

Institution: Manchester Metropolitan University

Unit of Assessment: A3 Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Improving services and outcomes for children who use augmentative and alternative communication (AAC) technologies

Period when the underpinning research was undertaken: 2004 - 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:
Janice Murray Juliet Goldbart Yvonne Lynch Helen Whittle	Professor Professor Senior Research Fellow Senior Lecturer Research Assistant	1992-present 1980-present 2016-2019 2011-2015 2017-2020

Period when the claimed impact occurred: 1 Aug 2013 - 31 December 2020 Is this case study continued from a case study submitted in 2014? No

1. Summary of the impact

Pioneering research into the recommendation and use of augmentative and alternative communication (AAC) technologies has underpinned significant changes in policy and clinical practice worldwide. Professor Janice Murray's research ensured assistive technology is a key priority in the DFE's EdTEch strategy and was a catalyst for the development of a Greater Manchester-wide AAC commissioning policy. The delivery of a GBP15,000,000 care pathway in England continues to benefit the 38,000 people in the UK with the most severe AAC needs, with year-on-year increases in appointments. Providers across the world use the model developed through her I-ASC project and other tools to review and deliver AAC services. Her research also forms the basis of training for thousands of speech and language therapists worldwide and informs decisions on AAC research, education and service provision in at least 43 countries.

2. Underpinning research

Murray has been at the forefront of research in the field of **Augmentative and Alternative Communication (AAC)** for over 25 years. Substituting for unintelligible speech, this set of tools enables a person to demonstrate their cognitive and linguistic capacity when natural speech is inefficient. Murray's approach is characterized by a commitment to embedding all stakeholders in the full research process and making a difference to the lives of those who use AAC.

In 2009, Communication Matters (the UK-wide AAC charity, which Murray then chaired), Manchester Metropolitan University, Sheffield University and Barnsley Hospital NHS Trust won a successful GBP467,751 Big Lottery grant for **Research Matters: an AAC Evidence Base** to gather fundamental information about the need for, and provision of, AAC. Building on earlier work (REF2014), Murray led the strands that focused on producing an evidence-based website and a case study database, and establishing a research network. She chose an inclusive Participatory Action Research (PAR) methodology, involving all stakeholder groups in the development of the website specification. This revealed a range of assumptions and misperceptions about what stakeholders need and want to inform their lives, their practice, their products and their research.

Previous research by colleagues Pennington, Marshall and Goldbart had outlined a case study template to support traditional researchers' consistent data collection, which included AAC-specific parameters and a methodology matched against the World Health Organisation International Classification of Functioning, Disability and Health framework (ICF, 2001). Murray used this as a starting point to develop a case study template with an accessible format for the collection of AAC research data. The universal template was appraised by practitioners, service users, industrial R&D groups, families and fellow academic researchers, leading to modifications including improvements to the language and data groupings, and ultimately to the production of an electronic version of the template as well as an **AAC Knowledge** website [1]. This was a new type of AAC resource and a world-leading model in terms of data content and access.

In 2010, Surveillance Cerebral Palsy Europe (SCPE) commissioned Murray, Lindsay Pennington, Tone Mjøen and Maria da Graça Andrada to produce a two-page speech scale to support paediatricians to rate the degree to which children with cerebral palsy are understandable to strangers and unfamiliar conversation partners. They found inter-rater reliability for the tool - the **Viking Speech Scale** - was moderate to substantial (k > .58 for all comparisons), test–retest



reliability was substantial to almost perfect for all groups (k > .68) and over 74% of raters found the scale easy or very easy to use, leading to its roll-out [2].

As the UK lead on **Becoming an Aided Communicator** (BAC): Aided Language Skills in Children and Adolescents aged 5–15 years (2011-19), Murray's research addressed the role that the language skills of children and young people play in AAC proficiency [3]. Whilst cohort homogeneity normally constrains quantitative research opportunities for AAC-related research, this 16-country collaboration was able to describe both quantitatively and qualitatively 100 children and young people who used AAC, offering the equivalent of a language acquisition trajectory through aided communication means.

Highlighting how language development was being ignored, and addressing public involvement (PI), this research informed the NIHR-funded award **Identifying Appropriate Symbol Communication aids for children who are non-speaking: enhancing clinical decision-making (I-ASC)** (2016-19), which attracted unprecedented funding for the field (GBP909, 931). Led by Murray, in collaboration with the University of Leeds and Barnsley Assistive Technology Service, I-ASC explored the clinical decision process related to AAC assessment and recommendations. It centred on developing new resources to support professionals in health, education and social care, as well as families and other key partners in the decision-making process for those who need AAC. It also aimed to improve the long-term health and well-being outcomes for children and young people who need to use symbolic communication aids as a substitute for speech through voice output technologies [4].

I-ASC's mixed methods approach included entirely novel quantitative research methodologies applied within the field of AAC research. The findings revealed a lack of explicitness in decisions and communication aid recommendations, and an alarming number of instances where decisions were based on incomplete pre-recommendation profiles and diagnostic assessment information. The research identified four key issues that contribute to inappropriate recommendation and potential abandonment of systems, resulting in many users failing to meet their academic potential. It also qualified and quantified the factors that best inform AAC decisions and recommendations [5]. Building on previous exemplary participatory action research (REF2014), I-ASC challenged the current gold standard model for PI. The team embedded PI throughout the lifecycle of the study from initial development of the bid, through data collection, analysis, synthesis and dissemination. In recognition of this innovation, the NIHR granted the team an extension to evaluate the co-production aspects of this unique study.

In parallel to I-ASC, The Communication Trust invited Murray to conduct a review of research-informed evidence of **literacy intervention practices** that support children who used AAC (GBP6,500) to help them to understand the reasons for inadequate literacy levels in AAC users **[6]**. Whilst many AAC users may aspire to use a text-based communication solution, literacy levels in this group are considerably below those expected for their cognitive abilities. Her findings identified three key areas ripe for further research: (i) identifying appropriate training content and support for educators, (ii) exploring the dosage of intervention support for different aspects of literacy education and how they relate to individual learning needs and (iii) developing descriptions of the characteristics of children who use AAC and their particular literacy needs.

3. References to the research

Note: Citations, Web of Science (citations versus expected citations) – Jan 2021

- 1. **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
- 2. Pennington, L, Virella, D, Mjøen T, da Graça Andrada M, **Murray** J *et al.* (2013). Development of The Viking Speech Scale to classify the speech of children with cerebral palsy, Research in Developmental Disabilities, 34(10) 3202-10. DOI: 10.1016/j.ridd.2013.06.035 *Citations: 56* (*expected 17.85*).
- 3. **Murray**, J, Sandberg, A, Smith, M, Deliberato, D, Stadskleiv, K and von Tetzchner, S (2018). Communicating the unknown: descriptions of pictured scenes and events presented on video by children and adolescents using aided communication and their peers using natural speech, Augmentative and Alternative Communication, 34(1), 1-10. DOI: 10.1080/07434618.2017.1420690.



- 4. **Murray**, J, **Lynch**, Y, **Goldbart**, J, Moulam, L, Judge, S, Webb, E, Jayes, M, Meredith, S, **Whittle**, H, Randall, N, Meads, D and Hess, S. The decision-making process in recommending electronic communication aids for children and young people who are non-speaking: the I-ASC mixed-methods study. Health Serv. Del. Res., 2020, 8(45). DOI:10.3310/hsdr08450
 5. Webb, EJD, Meads, D, **Lynch**, Y, Randall, N, Judge, S, Meredith, S, Moulam, L, Hess, S and **Murray**, J. (2019). What's important in AAC decision making for children? Evidence from a best–worst scaling survey, Augmentative and Alternative Communication, 35(2) 80-94. DOI: 10.1080/07434618.2018.1561750 *Citations: 3 (expected 2.89)*.
- 6. **Murray**, J. and **Goldbart**, J. (2011). Emergence of working memory in children using aided communication, Journal of Assistive Technologies, 5, 213–232. DOI: 10.1108/17549451111190623 *Citations: 13 (expected 6.33).*

Key funding:

- G1. Murray, J. /Communications Trust (PI). Research Matters: an AAC Evidence Base, Big Lottery, 2010-2013, GBP467,751 (C1613A2033).
- G2. Murray, J. (PI), Identifying Appropriate Symbol Communication aids for children who are non-speaking: enhancing clinical decision-making (I-ASC), NIHR: HSDR (2016-19), GBP909,931, 2016-19 (14/70/153), inc. PI evaluation extension, GBP85,000, 2019.
- G3. Murray, J. (UK PI) Becoming an Aided Communicator (BAC): Aided Language Skills in Children and Adolescents aged 5–15 years, Manchester Metropolitan University, Communication Matters and RCSLT, GBP45, 000, 2011-2019.
- G4. Murray, J. (Lead), ACE Centre, Innovate UK KTP, GBP212,000, 2017-20 (ID:10801).

4. Details of the impact

Approximately 338,000 people in the UK (0.5% of the population) need assistance from AAC tools. Decisions about who receives these tools, which tools they are allocated and how they are supported can have major impacts on their quality of life. Murray's research has significantly improved the evidence base for AAC, raising awareness and leading to increased funding and enhanced service provision for the 10% of AAC users with the most complex access and communication needs. Over the past five years, her work has addressed the lack of appropriate services for the remaining 90%. Equipping decision-makers with insights into need and provision, this has benefitted AAC users and those who work with, and care for them.

Policy: Murray was a founder member of the advisory group for the All Party Parliamentary Group (APPG) for Assistive Technology (2016). Her research insights helped to determine its remit. She also works with the think tank 'Policy Connect' (the APPG secretariat) to shape the annual programme. The APPG adopted schools as one of its three key areas of focus because Murray identified an opportunity to improve the provision of assistive technology (AT) in schools by providing the Department for Education (DfE) with stronger evidence and expertise. Policy Connect also used a briefing (2017) based on Murray's AAC and literacy research to garner the interest of the DfE's new EdTech Team when they were developing the 2019 EdTech Strategy. They have worked with the APPG closely since, feeding in I-ASC findings. Murray was 'critical in establishing this relationship' and ensuring the strategy addressed AT [A].

The final Edtech strategy listed 'Teaching practices: supporting access, inclusion, and improved educational outcomes for all' as one of its five priorities. It had two case studies on the use of AT, including a feature on AAC, and funded nine EdTech Challenges, including 6: Challenge the research community to "identify the best technology that is proven to help level the playing field for learners with special educational needs and disabilities." The DfE also established a stakeholder group of AT practitioners, and invited schools and colleges to apply for funding to develop 'Assistive Technology demonstrator' school status. They distributed GBP300,000 for 'trials of ground-breaking assistive technology for pupils with special educational needs and disabilities' to approximately 100 institutions. The case study template [2] was included in the associated research stakeholder report "to provide administrators with insights about the use of AT in educational settings in order to facilitate the effective delivery of AT devices and services."[B] Public services: As Chair of Communication Matters (2009-14), Murray worked alongside a Government-appointed Communication Champion and other experts to map the services and provision required for AAC, drawing on findings from Research Matters. This resulted in GBP2,500,000 of DfE grants for AAC services in England and Wales and a GBP15,000,000 care pathway in England for those with AAC needs. Leading to the establishment of specialist hubs, it made services less fractured, with people being seen more quickly as a result thereof. For



example, since 2015, over 1,145 people have accessed services through Ace Centre hubs alone (covering 1/5 of the population of England) with year-on-year increases in appointments highlighting the level of previously unfulfilled demand. Responding to raised awareness of AAC, the hubs are also training others dealing with those with less complex needs [C].

In 2017, Ace Centre approached Murray to lead a Knowledge Transfer Partnership (KTP) to help it to diversify its income streams. The KTP Associate developed a series of data visualisation dashboards that help the Ace Centre to understand referral rates and equipment costs and to report to the NHS. It has enabled the charity to demonstrate the positive impacts of the service and its value for money. It has also saved staff time and "supported Ace Centre's bids for more contracts and diversified activities that will expand the Charity's reach and meet the needs of more AAC users." [D]. For example, they are now realising 30%-40% recycling of equipment due to the Centre's role as a hub, and better understanding of the data with "cost efficiency savings of over 33% of the NHSE specialised AAC equipment budget" (approx. GBP2,000,000 over five years) [C].

In 2019, the Lead Health Commissioner for Greater Manchester Combined Authority (GMCA) issued a call for action after attending an I-ASC findings workshop that highlighted the variance in provision for children and young adults who do not meet specialised AAC service criteria. She asked Murray and the Ace Centre to lead a review and appraisal of local provision in order to agree standardised eligibility across Greater Manchester in the future. This resulted in the launch of an authority-wide Non-Specialist AAC aids policy (2020) to "ensure equity, consistency and clarity in the commissioning of non-specialist AAC Aids." The changes benefit the 90% of residents with AAC needs that existing services do not address [E].

Professional practice: Murray was appointed a Fellow of the Royal College of Speech and Language Therapists (RCSLT) in 2016 for her translational research in the field. In 2019, they invited her to lead the national review and development of AAC clinical guidelines for its 17,000 members, "ensuring best practice among the profession in the field of AAC, and ultimately best outcomes for service-users." The same year, she received the National AAC Award for research, in recognition of her work to further the evidence base around AAC. I-ASC was highly commended in the same category and the nominator proposed, "The work in decision making in AAC, through the NIHR funded project I-ASC, is probably the most innovative in the history of the field." In her roles on the Research Committee for the International Society for Augmentative and Alternative Communication (ISAAC) (2012-present, Chair of Council 2014-16) and the International Association of Communication Sciences and Disorders (IALP, AAC Committee Chair) her insights also inform decisions on AAC research, education, service provision and funding in over 43 countries [F].

More than 177,000 users in 164 countries accessed the case studies and templates from the AAC knowledge website [1] between 2013 and 2019, with over 15,000 return visitors. Used by professionals, parents and AAC users, these tools "improve the efficacy of AAC implementation and upskill less experienced clinicians". 59% of the 1,992 I-ASC website visits (55 countries, 2016-2020) also centred on the decision-making resources, which enhance communication aid recommendations and provide accessible information. Better-informed recommendations improve the academic and employment prospects of AAC users. Allocating the correct piece of assistive technology also has a value of approximately GBP500,000 per person over their lifespan, to the UK economy. Additionally, the Viking Speech Scale, now used in cerebral palsy surveillance registers throughout Europe, provides "an easy to use measure to characterize speech ability for professionals who are not trained as speech language pathologists." [G, H].

Murray's research is integral to training for many speech and language therapists, improving their capacity to recognise AAC needs and make informed decisions in practice settings. Her research and resources are embedded in undergraduate and postgraduate courses at institutions including Manchester Metropolitan University, Leeds Beckett, Trinity College Dublin, the University of Oslo and the University of South-Eastern Norway, and I-ASC is 'a foundation' of many of the Masters modules at The University of Pretoria. Between 2017 and 2019, she led an accredited PGCert in AAC, delivering training to 72 professionals who each manage between 20-90 AAC assessments per year. Graduates have embedded her resources and learning into their practice, leading to research-informed service improvements across the UK. For example, the AAC Lead for Gloucestershire reports "better outcomes for children and young people who use AAC" as seen in therapeutic outcome measures (TOMs) data. Communication Help through Assistive

Impact case study (REF3)



Technology (CHAT), a new AAC service that spans NHS Glasgow and Clyde, also used I-ASC materials and an outcome measures tool that Murray co-developed as Chair of Communication Matters to structure its provision and make decisions. **[H].**

Since August 2013, Murray has delivered 29 evidence-based study days and seminars to 2,180 professionals worldwide. In 2016, the Scottish Government funded her to develop an online package with National Health Education Scotland (NES), supporting AAC assessments and ensuring equity of service nationwide. Accessed by 4,295 users in 61 countries, its reach has surpassed this initial remit. The national AAC service in Scotland, Communication, Access, Literacy and Learning (CALL Scotland) has used the NES package, AAC Knowledge website and I-ASC materials across the professional learning and INSET training it has delivered to 4,251 professionals since 2014. It also used them in online modules accessed by 13,024 users (2018-2020) and wider activities, engaging AAC users, parents, carers and families. I-ASC highlighted the importance of the team around the child, and CALL's use of these resources with all stakeholder groups underlines their usability and value in this area [H, I].

Public involvement: The I-ASC Patient Involvement (PI) report provided critical insights into the demands of PI and the impact that involving vulnerable and marginalised people as coresearchers can have on a project. The NIHR highlighted I-ASC twice in its recent review of 'studies with important findings for those who commission, deliver, work in and use health and care services for people with learning disabilities' remarking that it was: "ground-breaking in the way that it has involved children with severe communication difficulties in co-producing the research." [J]. Murray's PI expertise changed the RCSLT's approach to consultation on its AAC clinical guidelines. Initially, the team only aimed to gather feedback from service users on public-facing information. However, under her leadership, they "invited service users to be involved in developing all areas of content (including member-only information) from the initial scoping stage of the project." The RCSLT Strategic Plan 2018- 21 includes a focus on service users: and "Professor Murray's knowledge and research in this area will help to ensure that the updated RCSLT AAC guidance is reflective of the RCSLT's vision." [F]

5. Sources to corroborate the impact

- **[A]** i Testimonial, Head of Health and Accessibility Policy, Policy Connect; ii APPG for Assistive Technology, Briefing: Communication and literacy, 13 December 2017.
- **[B]** i Department for Education, 'Realising the potential of technology in education: A strategy for education providers and the technology industry,' 2019; ii Department for Education, 'High-tech products to level the playing field for disabled pupils,' 22 January, 2020; iii Dave L Edyburn, 'Assistive Technology Stakeholder report: Researchers,' August 2020.
- **[C]** i Ace Centre year on year data, 2015-2020; ii Greater Manchester CCG, <u>Paper-2.7-GM-EUR-communication-aids</u>, 2020, 15-18.
- [D] i Ace Centre 'Our Ace Year in Numbers' 2019; ii Knowledge Transfer Network (2020), 'Project informs approach to improve treatment pathways, therapeutic outcomes and patient experience.'
- [E] i Workshop: <u>Greater Manchester-wide Criteria for Augmentative and Alternative</u>
 <u>Communication (AAC) Provision</u>, 3 July 2019; ii <u>Greater Manchester EUR Policy Statement on</u>
 Non-Specialist AAC Aids, 13 November 2020.
- **[F]** i Testimonial, Professional Guidance Manager, RCSLT; ii AAC Award nomination.
- **[G]** i Testimonial, Chair, Communication Matters; ii AAC Knowledge website analytics (Aug 2013-Dec 2019); iii IASC website analytics (2016-2020), iv Office of the Communication Champion, 'Specialised AAC provision. Commissioning national services,' 2011.
- **[H]** i Testimonials, PGCert students; ii Testimonials, Leeds Beckett, Trinity College Dublin, The University of Edinburgh, The University of Pretoria, The University of South-Eastern Norway and The University of Oslo.
- [I] i Details of training led by Murray; ii AAC module analytics; iii Statement, former Director, Scottish Centre of Technology for the Communication Impaired (SCTCI).
- [J] NIHR Dissemination Centre, '<u>Themed Review: Better health and care for all. Health and care services for people with learning disabilities.</u>'