



NEWS RELEASE

Communication Matters – Lottery funds for essential research

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Communication Matters¹, a UK wide charity which supports people with complex speech, language and communication needs, is delighted to have been awarded a research grant of £467,751 by the BIG Lottery² to fund a groundbreaking project. The project focuses on establishing better understanding of the need for and current practice in the provision of augmentative and alternative communication (AAC)³ throughout the UK, and improving accessibility to best practice evidence. Communication Matters will work collaboratively with Manchester Metropolitan University⁴, Sheffield University⁵ and Barnsley Hospital⁶ to deliver this exciting project over 3 years.

People of all ages, throughout the UK, with severe communication impairments currently face social isolation, mental health issues, a decreased quality of life and increased care costs. However, with the provision of AAC, which includes training for signing, the use of symbols and electronic voice output devices, this group can participate fully in family and community life. Crucially to date, key decision makers in local and national government have lacked evidence of level of need for AAC and best practice in service provision in order to plan for and manage resources effectively.

Current estimates suggest 365,000 people⁷ in the UK may need essential AAC resources but there is no definitive research assessing actual need. Equally, information about best practice, including early intervention, remains inaccessible in specialist databases, professional journals or unpublished. Even since ratification of The United Nations Convention of the Rights of Disabled People⁸, which refers to AAC, funding remains with local commissioners and no statutory right exists for assessment, provision of resources or ongoing support. The result is a postcode lottery in provision of crucial services.

Communication Matters is the UK Chapter of ISAAC⁹, the International Society for Augmentative and Alternative Communication, which is an NGO in Special Consultative Status with the Economic and Social Council of the United Nations. Dr Michael Clarke, Trustee of ISAAC (UK), said: "I am delighted that the significance of this essential research has been recognised with a grant



from the Big Lottery. This gives Communication Matters an important platform to focus on supporting the delivery of crucial services for the benefit of all people who need augmentative and alternative communication, as well as building capacity to develop our research expertise for the future.”

Professor Pam Enderby of Sheffield University, who will work closely with Barnsley Hospital Trust added: “There is an element of luck as to whether or not a person is provided with a communication aid as it is dependent upon where they live rather than what their needs are. This does not happen with other equipment provision - for example it is accepted that if you cannot walk you are provided with a wheelchair. By establishing how many people actually need AAC and how each area currently provides these vital services we hope to provide crucial evidence that will lead to the eradication of the current post-code lottery of provision in the UK.”

Dr Janice Murray, Research Lead at Manchester Metropolitan University added: “We are honoured to have been given the opportunity to research and develop a searchable on-line database that will be a first in this field, providing critical evidence on the benefits of early identification and intervention.”

The pioneering three year project is the result of widespread consultation with beneficiaries, their families and practitioners who have engaged in planning the project and will continue to be consulted throughout the its life. Toby Hewson, a Trustee of Communication Matters and CEO of Just Different, commented that: “Without AAC I would be unable to run my business which employs 9 people, this research is just what is needed to establish robust evidence which will facilitate all people with severe communication impairments of all ages, wherever they live to have a voice. It will contribute to them participating in family and community life, fulfil their potential and reduce their risk of mental illness and social isolation.”

The Big Lottery Fund distributes half of the National Lottery good cause funding across the UK. The Fund is committed to bringing real improvements to communities and the lives of people most in need.

Further information is available by visiting the Communication Matters website

<http://www.communicationmatters.org.uk/> or emailing research@communicationmatters.org.uk



Background Information

- 1 Communication Matters <http://www.communicationmatters.org.uk/>
- 2 BIG Lottery Research Programme
<https://www.bigresearchprogramme.org.uk/content.php?key=home>
- 3 Augmentative and Alternative Communication (AAC): see Appendix 1
- 4 Manchester Metropolitan University <http://www.rihsc.mmu.ac.uk/>
- 5 Sheffield University <http://www.shef.ac.uk/scharr/>
- 6 Barnsley Hospital <http://www.barnsleyhospital.nhs.uk/>
- 7 Estimated UK population needing AAC: see Appendix 1
- 8 United Nations Convention on Rights of Disabled Persons
<http://www.un.org/disabilities/default.asp?navid=12&pid=150>
- 9 ISAAC: International Society for Augmentative and Alternative Communication
<http://www.isaac-online.org/en/home.shtml>

Appendix 1

Augmentative and Alternative Communication (AAC) are the words used to describe extra ways of helping people who find it hard to communicate by speech or writing. AAC helps them to communicate more easily.

AAC includes many different methods. Signing and gesture do not need any extra bits and pieces and are called unaided systems. Others use picture charts, books and special computers. These are called aided systems. AAC can help people understand what is said to them as well as being able to say and write what they want.

Around 0.6% of the population¹⁰, over 350,000 people¹¹, in the UK would benefit from AAC including those with congenital and developmental conditions such as cerebral palsy, autism, ADHD, Dyslexia, Learning Difficulties, Learning Disabilities and those with acquired conditions including Stroke, Acquired Brain Injury, Motor Neurone Disease, Multiple Sclerosis, Muscular Dystrophy.

Communication Matters is the UK Chapter of the International Society of Augmentative and Alternative Communication (ISAAC). ISAAC is a special advisor to the United Nations and was instrumental in getting Augmentative and Alternative Communication (AAC) included in the UN Convention on the Rights of Disabled Persons

As the only organisation in the UK which focuses solely on AAC for **all people**, we have within the membership many experienced, skilled and internationally renowned professionals who work in the field of AAC including practitioners, researchers, manufacturers and distributors of resources and equipment as well other third sector organisations. Central to the membership are people who use AAC and their families.



www.communicationmatters.org.uk

0845 456 8211

References:

- 10 Blackstone, S. (1990) 'Population and Practices in AAC' Augmentative Communication News 3 (4)
11 <http://www.statistics.gov.uk/> (2001 Census)