented research to guide the program's efforts.

In spite of the cited positive developments, there is need for more concerted efforts to build a cadre of researchers at various levels including from within the ranks of persons with disabilities to promote CBR stakeholder involvement in research as well as promote quality research.

Conclusion

Results of baseline studies in the three countries indicate that there have been varying degrees of effort by CBR programs to promote documentation within CBR. However, a more systematic approach is required to address gaps in this area. To this effect, NAD has identified the need to strengthen

documentation and research efforts in CBR programs. These efforts need to be enhanced through building capacity in good documentation practices, promoting action research for evidence based planning and documentation of CBR results, and dissemination of good practices to inform CBR program development, advocacy and development policy. To accomplish these objectives, there is need to integrate documentation and research as an integral part of CBR programs.

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