

Institution: Manchester Metropolitan University
Unit of Assessment: A3 Allied Health Professions, Dentistry, Nursing and Pharmacy
Title of case study: The Impact of MMU Research on Transforming the Development of Services and Provision for Augmentative and Alternative Communication (AAC)
<p>1. Summary of the impact</p> <p>This case study describes significant health and wellbeing, and economic and social impacts deriving from a decade of MMU research into Augmentative and Alternative Communication (AAC). Impacts include the creation of www.aacknowledge.org.uk, the world's first AAC evidence base, an online source of evidence and information on AAC made accessible for lay people, families, people who use AAC service commissioners and providers, as well as other information and resources. A case study database has also been created which enables practitioners to improve the efficacy of AAC treatments. The database maintains detailed information on approaches to treatment that practitioners can interrogate. MMU research has also informed and influenced a wider political engagement with AAC issues leading to improved awareness and understanding of AAC as well as an increase of £6.5M funding for UK provision and services.</p>
<p>2. Underpinning research</p> <p>In 2004, MMU researchers Goldbart and Marshall co-authored a Cochrane Review [1] of research studies focused on communication interventions offered to children with cerebral palsy. This research review uncovered inconsistencies in the range of data gathered and interventions offered. A review of 20 studies revealed no common approach to data collection. Marshall, Goldbart and Pennington deduced that this inconsistency was counter-productive to the furtherance of the discipline in research terms and in 2007 they produced a paper in Disability and Rehabilitation [2] outlining a case study template and methodology for consistent data collection. The template was designed for traditional researchers, with the aim of generating academic rigour and credibility for the discipline. The case study template included data collection parameters specific to AAC and a methodology matched against the World Health Organisation International Classification of Functioning, Disability and Health framework (ICF, 2001).</p> <p>In 2009 Murray led a successfully funded £0.5M Big Lottery research grant alongside Sheffield University and Barnsley Hospital NHS Trust. The funding was awarded to Communication Matters, the UK-wide charitable organisation supporting developments in AAC chaired by Murray. The aims of the grant were (i) to map UK AAC service provision; (ii) to determine the prevalence of need for AAC in the UK, (iii) to produce an evidence based website, (iv) to develop a case study database and (v) to establish a research network. Murray led the latter three project elements.</p> <p>To address the third aspect of the award Murray, building on earlier work [3], chose an innovative research methodology involving all stakeholder groups in identifying what would make a robust evidence based website within the field of AAC. Participatory Action Research (PAR) facilitated the process of the researched becoming the researchers and informants. The field of AAC is eclectic and involves service users and their families as well as professionals from a range of disciplines, researchers and R&D representatives. The research process revealed a range of assumptions and misperceptions about what stakeholders need and want to inform their lives, their practice, their products and their research. This informed the structure, navigational elements and content of the final website design (www.AACknowledge.org.uk). This process of website development went through several iterations and modifications. The final product, in its initial evolution, was constrained purely by grant funding; the aim is for continuing development and growth of this resource in a manner that is responsive to its users and beneficiaries.</p> <p>To address the fourth and fifth aspects of the award Murray used Pennington, Marshall and Goldbart's work [2] as a starting point to explore the development of a single case study template, which would be user-friendly for practitioners, service users and general stakeholders as well as researchers, to create a common format for the collection of AAC research data. This innovative approach was designed to maximise the synergies between sometimes disparate AAC research data to ensure that all research and practice could make a valid contribution to the wider discipline. Murray ensured that the case study template was accessible by using plain language and by</p>

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reconfiguring the ICF codes. The case study template was appraised by practitioners, service users, R&D groups from industry, families and fellow academic researchers which led to several modifications including improvements to the language and data groupings and ultimately to the production of an electronic version of the template to make data collection and inputting a universal and accessible process [4, 5, 6]. Following the grant funded research period, the template and case study database is maintained and managed by Communication Matters; and operationalized by their Independent Research Panel, chaired by Murray. Since its launch in May 2013, a bank of 35 case studies has been established. This is both a new type of resource in AAC and world-leading in terms of data content and access. The accrued data may be accessed by anyone submitting an ethically approved research proposal exploring the experiences of people using AAC.

Key Researchers

Janice Murray. Appointed SL 9/9/1992; PL 9/01/2009

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

3. References to the research

[1] Pennington, L., Goldbart, J., Marshall, J. (2004) Speech and language therapy to improve the communication skills of children with cerebral palsy. In: The Cochrane Library Issue 2, Chichester: Wiley. doi: 10.1002/14651858.CD003466.pub2 (7 citations)

[2] Pennington, L., Marshall, J. and Goldbart, J. (2007) Describing participants in AAC research and their communicative environments: Guidelines for research and practice, Disability and Rehabilitation, 29, (7), 521 – 535 <http://www.ncbi.nlm.nih.gov/pubmed/17453973>

[3] Murray, J and Goldbart, J (2009) Cognitive and language acquisition in typical and aided language learning: a review of recent evidence from an aided communication perspective, Journal of Child Language, Teaching and Therapy, 25 (1), 31-58, doi: 10.1177/0265659008098660 (2 citations)

[4] Murray, J. and Goldbart, J. (2009). Augmentative and alternative communication: a review of current issues. Paediatrics and Child Health, 19(10), 464-468. doi:10.1016/j.paed.2009.05.003 (3 citations) *Invited paper designed to provide up-to-date expert knowledge for paediatricians and other doctors working in child health.*

[5] Murray, J., Martin, A., Pennington, L., Marshall, J., Enderby, P. & Goldbart, J (2013). A case study template to support experimental design in Augmentative and Alternative Communication and Assistive Technology. Disability & Rehabilitation: Assistive Technology. doi:10.3109/17483107.2013.851744

[6] Smith M. and Murray J. (2011). Parachute Without a Ripcord: The Skydive of Communication Interaction. Augmentative and Alternative Communication, 27(4), 292-303 doi:10.3109/07434618.2011.630022 (1 citation)

Quality Indicators

£0.5M Big Lottery Research Award (C1613A2033)

4. Details of the impact

Augmentative and Alternative Communication (AAC) is a method of communicating that supplements the ordinary methods of speech and handwriting where these are impaired. There are 316,000 people who are known to need AAC support in the UK (around 0.05% of the population) but there is widespread inequity of provision. Many people are missing out on specialist provision

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including the use of powered communication aids (source *Shining a Light on Augmentative and Alternative Communication*). MMU research has raised awareness of AAC nationally and internationally and researchers have contributed significantly to improving the evidence base, increasing funding, and enhancing service provision.

Impacts on the improving the evidence base in the UK and Internationally

MMU researcher Janice Murray was a key contributor to the Big Lottery funded *Communication-Matters Research Matters [A, B]* project which resulted in the development of two products: **the AAC Knowledge website** (<http://www.aacknowledge.com>) and **The AAC case study template and database**. The AACKnowledge website went live in December 2012 and had generated 5000 unique hits (by July 2013). The website was developed in response to research that found that the majority of those who work in the AAC field do not have access to scientific evidence or an academic knowledge base. The website was developed through comprehensive end-user engagement with researchers, practitioners, parents and families and commissioners and therefore had impact embedded into the project from its outset. ISAAC (The International Society for Augmentative and Alternative Communication) has officially recognised the website and promoted it internationally across its network of 50 countries. As a result, MMU researcher Murray is now Chair-elect of ISAAC's governing body (Chair from 2014-16) and helped them in turn to gain recognition within the UN as a specialist organisation awarded consultative status in complex communication needs and AAC. As the Chair of Communication Matters says, *"The AAC knowledge website is an innovative and ground breaking tool. This was a particularly timely piece of work in the light of changing political policy with regard to how AAC services will be delivered in the future. The importance of this work has been acknowledged by the international network (ISAAC) who has agreed the release of peer reviewed article submissions to be uploaded to the site"* [C].

As further acknowledgement of MMU's role in widening understanding and access to AAC research, Murray was invited to chair an independent AAC research panel to advise on national AAC research imperatives. MMU has been entrusted with maintaining the content on www.aacknowledge.com for the near future, recruiting a Research Associate, under Murray's supervision to manage this task.

Impact is being developed through the uptake of an AAC case study template and database that was funded as part of the research. The case study template provides an open access resource so that AAC professionals and practitioners can capture data and share approaches to different AAC challenges. Since launching in May 2013, a bank of 35 case studies has been established. These case studies are considered to be the foundation of a world leading resource in terms of data access and content as the data can be explored by anyone that submits an ethically approved research proposal around AAC issues. By August 2013 there had been 13 requests for information and 3 fully approved applications to access the data for live projects and 109 "hits" on the freely available case study template. The template had been used a further 33 times generating 31 elements of unique data. Although these numbers may seem small, this really does amount to significant progress in this research area. As the Manager of ACE Centre, a national AAC charity, says: [D] *"www.aacknowledge.com and the case study template are essential now and for the future in ensuring continued investment by the Government in AAC services and provision. These resources are the start of a necessary process to systematically capture a wide range of evidence on the impact of AAC on people who need this equipment and services and will be of significant benefit to service providers, commissioners and ultimately children and adults who need and use AAC"*

Communication Matters has its annual conference in September 2013 and is due to re-publicise these resources (typical attendance 400 delegates); it has also recently publicised the resources through its E-News which has a distribution list in excess of 3.5K. <http://www.raate.org.uk/uploaded/Gathering%20robust%20case%20study%20data.pdf> (copy link into browser)

Impacts on securing increased investment for AAC services and provision.

MMU research has had a major impact on recognition for AAC amongst UK policy makers leading to a significant additional total Government investment of £6.5M in AAC funding and services. In 2008 John Bercow, speaker of the House, published a “Review of services for children and young people (0-19 years) with speech, language and communication needs”. The report led to the appointment of a Communication Champion. MMU researcher Murray worked alongside the Government-appointed Communication Champion to map services and provision required for AAC in England and Wales. In March 2012, Murray led a joint delegation to a House of Lords reception that resulted in on-going discussions with politicians [E]. These discussions led to £2.5 million DfE grants for AAC services in England and Wales.

In 2012, the Scottish Government launched “A Right to Speak: Supporting Individuals who use Augmentative and Alternative Communication”. Murray’s advisory role to the Scottish Government informed the development of the report and ultimately resulted in the creation of a £4M pot for AAC provision in Scotland. [F]

5. Sources to corroborate the impact

[A] Final report: Communication Matters: Research Matters: An AAC evidence base, 2013 available at <http://www.communicationmatters.org.uk/shining-a-light-on-aac> corroborating impact of MMU researcher Janice Murray’s contribution to *Communication Matters Research Matters* project.

[B] Press release evidencing MMU’s role in the creation of www.aacknowledge.com available at: <http://www.communicationmatters.org.uk/news-item/2012-aacknowledge-website-launches>

[C] Written testimonial on file from Chair, Communication Matters, corroborating research impacts of <http://www.AACKnowledge.com> and the case study database on (AAC) services and provision.

[D] Written testimonial on file from Director, The ACE Centre, a national charity supporting AAC provision on the impact of MMU research on raising the profile and securing Government investment in AAC research.

[E] Link to web story “Janice takes fight to Parliament” (March 2012) corroborating impact of MMU research on political awareness raising and policy forming around AAC provision. <http://www.staff.mmu.ac.uk/manmetlife/news/view/janice-takes-health-fight-to-parliament>

[F] Testimonial on file from Educational Project Manager AAC, NHS Education for Scotland corroborating research impacts on AAC approach of the Scottish Government and wider impacts of research on AAC community.