Institution: University of East Anglia



Unit of Assessment: 3B – Allied Health Professions, Dentistry, Nursing and Pharmacy: Allied Health and Nursing

Title of case study:

The impact of Community-Based Rehabilitation (CBR) on improving access to rehabilitation services for people with disabilities

1. Summary of the impact

Community-Based Rehabilitation (CBR) is a strategy for rehabilitation, equalisation of opportunity, poverty reduction and social inclusion of people with disabilities in low and middle income countries. Outcomes from CBR have been shown to increase independence, and enhance mobility and social inclusion of people with disabilities in low and middle income nations. CBR is currently implemented in over 90 countries and has enabled thousands of disabled children and adults across the globe to receive rehabilitative care within their own communities. CBR works by establishing community-based programmes which reach into areas that conventional services cannot. such as rural areas in developing countries with limited infrastructure; it is able to do this as programme leadership is not restricted to professionals but also involves the people with disabilities, their families and communities. Hartley has played a significant role in providing the evidence required by governments and NGOs to implement CBR to enable children and adults in developing countries to benefit from improved communication, education and community development. Hartley provided research evidence to help the approach develop from simple rehabilitation to an extensive mix of education, livelihood and empowerment. She fostered regional and global networks of practitioners and researchers, such as the CBR Africa Network, and these capacity building, networking and knowledge exchange activities have ensured that CBR research has had an impact in practice on a global scale.

2. Underpinning research

Prof Hartley joined UEA in January 2006, retiring to become Emeritus Professorial Fellow in 2011-2012. Her research into CBR directly informed the development of participatory approaches to promote equal access to healthcare, education, skills training, employment, social mobility and political empowerment in low and middle income nations. CBR recognises that disability is not just a health condition but is influenced strongly by social factors and the wider context in which a person with a disability lives. Responses to disability must recognise this multi-dimensional nature of disability and be community orientated. This approach is based on WHO's International Classification of Functioning, Disability and Health (ICF), which stresses the environmental context of disability (research reference 1) and the impact within families (research reference 4).

Prof Hartley was instrumental in initiating tangible advances in the field of CBR over the last decade. The invited commentary in the Lancet (research reference 3) reviewed the opportunities and challenges faced by CBR and gave recommendations for future directions from a research, managerial and policy perspective. Her pioneering research at UEA has focussed on identifying best practices (research reference 5), selecting indicators of change, and developing instruments to assess the quality of CBR programmes (research reference 6), in order to feed back into the evolving evidence base. This methodological research affects directly a community's own capacity and ability to monitor and assess development, providing essential tools for conducting ongoing self-directed research. Hartley's work includes: conceptualisation of the contribution of CBR (research reference 3); pragmatic, low cost, community-based methods of identifying people with disabilities (research reference 4); using community/researcher partnership to develop more culturally-relevant interventions for children with communications disabilities (research reference 3) and using systematic synthesis reviews to evaluate evidence from CBR evaluation reports (research reference 1).

A further example of Prof Hartley's impact is underpinned by the work carried out by the Pan-African Community-Based Rehabilitation Network (<u>Afri-CAN</u>), of which she was a founder member and Executive Director for over 10 years. The organisation has generated practitioner guidelines in the form of CBR manuals, educational resources and has hosted conference events to disseminate localised findings to the international community. Much of Africa still has an oral rather



than a printed tradition of information exchange, and hosting international conferences is a critical element for knowledge transfer. The conferences hosted by Afri-CAN in 2001, 2004, 2007 and 2010 have enabled practitioners and innovators of CBR to impart high quality information and describe future schemes, all with the ultimate goal of improving CBR and the lives of people with disabilities in developing countries.

UEA researchers: Adeoye, Hartley, Seeley, Xiong.

Non-UEA researchers: Carter (University College London - UCL), Finkenflugel (Erasmus University, Rotterdam), Gona (Kenya Medical Research Institute), Kuipers (University of Queensland), Muhit (School of Hygiene and Tropical Medicine), Murira (Kenya Medical Research Institute), Mwangoma (Kenya Medical Research Institute), Newton (UCL), Thomas (Asia-Pacific Development Centre on Disability, Bangkok), Wirz (UCL)

3. References to the research

Peer-reviewed Journal Articles (UEA researchers in bold)

1. Xiong,T. Hartley,S. (2008) Challenges to linking health status outcome measures and clinical assessment tools to the ICF

Advances in Physiotherapy **10** 152-156 doi: 10.1080/14038190802331401 This paper focuses on using the International Classification of Functioning, Disability and Health (ICF) as a universal framework to examine health status outcome measures and clinical assessments. Prof Hartley worked with Dr. Tenbing Xiong at UEA, who is corresponding author for this article.

2. Kuipers, P, Wirz, S and **Hartley, S** (2008) Systematic synthesis of community-based rehabilitation(CBR) project evaluation reports for evidence-based policy: a proof-of-concept study.

BMC International Health and Human Rights **8** 1-15 doi: 10.1186/1472-698X-8-3 This research output was supported by the European Commission. Qualitative analysis was conducted on the 'recommendation' sections from 37 evaluation reports, arising from 36 disability and development projects in 22 countries.

3. **Hartley, S**, Murira, G, Mwangoma, M, Carter, J and Newton, CR (2009) Using community/researcher partnership to develop a culturally relevant intervention for children with communication disabilities in Kenya.

Disability and Rehabilitation **31** 490-499 doi: 10.1080/09638280802061944 A culturally relevant community-based intervention for children with communication disabilities in Kenya through a community/researcher partnership was developed. Support for the research came from the Kenya Medical Research Institute (KEMRI), which is allied to the Wellcome Trust, UK. Funding was awarded to Dr. Charles Newton at UCL.

4. Gona, JK, **Xiong, T**, Muhit, MA, Newton, CR and **Hartley, S** (2010) Identification of people with disabilities using participatory rural appraisal (PRA) and key informants (KI): A pragmatic approach with action potential promoting validity and low cost.

Disability and Rehabilitation **32** 79-85 doi: 10.3109/09638280903023397 Prof Hartley was assisted at UEA by Research Associate, Dr. Tenbin Xiong, corresponding author. The output was supported by the C.P. Charitable Trust and Prof Hartley was awarded the funding. Additional support was given by KEMRI, Wellcome Trust to Dr. Charles Newton. The study concluded that the participatory rural appraisal and key informant approaches could be fast and cost-effective methods for identifying people with disabilities as an alternative to expensive and time-consuming conventional surveys.

5. **Hartley S.**, Finkenflugel H., Kuipers P., Thomas M. (2009). Community-based rehabilitation: opportunity and challenge

The Lancet **374** 1803-1804 doi: 10.1016/S0140-6736(09)62036-5

This invited commentary describes the reach of CBR, reviews recent advances and recommends future directions from a research, managerial and policy perspective.

6. Adeoye, A, Seeley, J and Hartley, S (2011). Developing a tool for evaluating community-based rehabilitation in Uganda

Disability and Rehabilitation **33** 1110-1124 doi: 10.3109/09638288.2010.521613



Prof Hartley was assisted by Dr Adewale Adeoye in the Faculty of Health at UEA and collaborated with Professor of International Development, Janet Seeley, in the Faculty of Social Sciences. The research was led by Prof Hartley and supported by the CP Charitable Trust. The research developed a short, feasible tool that can be amended for use to evaluate other CBR programmes.

Key Research Grants (awarded to UEA with Prof Hartley as Principal Investigator):

- **Title**: Research capacity development in community based disability studies. **Sponsor**: Ka Tutandike Trust, UK. **Period**: 01/10/05 30/09/10. **Value**: £ 201,220.89.
- Title: CAN The Community Based Rehabilitation Africa Network. **Sponsor**: CP Charitable Trust, UK. **Period:** 01/04/2006- 31/10/2010. **Value**: £199,925.00.
- Title: Linking Disability to Rehabilitation. CP Charitable Trust, UK. Period: 01/01/2008-31/12/2010. Value: £ 105,250.00

4. Details of the impact

Community-based rehabilitation began as a way of ensuring that people in low and middle income countries got access to medical rehabilitation, growing into a strategy for individual empowerment and community development which is used in more than 90 developing countries worldwide. Key steps in developing the field of CBR have been: to widen the approach so as to recognise the multi-dimensional nature of disability and thus of appropriate CBR programmes; to increase the evidence base on the effectiveness of CBR; and to build alliances and partnerships, between practitioners and people with disabilities, between different approaches (health, rehabilitation, education, livelihood, empowerment) and across countries and continents. In all of these endeavours and in each area, Hartley has made a major impact during the REF period through her research and her capacity building, networking and knowledge exchange activities.

Impact through the World Report on Disability and the WHO Guidelines: Hartley's impact is corroborated by her role as co-editor and major contributor to the WHO's first World Report on Disability (source A). In particular, together with Maya Thomas, she ensured that the report reflected the multi-dimensional approach to rehabilitation (chapter 4), that the chapter on education reflected best practice in terms of inclusive education in Africa and other low income settings, and finally she ensured that CBR was cited in every chapter as the route to empowerment and participation of disabled people and their families in developing countries. Six of the eight chapters cite work written or edited by Hartley, and her twelve different citations make her one of the most widely cited authors in the report as a whole. The report has since been implemented in more than 90 different countries, in collaboration with national governments, and tens of thousands of print and download copies are now in circulation and active use in the disability sector.

The WHO report is supported by the International Labour Organisation (ILO), the United Nations' Educational, Scientific and Cultural Organisation (UNESCO), and the International Disability and Development Consortium (IDDC) who all operate under the global implementation of the United Nations' Convention on the Rights of Persons with Disabilities (2008). The UN implementation guidance describes CBR as, "a flexible, dynamic and adaptable strategy that includes access to health care, education and vocational training, income-generating projects, and community participation and inclusion." Hartley was a major contributor to the CBR Guidelines published by the WHO/ILO/UNESCO/IDDC consortium (source B). The guidelines provide a common understanding and approach for CBR; bringing together all that is known about the approach from around the world and providing the framework for action as well as practical suggestions for implementation and guidance. The guidelines also promote evaluation of CBR programmes on the effectiveness and efficiency of CBR in diverse contexts; Hartley's research has not only influenced the guidelines but also developed methodologies to achieve these goals. The guidelines systematise the CBR multi-dimensional approach, and offer tools for evaluation of CBR. They have had global impact with 8,500 English copies in circulation and are available in six other UN languages. The Guidelines cite publications affiliated with UEA in several places (e.g. source C) and list them as essential further reading for practitioners and researchers. The CBR guidelines are incorporated into the core message and business of many international charities. Handicap International have the guidelines to download and guidance to use them, as they believe that "This approach is expected to impact on millions of people with disabilities in developing countries, many



of whom currently live in situations of poverty and exclusion."

Impact through the CBR Africa Network (CAN): The Africa Network CAN is a continental network of CBR which has now combined with Asia Pacific CBR and Americas CBR Networks to form a CBR Global Network. The CBR Guidelines (source B) are the founding document of this global network, and have played a unifying and strengthening role in the movement as a whole. Hartley was an organiser of the Abuja, Nigeria 2010 conference where the CBR Guidelines were launched (source D). It was a seminal day for CBR and the conference was advertised on the 'UN Enable' resource (source E). The conference "provides an opportunity for people to share information, knowledge, and experience on how disability concepts and CBR programmes can link together to help improve the quality of life for persons with disabilities and their families." (source F). To ensure that discussions and thoughts from the conferences are widely disseminated and shared, CAN has taken up the responsibility of compiling books that are based on the conferences, but developed further through reflection and collaborative writing between the participants; 'CBR: inclusive policy development and implementation' resulted from the 2007 conference in South Africa and was published by UEA in 2008 and is free to download from the Afri-CAN website. The text is recommended reading in the World Report on Disability (source A) and the CBR Guidelines (source B).

5. Sources to corroborate the impact

A. WHO World report on disability (2011)

The report references both authored and edited work by Prof Hartley and texts affiliated with or, published by UEA. These include: chapter 1: Understanding Disability (ref 109); chapter 2: Disability- a global picture (ref 104); chapter 4: Rehabilitation (ref 227 and ref 173); Chapter 5: Assistance and Support (ref 59); Chapter 7: Education (ref 24 & 59). In addition, Hartley's research was referenced in chapters: 3 (ref 227), 4 (ref 107) 5 (refs 26, 39) 7 (ref 127). Hartley is listed as a member of the Editorial Committee (p.xv) and her contribution acknowledged (p.xix). Hartley is listed specifically as a contributor to the Rehabilitation chapter (p.xvi) and the chapter entitled, "The way forward: recommendations" (p.xvii). Hartley is also named as a Regional Consultant for the African Region (p.xviii).

B. WHO CBR Guidelines (2010)

The <u>Introduction booklet</u> states that CBR is implemented in over 90 countries worldwide (page 11). The guidelines provide a conceptual overview with suggested goals and outcomes and are available in 7 languages. Prof Hartley is acknowledged as a Contributor (page 3), listed as a Peer Reviewer (page 4) and UEA research is referenced in the recommended further reading section (page 30) as well as in the <u>Health Component</u> (page 71).

- *C.* CBR: inclusive policy development and implementation, 2008. Norwich, UEA. Available <u>online</u> *This edited text by Prof Hartley and Joan Okune compiled the conference proceedings from the 3rd CBR Africa Conference, South Africa, 2007. It is referenced four times in Source 1 and twice in Source 2. Hartley authors one chapter within the book and is cited extensively throughout.*
- D. <u>CBR Africa Network</u> Conference, 2010 in Abuja, Nigeria on October 27th, 2010 This conference launched the new WHO/IDDC CBR and Inclusive Development Guidelines. The conference was attended by 385+ delegates from 51 countries and organised by the organisation of which Prof Hartley is now Patron.
- *E.* <u>The Who Newsletter On Disability And Rehabilitation, Issue No. 11, October 2010</u> *This newsletter describes the launch of the CBR Guidelines (Source 2)*

F. The United Nations Enable Newsletter

The Enable Newsletter is prepared by the Secretariat for the Convention on the Rights of Persons with Disabilities. In the <u>July-September edition</u>, 2010, the advertisement for the conference reads, "The Conference will be held under the theme "Linking CBR with Disability and Rehabilitation" in Abuja, Nigeria. It aims to promote better CBR practices in Africa and provides an opportunity for people to share information, knowledge, and experience on how disability concepts and CBR programmes can link together to help improve the quality of life for persons with disabilities and their families." Prof Hartley is given as a point of contact.