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Without a voice

Thousands of children may be missing out on the right to communicate.

Cathy Harris assesses the implications of a landmark AAC report

If you are unable to walk, it is natural to expect access to a wheelchair. If you cannot talk or express yourself, why then are you unable to access a communication aid that could change your life, giving you the independence a wheelchair gives the non-walker?

It is a human right to be empowered to communicate. Yet in the UK, low levels of public recognition exist around augmentative and alternative communication (AAC) and in particular the needs and abilities of those who need AAC support. Without access to AAC, life for those with speech difficulties can be lonely, difficult and isolating.

There is currently little consistency in how people are identified, assessed and offered AAC devices and there is great variation in service provision across the UK. The bottom line is that many local areas are failing to make effective provision and support available.

The tides are shifting, though. In the last few years we have seen the benefits of increased awareness of the vital importance communication plays in our children's lives and how recognising a language delay or more complex speech, language and communication needs (SLCN) can change outcomes.

This has been thanks to efforts stemming from John Bercow MP's

Life for those with speech difficulties can be lonely, difficult and isolating

influential *Bercow Review of Services for Children and Young People with Speech, Language and Communication Needs*, the work of Jean Gross in her role as the Government's Communication Champion, and that of the Hello campaign (National Year of Communication).

A new report, *Shining a Light on Augmentative and Alternative Communication*, places AAC firmly in the spotlight, providing up-to-date information on this important issue.

Explaining AAC

Children or adults may have difficulty expressing themselves in a way that is understood by others. This could be due to a lack of speech, difficulties with speech intelligibility or motor speech difficulties (controlling the physical movements necessary for speaking), and can result from many congenital or acquired difficulties, such as cerebral palsy or stroke.

AAC covers a range of strategies, equipment, systems, methods and techniques used by people who have impairments of speech, language or communication.

These approaches may be unaided or aided and used to augment or provide alternative approaches that utilise visual, spoken and written mediums. AAC can include use of eyes, facial expression, gesture, signing, symbols,

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Without the right support, communication can be challenging for those with SLCN.

communication boards or books and technology-based systems such as voice output communication aids (VOCAs). AAC may incorporate the integration of a range of different systems in different settings.

The idea behind AAC is to use a person's abilities, whatever they are, to compensate for their difficulties and to make communication as quick, simple and effective as possible when speech is impaired.

The *Shining a Light on AAC* report has put forward new definitions including:

Unaided communication

This refers to those methods of communication which do not involve additional equipment, such as signing, body language, eye pointing, facial expression and gesturing.

AAC usage at a glance

Research estimates suggest that:

- just over 0.5 per cent of the population could benefit from some type of AAC. This equates to nearly a third of a million people across the UK
- more than 75,000 children and young people across the UK are benefitting or may benefit from AAC support
- of these, 7,500 children and young people could benefit from powered communication aids
- only 2,000 children and young people currently have access to powered communication aids, suggesting that 5,500 of those who could benefit are currently without access.

The statistics are for children and young people aged from birth to 19 in the UK, based on 2011 mid-year data (an update of the 2011 census data, Office for National Statistics).

The time taken to seek funding for services has a negative impact on provision

Aided communication

This describes those methods of communication which involve using additional equipment, such as picture, symbol, letter or word boards, or books and technology-based systems such as voice output communication aids. This may be used alongside speech and unaided communication.

Low-tech aided communication

These systems are those that do not require power to function, such as picture, photo/symbol, letter or word boards or books. It can also include objects of reference, or the use of everyday objects that support communication.

High-tech (powered) aided communication

These technology-based systems require some power to function, ranging from systems such as single recorded message output devices to more complex systems that take text or symbol input and produce a speech output.

Communication aid

A communication aid is a piece of equipment that helps a person to communicate. These aids range from letter, word, symbol or picture boards to any technology-based system such as a voice output communication aid.

The evidence about AAC

The research was the culmination of a three-year AAC Evidence Base research project funded by the National

Lottery through the Big Lottery Fund. Commissioned by Communication Matters, the research was carried out by the University of Sheffield, in collaboration with an honorary researcher from Barnsley Hospital NHS Foundation Trust, and Manchester Metropolitan University.

It has, for the first time, brought together the prevalence figures around those who are currently using AAC as well as looking at any unmet need (see panel bottom left).

The research identified that new technologies have emerged, and continue to develop rapidly, bringing more and more opportunities for professionals to support those who have difficulty communicating.

One of the biggest challenges we face is a lack of consistency in service provision across the UK, with almost no services currently having the interdisciplinary skills and resources to meet the most complex AAC needs for children and young people. The time taken to seek funding to support these services has a negative impact on provision, and absorbs a considerable amount of professional time.

AAC often does not get the same amount of attention and resources as other areas of SEN and disability provision. Jean Gross recalls an encounter which clearly highlights this predicament: "I vividly remember a teacher saying to me, of a disabled child, 'We can get him a special cup to drink from, but not the means to tell us he's thirsty; we can get him a specially adapted bed, but not the means to tell us he's tired; we can get him an all-singing and dancing wheelchair, but not the means to tell us whether it's comfortable.'"

Service commissioning and funding arrangements are often inconsistent and sometimes dependent upon in-year savings from other budgets. This is making it difficult for services to plan

strategically and to ensure maintenance and replacement of communication aids are built into continuing care plans.

Less than five per cent of the 92 AAC services surveyed in the research reported joint service funding arrangements, which is concerning. Joint commissioning has been highlighted as vital in improving the integration of services across health, education and care settings and avoiding disputes over responsibility for funding.

There is a growing need for AAC in the UK yet what is lagging behind is commissioning of services, funding arrangements and specialist expertise. There is a postcode lottery of support and provision for both children and adults who use AAC. This isn't just a postcode lottery based on where you live but also a lottery based on your age, disability and even literacy skills. For those who use AAC, and their families, the biggest issue is the constant barriers they face around securing funding for services and equipment.

An ideal service model for AAC

The research highlighted that although the majority of people who use AAC and their families and carers expressed frustration with all or some part of

“We can get him a specially adapted bed, but not the means to tell us he’s tired”

the AAC service they received, many were satisfied with AAC services – demonstrating what good services can offer.

Through the research project, a service model for the provision of AAC services, including powered aided communication, was defined using contributions from those affected by AAC, their families and the professionals who work with them. The model details the components of effective service provision. Broad categories include:

- assessment
- funding
- training
- customisation and maintenance
- support
- research and development
- education and advice.

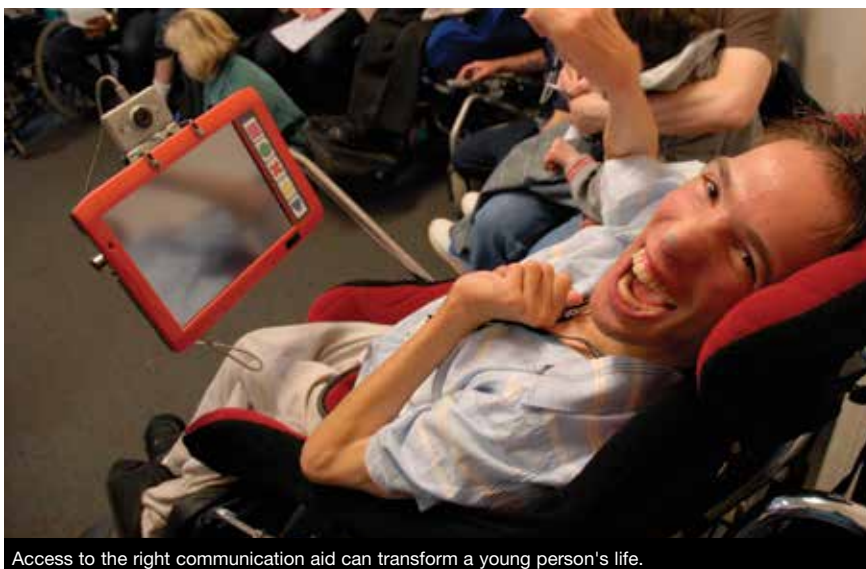
Empowering others around AAC

It is recognised that professionals working with people who use AAC need

continual specialist training and support. A welcome contribution to the field of AAC is the development of a case study template that will gather data to advance knowledge around AAC undertaken by Manchester Metropolitan University. This is an important support tool for local services auditing their outcomes.

The AAC research findings enable us to look at the real picture around AAC needs and the lack of provision available. It is crucial that everyone involved continues to lobby and campaign to seek improvements in funding for provision of AAC services and devices.

Enabling people to communicate improves their quality of life and offers children and young people new opportunities in their education and friendships, helping to increase their independence. It is unacceptable for any child, young person or adult to be left without access to a voice. **SEN**



Access to the right communication aid can transform a young person's life.

Further information

Cathy Harris is Chair of Communication Matters, which provides help and support with AAC to parents and professionals. A copy of the *Shining a Light on AAC* report, along with information about sources of funding, assessment services and support services for AAC, can be found on the charity's website: www.communicationmatters.org.uk

The AACknowledge website brings together knowledge, information, research and case studies on AAC in variety of formats. It has been developed to empower AAC users, parents, carers and professionals to improve support and services for people with speech difficulties: www.aacknowledge.org.uk