



Press release - Embargoed for release on 22.04.2013

THOUSANDS MISSING OUT ON RIGHT TO VOICE

Communication Matters – the lead UK wide charity which works for and brings together everybody who has an interest in Augmentative and Alternative Communication (AAC) - calls for improvements in funding for provision of AAC services and devices

23,000 people across the UK may be living without access to a powered communication aid that would enable them to have a voice, and help them to reach their potential, according to new research *Shining a Light on Augmentative and Alternative Communication* released today (22.04.2013) by Communication Matters.

Nearly a third of a million people across the UK (316,000¹) are benefiting or may benefit from AAC support, according to the report – the culmination of a three year AAC Evidence Base research project. Of these 31,600² people could be using powered communication aids yet the research suggests only around 9,000 are currently.

The new findings, which exposes the great variation in service provision across the UK, stem from research carried out by the University of Sheffield. The research highlights there is little consistency in identifying, assessing and providing AAC systems and many local areas are failing to make effective provision.

The report also found that:

- New technologies have emerged, and continue to rapidly develop, bringing more and more opportunities to support those who have difficulty communicating
- Service commissioning and funding arrangements are often inconsistent and sometimes dependent upon in-year savings from other budgets, making it difficult for services to plan strategically and to ensure maintenance and replacement of communication aids are built into continuing care plans
- The time taken to seek funding to support these services has a negative impact on provision--- and absorbs a considerable amount of professional time
- Although the majority of people who use AAC and their families and carers expressed frustration with all or some part of the AAC service they received, many were satisfied with AAC services-- demonstrating it is possible to provide a good service
- There is little consistency in service provision across the UK with few services that meet the ideal classification of a specialised service with the interdisciplinary skills and resources to meet the most complex AAC needs

¹ Research report estimates just over 0.5% of the population could benefit from some type of AAC. This equates to 529 people per hundred thousand population

² Research estimates approx. 0.05% of the UK population could benefit from powered communication aids yet average known use 0.014% of population suggesting fewer than half of those who could benefit from powered aided communication have access to it. This is likely to be a low estimate given rapid advances in technology and changing demography

- Less than 5% of the 92 AAC services surveyed reported joint service funding arrangements.
Joint commissioning is viewed as vitally important to improve the integration of services across health, education and care settings, and avoid disputes over responsibility for funding³
- A large unmet need for AAC support and communication aids exists for people with Alzheimer's / Dementia and Parkinson's making up nearly half the total (45.9%) of people who could benefit from using AAC.
- People with cerebral palsy make up the largest single group of people who currently use powered communication aids (32% of users)

The report also describes research undertaken by Manchester Metropolitan University, which included the development of a template for gathering case study data to advance knowledge in the field of AAC. In addition, Manchester Metropolitan University worked with Communication Matters to create a new AACknowledge website www.AACknowledge.org.uk. This first of its kind website worldwide empowers AAC users, parents, carers and professionals to improve support and services for people with speech difficulties.

Katie Holmes, Research Manager for Communication Matters, says: "This research report is a wake up call; it highlights growing need for AAC in the UK yet what is lagging behind is commissioning of services, funding arrangements and specialist expertise. It has confirmed what we knew anecdotally: that there is a postcode lottery of support and provision for both children and adults who use AAC, with a particular dearth around support for adults.

"For those who use AAC, and their families, the biggest issue is the constant barriers they face around securing funding for much needed services and equipment. With advancing technology developments, professionals working with people who use AAC need continual specialist training and support. Too much of their time is currently spent battling for funding when it could be better used to support individuals and increase skills and confidence in the AAC field."

Cathy Harris, Chair of Communication Matters, says: "This research paints a concerning picture for children and adults who need AAC and their families. It shines a light on the real picture around AAC needs and the lack of provision available. Too often individuals are left without access to AAC systems and services. It is unacceptable that there is no consistent approach to ensure that every potential communication aid user has a voice.

"It is a human right to be empowered to communicate. If you are unable to walk, it is natural to expect access to a wheelchair so why are those who cannot talk denied access to a communication aid? Without AAC life for those with speech difficulties can be lonely, difficult and isolating. This is all compounded by the low levels of public recognition that exists in the UK.

"Communication Matters are calling for improvements in funding and provision of AAC devices alongside greater public awareness. We are working closely with the Department for Education, NHS England and our strategic partners in Wales, Scotland and Northern Ireland to influence the future commissioning of specialised AAC services in the UK."

³ Two Years On: final report of the Communication Champion for children, Jean Gross, December 2011
http://www.thecommunicationtrust.org.uk/media/9683/nwm_final_jean_gross_two_years_on_report.pdf



AAC covers a huge range of techniques which support or replace spoken communication. These include gesture, signing, symbols, communication boards and books, as well as powered and computerised devices such as voice output communication aids (VOCA's).

The research was led by Communication Matters in partnership with the University of Sheffield, in collaboration with an honorary researcher from Barnsley Hospital NHS Foundation Trust, and Manchester Metropolitan University. It was funded by the National Lottery through Big Lottery Fund.

To download the *Shining a Light on Augmentative and Alternative Communication* report, visit <http://www.communicationmatters.org.uk/shining-a-light-on-aac>

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For more information

For more information, to arrange a interview with representatives from Communication Matters / University of Sheffield / Manchester Metropolitan University or to discuss case studies, please contact Laura Smith at Consilium Communications on 07766 651366 / lsmith@consiliumcommunications.co.uk or Della Bolat on 07841 763833 / dbolat@consiliumcommunications.co.uk

Notes to editors

About the *Shining a Light on Augmentative and Alternative Communication* report

- The *Shining a Light on Augmentative and Alternative Communication* report is the culmination of research compiled through the AAC Evidence Base research project. It was funded by the National Lottery through Big Lottery Fund.
- 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.
- As part of the AAC Evidence Base research project, the University of Sheffield in collaboration with Barnsley Hospital undertook research to provide for the first time a picture of current AAC service provision in the UK and the number of people that could benefit from AAC
- This work resulted in the development of a research generated framework of components that make up an AAC service, including the provision of powered aided communication, developed with those affected by AAC, their families and the professionals who work with them.
- Manchester Metropolitan University were commissioned to advance knowledge in the field of AAC by creating a case study template for gathering data and evidence of best practice. This data will be made available to researchers who request it from Communication Matters.
- Manchester Metropolitan University also worked with Communication Matters to develop a groundbreaking website www.aacknowledge.org.uk bringing together current knowledge, information, research and case studies on AAC in a variety of formats.
- As a result of the project, a Research Involvement Network has been set up by Communication Matters to help researchers find participants.
- To download the *Shining a Light on Augmentative and Alternative Communication* report, visit <http://www.communicationmatters.org.uk/shining-a-light-on-aac>
- The full report from the University of Sheffield will be available from 1st May 2013

About Communication Matters

- Communication Matters is the UK wide charity which works for and brings together everybody who has an interest in AAC (Augmentative and Alternative Communication). Membership includes people who use AAC, family members, professionals who support them and suppliers who design and manufacture AAC solutions.
- In the UK today, it is estimated that over 300,000 children and adults will need AAC at some point in their lives. 10% of them, 30,000, have the most complex needs, which demand access to specialised AAC services and equipment.
- Communication Matters values people who use any form of communication and promotes the individual's right to participate in all aspects of life by using their most appropriate means of communication to express their thoughts, feelings, needs and desires.



LOTTERY FUNDED

- The term AAC is used to describe the different methods that can be used to help people with disabilities communicate with others. As the term suggests these methods can be used to supplement or as an alternative to speech.
- People (children or adults) may have difficulty expressing themselves in a way that is understood by others. This could be due to lack of speech, difficulties with speech intelligibility, motor speech difficulties (controlling the physical movements necessary for speaking), and can result from many congenital or acquired difficulties e.g. cerebral palsy or stroke.
- Communication Matters is managed by a Board of Trustees elected by its Associate members. The Trustees volunteer their time and expertise to run the organisation.
- For more information, visit www.communicationmatters.org.uk

