

<p>Institution: Manchester Metropolitan University</p>
<p>Unit of Assessment: A3 Allied Health Professions, Dentistry, Nursing and Pharmacy</p>
<p>Title of case study: Research-informed development of appropriate services for people with disabilities in Majority world countries (underserved countries)</p>
<p>1. Summary of the impact This case study describes the impact of research by Julie Marshall and Juliet Goldbart on international development; specifically on the lives of people with significant disabilities in Majority world countries. Research on delivering appropriate services to people with speech, language and communication disabilities has led to a Nuffield-funded project to mentor graduates from the first speech and language therapy qualifying programme in East Africa, providing much needed professional input in Uganda, Kenya, Rwanda and Tanzania.</p> <p>Related research on the need for appropriate services, and the form these services might take, has resulted in a model of service delivery in slum areas (bustees) of Kolkata (formerly Calcutta), which has now been rolled out to 69 sites across the Greater Kolkata area.</p> <p>In addition to direct impact on rehabilitation services, impact is evident in the development of culturally appropriate training materials and training for health and education workers in East Africa, India and the U.K.</p>
<p>2. Underpinning research The impact is underpinned by two sustained and interconnected programmes of research; Marshall's engagement with a range of speech and language therapy service developments in East Africa since 1988 and Goldbart's extensive collaboration with the Indian Institute for Cerebral Palsy (IICP) since 1986.</p> <p>Although people in the Majority World are disproportionately affected by significant disability (Global Health Observatory, 2004), health, education and social care provision is severely limited. Western models of service delivery are unlikely to be practical given the dearth of professional staff, and may not be culturally appropriate in form or content. Research in Kolkata explored the lives and service needs of families with children with cerebral palsy and contrasted this with Western models of service delivery [1, 2]. These studies revealed the commitment of even the poorest parents to finding services for their children with disabilities, but the overwhelming difficulties in attending conventional services experienced by families living in bustees. Findings, supported by local survey data, informed the development of a model of service delivery through mother and child health workers, employed or volunteering with non-governmental organisations (NGOs) with established credibility in the bustees. Initially three NGOs agreed to participate and the model of training these staff and development of an appropriate needs assessment for the slum areas was piloted and evaluated in five bustees. The action research method enabled the emergence of a culturally appropriate model of service delivery which was sustainable within existing NGO resources [5].</p> <p>In a parallel development, research funded by the Royal College of Speech and Language Therapists Marshall and Goldbart studied the experiences of international students who studied speech and language therapy (SLT) in the U.K. [e.g. 4]. The findings demonstrated that U.K. SLT qualifying programmes were not providing appropriate education for students from countries with little history of SLT services to feel competent to work in their home countries. These students and graduates would also welcome support once qualified. Poor preparation and support for returning to their home contexts may have contributed to limiting the number of Majority World students who returned home to take up and remain in SLT posts on graduation, which in turn leads to SLT services in some Majority world countries remaining extremely limited, despite government and third sector funding. In such countries, services often continue to be provided by a small number of Minority world volunteers.</p> <p>The challenges of providing SLT services in sub-Saharan Africa have been researched by Marshall [e.g. 3] demonstrating a dearth of appropriate services for children with speech and language difficulties, and leading to her involvement in the planning of the first SLT qualifying programme in East Africa. As SLT is not yet established as a profession, and the support for new graduates would be minimal, Marshall devised a mentoring project to provide professional support and guidance from a group of SLTs with experience of working in under-served countries. This Nuffield-funded project is currently in progress.</p>

Key Researchers

Juliet Goldbart. Appointed L2 1/10/1980; SL 1/10/1988; Reader 1/10/2001; Professor 5/1/2009.
Julie Marshall. Appointed SL 11/2001; Senior Research Fellow 2005 to present.

3. References to the research

- [1] Goldbart, J. & Mukherjee, S. (1999b). The appropriateness of western models of parent involvement in Calcutta. Part 2: Implications of family roles and responsibilities, *Child: Care, Health and Development*, 25, 348-358. DOI: 10.1046/j.1365-2214.1999.00139.x (4 citations)
- [2] Goldbart, J. & Mukherjee, S. (2001). A comparative evaluation of two models of service delivery for families with a child with cerebral palsy, *International Journal of Rehabilitation Research*, 24, 325-328. DOI: 10.1097/00004356-200112000-00010, (4 citations)
- [3] Marshall J. (1997) Provision for children with speech and language difficulties in Tanzania. *International Journal of Disability, Development and Education* 44(4): 341-365. DOI: 10.1080/0156655970440405, (3 citations)
- [4] Marshall J., Goldbart, J. & Evans, I. (2004). International students of speech and language therapy in the UK: do we meet their needs? *International Journal of Language and Communication Disorders* 39(2): 269-284. DOI: 10.1007/s10734-004-6350-4, (2 citations)
- [5] Sen, R. & Goldbart, J. (2005). Partnership in Action: Introducing family-based intervention for children with disability in urban slums of Kolkata, India, *International Journal of Disability, Development & Education*, 52 (4), 275-311. (6 citations)
- [6] Wylie, K., McAllister, L., Davidson, B & Marshall, J. (2013) Changing practice: Implications of the World Report on Disability for responding to communication disability in underserved populations. *International Journal of Speech Language Pathology* 15(1), 1-13. DOI: 10.3109/17549507.2012.745164, (21 citations (WoS))

Quality Indicators

- i) The IICP collaborations were funded by a Department for International Development (DfID) Higher Education Link grant to Indian Institute for Cerebral Palsy, Manchester Metropolitan University and School of Physiotherapy, Cardiff University, from 2000 to 2002, and a DfID grant from 1998-9.
- ii) The study of international SLT students in the UK was funded by the Royal College of Speech and Language Therapists (£6000)
- iii) The mentoring project is funded by Nuffield Foundation (£80,000) from 2011-2014.
- iv) In response to the World Report on Disability (2012), Marshall was invited to co-edit a special edition of the *International Journal of Speech-Language Pathology*, aimed at informing and influencing policy makers, service leaders and practitioners throughout the world. In the first three months since publication, this special edition, of which [6, above] was the lead paper, had 4655 full text downloads.

4. Details of the impact Impact is demonstrated in three inter-related areas; impact on direct beneficiaries of rehabilitation services, the development of culturally appropriate training materials, and training for health and education workers both “in-country” and in the UK.

Direct impact:

The initial 3-year action research bustee project (2000-2002), evaluated by Sen & Goldbart [5], was implemented in five urban slums in Kolkata, offering individualised home-based intervention for parents and their child with disabilities, through three mother and child welfare NGOs. IICP trained and mentored community development practitioners who were already working in the bustees, to deliver rehabilitation guidance in addition to their usual role in mother and child welfare. Community development work was also undertaken to increase awareness and acceptance of people with disabilities. *“Path breaking work was done through this tripartite link that reached IICP’s services to the doorsteps of persons with disability and their families living in Kolkata’s slums.....The work with the 3 partners in 14 urban slums, 22 persons with disability and families and thirty-eight field workers has now spread to 7 NGO partners, 69 slums and helped 772 children and adults and their families and more than 552 people including field workers have participated in training and awareness programmes.” [A]*

The impact is expanding outside Kolkata, with one corporate organisation providing services in two rural villages and three partner organisations in districts outside KMC involved in training trainers for their own districts. Six organisations (three in other Indian states and three in the districts of West Bengal) are being supported to become zonal training agencies for persons with disability in

rural areas. [A,D]

Through her research in the UK and East Africa, Marshall became involved in planning East Africa's first SLT qualifying programme, at Makerere University, Uganda. As SLT is not yet an established profession, and support for new graduates would be minimal, she devised a mentoring scheme to provide professional support and guidance from SLTs with experience of working in under-served countries. This project, funded by the Nuffield Foundation has, since September 2011, provided and evaluated direct in-service training for graduates of this new programme and SLTs working in Kenya, support for the university staff in delivering and developing the SLT degree, provided remote and face-to-face one-to-one mentoring for each member of staff and graduate and support for the strategic development of services for people with communication disabilities in Uganda. *"This mentoring programme has benefited me and my institution beyond expectation, and I have gained more confidence following this training. e.g the training on communication and people with severe profound learning difficulties has increased and enabled me to have appropriate assessment and intervention approach to this client group based on intensive interaction, promoting intentional communication and engaging with object and event. The clinical audit training/forms have been useful in ensuring systematic data collection, which are helpful in evaluating service, source of research data, preparation of annual unit report and control of caseload including reducing chances of bias in the waiting list."* [B]

Two cohorts of students (n=19) have graduated from the programme and are now working in Uganda, Kenya, Tanzania, Nigeria and Rwanda, adding significantly to the very small numbers of SLTs in these countries. Four graduates are currently teaching on the programme and form a core of indigenous lecturing staff. These four also provide the first indigenous languages SLT service at Mulago University hospital in Kampala.

Sixteen mentors support the graduates from the Makerere programme, as well as other SLTs from Uganda and Kenya, who have joined the project. Participants are developing clinical audit tools that are currently generating data to demonstrate the need for further service developments and have designed case history and assessment materials. Lecturing staff have been supported to revise and gain approval for a new undergraduate curriculum for SLT at Makerere University. Graduates have also been supported to present at national and international conferences and to write papers for publication. *"David's skills as a clinician have benefited from this project in a number of ways, specifically in being able to access support that is culturally appropriate to settings in which he works, rather than having to travel abroad to receive this support."* [C]

People with communication disabilities and their family members have been empowered by involvement in the mentoring project's advisory group and feature on the project website: http://www.rihsc.mmu.ac.uk/projects/project_profile3.php?projectid=444. See also [E].

Marshall is currently also involved in research based at University of Sydney, mapping services for people with communication impairments across Sub-Saharan Africa and is providing advice to Moi University, Kenya regarding establishment of a further SLT qualifying programme.

Culturally appropriate training materials and resources: In 1998 DfID funding enabled Goldbart, with Warrick (Canada) to develop a manual and video-based training course for use with families with a child with severe communication impairment related to intellectual and/or physical impairment. This course, informed by Goldbart and Mukherjee [e.g. 1,2] was intended for use in both literate and non-literate communities. The resulting course Learning About the World has been distributed by IICP since 1999.

Informed by [3 and 4], graduates from the Ugandan SLT programme are developing culturally appropriate assessment, intervention and service evaluation materials. The Dean of Makerere University's School of Medicine says *"The benefits are widespread and include: development of appropriate interview and assessment resources, data collection about SLT work through clinical audit, development of the BSLT programme curriculum, encouragement and advice on how to engage in research."* [F]

Through work with Communication Therapy International Marshall has developed training materials (e.g. reading lists, pre-departure briefing) and short courses (e.g. for VSO volunteers) for SLT planning to work in underserved countries. A manual was produced to accompany the

Impact case study (REF3b)

course in Kenya 1995 (see below) which has since been made available to people working in a number of underserved countries, including Kenya and Tanzania, as well as being utilised by participants in the Ugandan mentoring project: Marshall J. & Warner J. (Eds) (1996) An introduction to Communication Disorders in Children. A book for workers in less developed countries. (Unpublished).

Training and development: Goldbart has run many training workshops for students and staff at IICP and service providers from the Kolkata area and beyond. In 2011, with Janice Murray (also MMU), she ran courses for students, practitioners, policy makers, speech and language pathologists from organisations in West Bengal, Delhi, Mumbai, Mysore and Chennai as part of the 3rd All India AAC conference. *“workshops on working with persons with PMLD and evidence based practices were conducted for participants comprising students, practitioners, policy makers, speech and language pathologists mainly from Kolkata. Both Professors presented papers to around 100 practitioners, technology developers, parents and adults with disability from many parts of India representing institutes of technology, universities, NGOs, specialist centres for disability, speech therapy training colleges and employers of persons with disability.”* [A]

Marshall supported SLTs in East Africa in 2009, running training on setting up a professional association and planning for sustainable services. *“Experiences gained from being part of the project, i.e Capacity building for Makerere University Speech Language Therapy staff, begins to inform me and hopefully other colleagues teaching on the [programme], on how best as recipients of projects, we can create paths, programmes and projects, through partnerships, which paths, projects and programmes are contextually relevant, all aimed at developing sustainable services for people with communication disabilities in Uganda.”* [G]

Graduates from the Makerere SLT programme have contributed significantly (as president, treasurer and secretary) to the development of the Association of Speech and Language Therapists in East Africa (ASLTEA) in 2012, and in organising and presenting at the Biennial East African Conference on Communication Disability, which in 2012 had representation from 16 countries. Report available at:

[http://www.academia.edu/1906539/4th East African Conference on Communication Disability 2012 Summary Report](http://www.academia.edu/1906539/4th_East_African_Conference_on_Communication_Disability_2012_Summary_Report)

Marshall and colleagues ran training at the Kenyan Institute of Special Education, Nairobi, on supporting children with communication disability (1995) funded by DfID. Marshall also supports UK based SLTs wishing to work in underserved countries through founding and being a committee member of Communication Therapy International and contributing to training e.g. NW NHS AHP training: Marshall J. (2012) Volunteering in AHP (Speech and Language Therapy). Invited presentation at North West International Health Care in AHP. Manchester, UK. March.

5. Sources to corroborate the impact

[A] Excerpts from written testimony on file from the Director, Indian Institute for Cerebral Palsy (IICP), Kolkata, India corroborating impacts on establishing international services and provision

[B] Testimony on file from Makerere SLT programme graduate (1st cohort) now SLT at Muhimbili National Hospital in Dar es Salaam, Tanzania corroborating impacts on the international professionalization of SLT services in underserved countries.

[C] Testimony on file from SLT and Project Coordinator, Yellow House Children’s Service, Kenya corroborating the impact of MMU’s SLT mentoring project on upskilling clinical participants and the further impacts that this has on the wider profession.

[D] IICP Annual Reports on file and available on request or <http://www.iicpindia.org/PDF/AR.pdf>

[E] You-Tube video on SLT in Uganda – <http://www.youtube.com/watch?v=GAPs07i9LZg> (1,801 hits at 20/11/2013)

[F] Excerpt from written testimonial on file from the Dean of Makerere University’s School of Medicine corroborating the impacts and benefits of MMU research on establishing SLT provision and services in East Africa and Nigeria.

[G] Corroborated by written testimonial on file from volunteer lecturer on SLT programme, Makerere University.