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| Institution: Manchester Metropolitan University | | |
| Unit of Assessment: A3 Allied Health Professions, Dentistry, Nursing and Pharmacy | | |
| Title of case study: Enhancing the lives of people with communication and profound intellectual disabilities, in under-served contexts | | |
| Period when the underpinning research was undertaken: 1 Jan 2000 – 31 December 2020 | | |
| Details of staff conducting the underpinning research from the submitting unit: | | |
| Name(s): | Role(s) (e.g. job title): | Period(s) employed by submitting HEI: |
| Julie Marshall | Professor | 2001-present |
| Juliet Goldbart | Professor | 1980-present |
| Sue Caton | Research Fellow | 2000-present |
| Period when the claimed impact occurred: 1 August 2013-present | | |
| Is this case study continued from a case study submitted in 2014? No | | |
| <p>1. Summary of the impact</p> <p>Our collaborative research has produced sustainable, low-cost interventions that improve care and life chances for people with communication and profound intellectual disabilities but limited or no access to support services. Our research underpins delivery of disability services to low-income families across 137 sites and 87 wards in West Bengal. It has also helped the United Nations High Commissioner for Refugees (UNHCR) to increase their awareness of, and support for, refugees with communication disabilities. Research-based training and mentoring supported the establishment/development of the Speech and Language Therapy (SLT) profession in five African countries and Sri Lanka, and equipped over 500 UK-based practitioners to work in low- and middle-income countries (LMICs). Our interventions also shaped the curriculum for children in Wales with profound intellectual disabilities, and informed training materials used by thousands of professionals and families across Europe.</p> | | |
| <p>2. Underpinning research</p> <p>Professors Juliet Goldbart and Julie Marshall have been at the forefront of research into communication and profound intellectual disabilities for over three decades, seeking to realise changes that protect the most vulnerable in society by recognising their lived experiences, and those of the people who work with them. They have collaborated with charities, universities and humanitarian providers in locations worldwide, where services for these groups are minimal to non-existent, establishing prevalence and need, and identifying factors that can challenge stigma, to deliver culturally-appropriate provision.</p> <p>This case study builds on a sustained body of research with speech and language therapy (SLT) services in East Africa and the Indian Institute for Cerebral Palsy (IICP), which began in the 1980s (REF2014). From 2000-2002, Goldbart worked with the IICP to conduct a series of studies to inform and evaluate disability services for very low-income families in slum areas of Kolkata. They contrasted the lives and needs of families with children with cerebral palsy in Kolkata with Western models of service delivery. The research revealed that although even the poorest parents were committed to finding support for their children, families living in bustees (shanty towns) faced overwhelming difficulties in attending conventional services. The action research method generated a culturally-appropriate model of service delivery, which was sustainable within existing NGO resources [1].</p> <p>Over the past 20 years, Goldbart has followed a related programme of research that has extended the evidence base for communication assessment and intervention for children and adults with profound intellectual disabilities. She has also examined how practitioners use these approaches and their applicability to diverse settings. Her studies identified disparities between usage levels and the quality of evidential and theoretical support, which create uncertainty about the efficacy of interventions. This affects staff confidence and can result in uneven outcomes [2]. Marshall and Goldbart's research has also demonstrated how cultural factors affect the services received by people with communication disabilities. Findings from studies on how parents and the workforce conceptualise communication, communication disability, intervention and cultural influence also identified behaviours and approaches that may inhibit or improve engagement, to support service providers in their decision-making [3].</p> <p>Marshall, Goldbart and Evans' Royal College of Speech and Language Therapy (RCSLT)-funded investigation into international students' experiences of studying speech and language therapy in the UK (2002, REF2014) found that many graduates were inadequately</p> | | |

prepared to work in their home countries. This led to the co-development of in-service training and mentoring for graduates and staff on a new SLT degree programme, at Makerere University, Uganda, to reduce dependence on ex-patriate volunteers. The research project (2011-2015, GBP79,969) provided lessons about the development of new services and professions in low-income settings, identifying approaches that worked, and barriers, such as the lack of jobs and peer networks. Concurrent research demonstrated a dearth of speech and language therapists in Sub-Saharan Africa more broadly and a need for culturally-appropriate provision [4].

Related insights into understandings of language development and delay culminated in **LEAP**: a project that responded to Yellow House Children's Services' (2015) findings, which showed that many street-connected children in Western Kenya had a communication disability, and identified a lack of teacher training. **Chance for Childhood** (CFC) enlisted Marshall and Dr Carol Taylor to carry out collaborative qualitative research, using interviews, focus groups and interactive arts-based methods, to inform service development. The findings illuminated the experiences, attitudes, beliefs and wishes of street-connected children with communication disabilities and their main caregivers at home and in school [5].

More recently, Marshall and Manchester Metropolitan PhD student, Helen Barrett, collaborated with **UNHCR Rwanda**, on **three projects** aiming to **improve service provision** after UNHCR identified communication disability as a particular risk factor for exclusion from Sexual and Gender Based Violence (SGBV) services. The first project sought to understand responses to SGBV for refugees with communication disabilities. It found this group is highly vulnerable and that individual environmental and social factors are contributory [6]. This informed the second project, which centred on the understanding and prevention of SGBV and on Sexual and Reproductive Health Education (SRHE), demonstrating a demand for services and workforce knowledge gaps. The third was an impact-oriented project, which led to the delivery of an intervention to increase 'Communication Access' in refugee communities.

3. References to the research

- [1] Sen, R. and **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 and Education*, 52 (4), 275-311. DOI: [10.1080/10349120500348623](https://doi.org/10.1080/10349120500348623)
- [2] **Goldbart, J.**, Chadwick, D and Buell, S. (2014). Speech and language therapists' approaches to communication intervention with children and adults with profound and multiple learning disability. *International Journal of Language and Communication Disorders*. 49(6), 687-701. DOI: [10.1111/1460-6984.12098](https://doi.org/10.1111/1460-6984.12098).
- [3] **Marshall J, Goldbart J**, & Philips J. (2007). Parents' and speech and language therapists' explanatory models of language development, language delay and intervention. *International Journal of Language and Communication Disorders* 42 (5), 533-555. DOI: [10.1080/13682820601053753](https://doi.org/10.1080/13682820601053753)
- [4] **Marshall, J.** & Wickenden, M. (2018). [Services for people with Communication Disabilities in Uganda: supporting a new Speech and Language Therapy profession](#). *Disability and the Global South*. 5, 1, 1215-1233.
- [5] Taylor, C., Sotiropoulou, C., Rochus, D. & **Marshall, J.** (2019). Street connected children with communication disabilities and their caregivers in Western Kenya: experiences, beliefs and needs. *Disability and Rehabilitation*. DOI: [10.1080/09638288.2019.1699174](https://doi.org/10.1080/09638288.2019.1699174)
- [6] **Marshall, J** and Barrett, H (2018). Human rights of refugee-survivors of sexual and gender-based violence with communication disability. *International Journal of Speech-Language Pathology*, 20, 1:44-49. DOI: [10.1080/17549507.2017.1392608](https://doi.org/10.1080/17549507.2017.1392608)

Funding and quality indicators:

- G1. Goldbart, J, Marshall, J, Evans, R, International SLT students in the UK: do we meet their needs? RCSLT, 2002, GBP6,000.
- G2. Marshall (PI) & College of Health Sciences, Makerere University, Mentoring staff to develop Ugandan services for people with communication disabilities, Nuffield Foundation Africa Programme, 2011- 2015, GBP79,979.
- G3. Marshall, Supporting staff to design and deliver SLT Master's degree programme, Tropical Health and Education Trust (Dfid), 2014-2015 GBP5,020.
- G4. Marshall (PI) LEAP: Street-connected children with communication disabilities in W Kenya, Chance for Childhood (Comic Relief), 2016-2019, GBP80,000.

- G5. Marshall (PI), 'Supporting refugee-survivors of SGBV who have a communication disability – Rwanda,' Humanitarian Innovation Fund, 2016, GBP10,000.
- G6. Marshall (PI) Understanding the need for SGBV prevention/support and SRHE service for refugees with Communication Disabilities in Rwanda, Humanitarian Innovation Fund and Speech Pathology Australia, 2018-19, GBP49,900.
- G7. Goldbart, Routes for Learning revision, Welsh Government, GBP4,000.
- Output reference [3] was cited in the Department for Education's *'The perspectives of children and young people who have speech, language and communication needs, and their parents'* (2012) commissioned in response to the Bercow review of services for children and young people with speech, language and communication needs.

4. Details of the impact

Communication and related disabilities impact on every aspect of the lives of the people living with them, their families and carers. Although an estimated 80% of the 1 billion people with a disability live in the Majority World (UN, 2020), workforce and infrastructure are limited and high-income country models of service delivery are unlikely to be practical. Our research has underpinned the development and delivery of low-cost interventions, which enable local services to become self-sustaining, increasing capacity and delivering more culturally-appropriate provision. From small-scale beginnings, this has expanded beyond national borders, reaching large, disconnected populations and informing practice in under-served contexts in Europe. It has benefitted education providers, SLTs and allied professionals, the UNHCR, charities, and those they work with and care for.

Establishing the SLT profession: The Makerere project gave the 25 graduates and staff, *"the extra skills and confidence to go out and find jobs and offer therapy despite the lack of government sector positions."* 19 of the Ugandan graduates practised there as SLTs following the project, increasing the national practitioner base for the estimated 2,800,000 people with communication disabilities by 280%. Two work in Kenya, where they were instrumental in setting up the national Association of Speech and Language Therapists. One returned to Rwanda, two to Tanzania and one went to work in the USA. Because of this, *"hundreds of people across five countries who would not have received speech and language therapy before, are doing so."* Two of the former mentees now lead the degree programme and others have taken the peer-mentoring aspect forward with subsequent graduates. The 49 graduates and their 16 mentors also use, and build on, project materials to deliver culturally-appropriate support **[A]**.

When the University of Ghana launched a Master's degree in speech and language therapy in 2016, Marshall helped programme leads to plan their activities more strategically, using learning from Makerere. The British Ghanaian Therapy Partnership (BRiGHt) also developed a mentoring programme for the first cohort of graduates, which built in the *'essential ingredients'* (peer mentoring, pairing mentees with mentors that had visited the country) of the Makerere programme. Marshall's research was: *"key throughout the process of creating a programme, evaluating the teaching and learning, and subsequently ensuring that newly-qualified graduates receive appropriate support and supervision"*. The programme more than trebled service provision from five to 17 SLTs (15 of whom are Ghanaian), and graduates will support subsequent cohorts. In project evaluations, mentees *"consistently reported that the support of the mentors assisted them with problem-solving and building understanding of clinical and professional issues in their first year of practice."* **[B]**. Marshall also worked with the RCSLT and over 100 local providers to guide the development of The Sri Lankan Association of Speech & Language Pathologists (2014), which delivers much-needed support for the dispersed community of practitioners, which grew from one in 1988 to 300 in 2019 **[C]**.

Building capacity: The culturally-appropriate model that Goldbart's action research in Kolkata generated fed into the development of the 'Sangam' service model (REF2014), which continues to grow. Reaching the doorsteps of those living in the slums of West Bengal and beyond, it provided services for 311 people with disabilities and 293 families, operating through 11 partner organisations (+57% on the numbers reported in REF 2014) between April 2014 and November 2019. It also delivered training and advice to 977 community members and 387 field workers and professionals (+147%), increasing capacity and enhancing quality of life and community acceptance for otherwise highly-marginalised children and adults, and their families. By December 2020 it had increased its reach to 137 sites (+98%) and 87 wards **[D]**.

Marshall helped the LEAP project team to adapt an assessment, developed in the Makerere project, for use with street-connected children, improving the accuracy of screening for communication difficulties in Western Kenya. The team reports that this has benefitted ‘*several hundred children*’ since 2017. They also co-developed a checklist, which Learning Support Assistants have used to screen children for communication disabilities in schools, extending SLT support to over 100 children. Marshall’s research underpinned qualitative research methods training, which was cascaded down to local organisations via five local workers, including Makerere graduate, David Rochus, who manages Yellow House Kenya. Eight staff at Kisumu Urban Apostolate Programme (KUAP) - partners in the LEAP project - reported improved understanding of communication difficulties. All now use the skills in their social and counselling work practice. Yellow House used the learning to collect data, which they say gave them “*a foundational experience for [the charity’s] future research*”, informing strategic planning. Marshall also trained nine members of Chance for Childhood, who then trained 15 others to identify and assess children with communication disabilities in Northern Rwanda, facilitating access to education [E].

Marshall has advised the RCSLT on international engagement since 2014, working in partnership with Clinical Excellence Network: Communication Therapy International, which she co-founded and chairs. She has embedded insights from her research into training and mentoring for over 500 UK-based SLTs and other associated healthcare professionals. For example, in 2019, she led a study session for 115 health professionals and service leads, on using lessons from LMICs to create culturally-appropriate services in the UK. RCSLT has used her research to develop best practice positions on work in LMICs, and guidelines on joint working in underserved countries, which they say “*allows SLTs and others that want to work in LMICs to be much more well informed and prepared in the delivery of their services (whether speech and language, dysphagia assessments and more)*”.

Since August 2013, Goldbart has also delivered invited masterclasses on communication and profound intellectual disabilities in Russia, South Africa, Bulgaria, Ireland, Portugal, Germany, Italy, Finland and Norway, equipping over 1,500 practitioners and family members with skills, techniques and low-cost interventions proven to work in underserved contexts [F].

Communication and People with the Most Complex Needs: What works and why this is essential – a report that Goldbart and Caton produced for Mencap in 2010 - remains central to the charity’s guidance for PMLD (Profound and Multiple Learning Difficulties). It is used in a range of current guidance including its Raising our Sights ‘how to guide’ on communication (2012), which supports local commissioners to ensure PMLD and their families get the support and services they need, and ‘Valuing the views of children with a learning disability’, produced with the Challenging Behaviour Foundation, for education, healthcare and care professionals (2017). The report and Goldbart *et al.*’s research on communication intervention informed The Irish Association of Speech and Language Therapists (IASLT)’s 2019 position paper on SLT service provision for adults with an intellectual disability and communication needs. Report insights and Goldbart’s contemporaneous research on communication and PMLD also shaped the updated ‘Routes for Learning’ curriculum, which she originally co-developed. ‘Routes for Learning’ is the Welsh Government’s mandatory approach for all statutory provision: it will enhance the support delivered to all children with PMLD in Wales. As with the previous iteration, it is likely that many other schools will adopt it internationally [G].

Improving service access for refugees with communication disabilities: Refugees in Rwanda take part in a biannual verification process, which provides the UNHCR with data on needs, and improves access to support services. Previously, few refugees with communication disability were identified and so Barrett used Marshall’s findings on communication rehabilitation in sub-Saharan Africa to develop a communication disability-screening tool for use in the verification process. UNHCR Rwanda has used it in two camps and two urban areas, improving identification and pathways to support [H].

Using a MetroPolis fellowship (see REF 5b), Marshall worked with UNHCR Rwanda to identify and tackle issues around ‘mainstreaming’ the understanding of, and responses to, refugees with communication disabilities, building capacity to provide inclusive and sustainable services. The project expanded on findings from the first two UNHCR projects and her earlier research on communication disability services in under-resourced settings. Marshall and Barrett interviewed over 60 people, including staff from UNHCR, partner organisations, refugees and

other stakeholders, to determine their priorities, needs, challenges and experiences. Marshall then worked with Barrett and UNHCR colleagues iteratively to adapt a UK-designed training programme (Communication Access UK) to the Rwandan refugee context. They trained 53 people (UNHCR staff, NGO staff and members of the refugee community), including 12 who were also trained as trainers. In immediate post-training evaluation, the groups all reported feeling better-equipped to help people with communication disabilities. The training encouraged them to “*actively communicate with people with communication disabilities even though we are not experts*”. An impact assessment carried out by interviewing 20 participants, eight months after the training, showed that 100% recalled the main messages of the training and gave examples of how they had changed their behaviour in relation to people with communication disabilities. 45% described being sought out to support PWCD. All rated the course highly and requested further training [I].

The Department for International Development (DfID) used Marshall’s findings on refugees with communication disabilities, to support its economic case for investing in preventing violence against women and girls with disabilities in Low and Middle-Income Countries (2018). The research shaped the guidance Marshall has offered as a consultant to the Communicating with Disaster Affected Communities (CDAC) Network since 2018, informing service delivery for the estimated 18,750,000 people in humanitarian contexts who have disabilities. The Director of Policy and Public Affairs at the RCSLT states that Marshall and Barrett’s research on SGBV “*contributed to the influencing strategy of the International Communication Project (a partnership of professional speech and language policies seeking to influence UN disability policy, amongst other things) and has been a powerful tool to raise awareness with decision-makers and opinion-formers.*” The research was reported at the UN Conference of State Parties (COSP) to the Convention on the Rights of Persons with Disabilities (CRPD), in a panel on ensuring inclusion of persons with disabilities. It also informed a ‘*central element of [the RCSLT’s] response to the United Kingdom legislation on domestic abuse,*’ (2019), which is currently before Parliament, to evidence ‘*the disproportionate impact and prevalence*’ of SGBV on people with communication disability. [J, F].

5. Sources to corroborate the impact

[A] Testimonial from former course coordinator, Makerere University.

[B] i Testimonial from BRiGHt (British-Ghanaian Therapy) partnership; ii Stokes, J, Wylie, K, Bampoe, J and Asiedua Owusu Antwi, A, (2020) Summary Report, UK - Ghana Speech and Language Therapy Remote Mentoring Project, Oct 2017-2019.

[C] Records of RCSLT work in Sri Lanka (flyer, schedule and press coverage).

[D] i Data from Honorary Secretary of Indian Institute of Cerebral Palsy; ii IICP web page ‘[Community-based services](#).’

[E] i Testimonial from Managing Director and Clinical Lead, Yellow House Health and Outreach Services; ii Musanze, Rwanda, *Training in Rwanda Report Summary*, MAITS Global Disability Training. Available from: <https://www.maits.org.uk/rwanda/>

[F] i Collated training records; ii Testimonial, Director of Policy and Public Affairs, RCSLT.

[G] i Raising our Sights’ How-to guide 3 – communication, Mencap, 2012; ii “Valuing the views of children with a learning disability, Mencap and the Challenging Behaviour Foundation, 2017; iii IASLT, [Speech and language therapy service provision for adults with an intellectual disability and communication needs](#), 2019; iv Education Wales, [Routes for Learning Guidance](#), 2020.

[H] Contact details to corroborate claim available on request.

[I] i Feedback from UNHCR workshops and evaluations; ii UNHCR case study of promising practice.

[J] i Van der Heijden, I and Dunkle, K, ‘What works evidence review: Preventing violence against women and girls with disabilities in lower- and middle-income countries (LMICs),’ September 2017; ii CDAC, ‘Collective communication and community engagement in humanitarian action: how to guide for leaders and responders’, CDAC Network, 2019; iii Invitation to join CDAC network expert panel; iv UNTV: ‘[People with communication disability speak up for inclusion and participation: How the implementation of the CRPD and the SDGs can support this right](#)’ (COSP12 Side Event) 00:31:00; v Written evidence submitted by the Royal College of Speech and Language Therapists (Domestic Abuse Bill - [DAB02](#)), June 2020.