Communication Matters – Research Matters: an AAC Evidence Base

The AAC Evidence Base research project is a three-year project funded by the National Lottery through Big Lottery Fund. It is led by Communication Matters, the UK charity for people of all ages and ability who need to use Augmentative and Alternative Communication (AAC). Communication Matters is working with three research partners: the University of Sheffield, Barnsley Hospital NHS Foundation Trust and Manchester Metropolitan University. The research work started on 14 June 2010.

Project Context

Communication is a fundamental human right enshrined in the UN Universal Declaration of Human Rights and the UK Human Rights Act. It is an essential life skill, central to social interaction and vital for development. Without the right resources and support, people with communication difficulties face social isolation, a decreased quality of life and increased care costs.

People of all ages with severe communication impairments use AAC methods. These include signing, use of symbols and voice output devices. The UN Convention on the Rights of Persons with Disabilities recognises AAC as a method of communication and includes an obligation to promote the availability and use of new technologies including AAC. It has been ratified by the UK but despite this many people with communication difficulties still struggle to get the services and support that they need in order to communicate and participate more fully in society.

No definitive data set exists that establishes how many people might benefit from AAC in the UK. Best estimates available are based on Blackstone's (1990) USA study suggesting approximately 0.4% of the population need AAC. More recent work (Scope, 2008) suggests 0.4 to 1% of the UK population would benefit. The AAC community commonly cites 0.6% (365,000 individuals).

Funding for AAC is devolved to local commissioners but there is no statutory right to assessment, equipment or ongoing support. As there is no robust evidence regarding need and effective service provision, it is difficult for commissioners to decide how best to allocate limited resources to AAC. The result is a postcode lottery in provision of crucial services. Information about best practice such as early intervention remains inaccessible in specialist databases, professional journals or unpublished. Professionals acknowledge that there is a real lack of experience in the field of AAC with many

simply being unaware of what might be available for their clients. Families and individuals are consequently denied this information.

The need for this research was identified by Communication Matters members via a number of action research methodologies: an on-line survey (438 respondents, January 2008) prioritised the work of the organisation making clear that to raise awareness of need and influence service provision robust evidence was essential. Beneficiary workshops supported this. Researcher workshops demonstrated widespread support for a beneficiary led approach to research. Researchers and potential participants asked for a centrally managed participant database to avoid overexposure of some groups.

This groundbreaking project will provide fundamental information about the need for, and provision of, AAC which can be used to improve services across the UK. It will provide access to current knowledge in an online AAC Evidence Base which will present information in a variety of accessible formats. Communication Matters will establish a Research Involvement Network that will promote the involvement of people who use AAC in research.

Project Objectives

- To improve the quality of life of people with severe communication impairments who need AAC in the UK by raising awareness of their needs and by improving service provision.

- To provide access to information and current knowledge about AAC to a wide audience, including people who use AAC and their families, through the online AAC Evidence Base.

- To promote the involvement of people who use or need AAC in research projects.

- To develop Communication Matters' capacity to influence the research agenda in the field of AAC and to develop and lead further research projects.

Project Structure & Governance

The AAC Evidence Base research project is a three-year project funded by the National Lottery through Big Lottery Fund. A grant of £467,751 was awarded to Communication Matters in December 2009. Communication Matters is leading the project and working with three research partners: the University of Sheffield, Barnsley Hospital NHS Foundation Trust and Manchester Metropolitan University. The research work started on 14 June 2010.

As the grant holder, Communication Matters is responsible for ensuring the project meets its objectives and delivers its outcomes, and managing the partners' contribution to these; and for reporting to the Big Lottery Fund. Communication Matters has appointed a Research Manager (3 days a week) who is responsible for the

day to day management of the project. It has also appointed a Research Lead (1 day per month) who is responsible for providing advice on governance issues to the Board of Trustees and dissemination. In the third year of the project an administrator will be employed to maintain the AAC Evidence Base.

Communication Matters has set up an Independent Research Panel. The panel is made up of representatives from across the AAC community, including a person who uses AAC, a family member, a professional carer, a commissioner of services, a supplier and researchers. The role of the Independent Research Panel includes providing advice and guidance on current and proposed research projects. The Panel meets twice a year and provides independent oversight of the research project.

Research Questions
The research questions are:

- How many people are using AAC?

- What are the routes to provision of AAC?

- What type of information is required in the evidence database and in what formats should information be available to support wide access?

The **University of Sheffield** and **Barnsley Hospital** will use a range of quantitative and qualitative methods to investigate the need for AAC and to map current service provision. The Principal Investigators are Professor Pam Enderby at the School of Health & Related Research (ScHARR), University of Sheffield; and Simon Judge from Assistive Technology Services at Barnsley NHS Trust. Simon Judge is an honorary researcher at ScHARR.

The University of Sheffield has recruited two research assistants who will conduct the quantitative and qualitative research over two years starting December 2010. Systematic reviewers and a data modelling consultant will also work on the project.

Manchester Metropolitan University will develop the online AAC Evidence Base. The Principal Investigator is Dr Janice Murray at the Research Institute for Health & Social Change. A research assistant has been appointed and there is also a part-time co-researcher who is a person who uses AAC.

In addition Communication Matters will develop the Research Involvement Network. This will link researchers with people who are willing to take part in research into AAC, either as participants or advisers.

The research findings will be widely disseminated and targeted information will be delivered to decision makers in national and local government; commissioners of services and professionals.

www.communicationmatters.org.uk/research

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