Communication Matters – Research Matters: an AAC Evidence Base

November 2012

2012 – destination in sight

Learning objectives

- You will learn something new about the research project

- You will gain insight into some of the research methodologies used

- You will learn about how you may be able to use the outcomes of the research to support your work

The AAC Evidence Base project

£468k grant from Big Lottery Fund

UK-wide research

High tech & low tech AAC

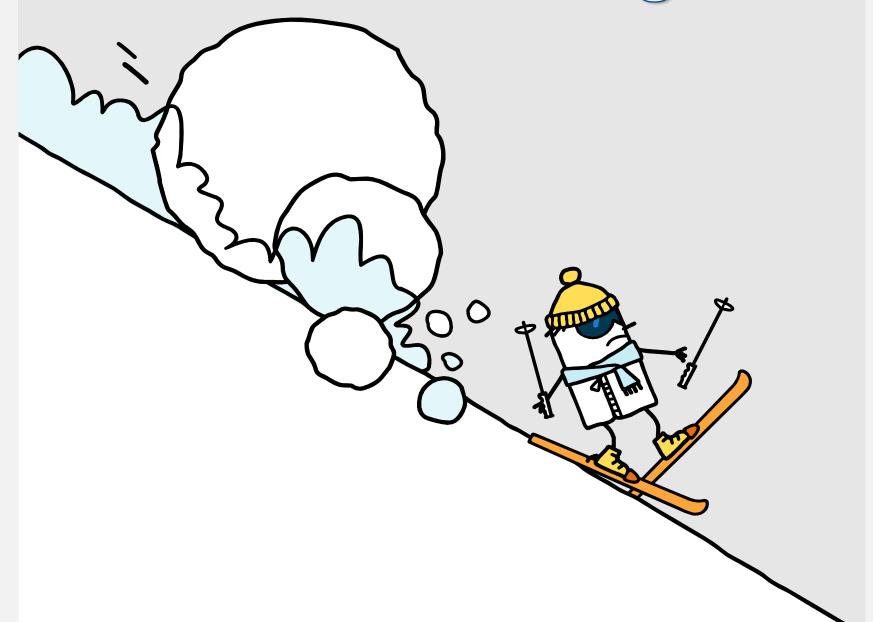Started June 2010

Results in 2012 - 2013

Our research partners

Manchester Metropolitan University

The University Of Sheffield.

Barnsley Hospital NHS
NHS Foundation Trust

Project outcomes

- Increase awareness of the need for AAC

- Increase understanding of current AAC provision

- Improved access to evidence about AAC

- Building research capacity

The avalanche of change

University of Sheffield & Barnsley Hospital

- Increase awareness of the need for AAC
- Increase understanding of current AAC provision

The data mountain

Prevalence - quantifying AAC use, need and unmet need

Numbers for use and need

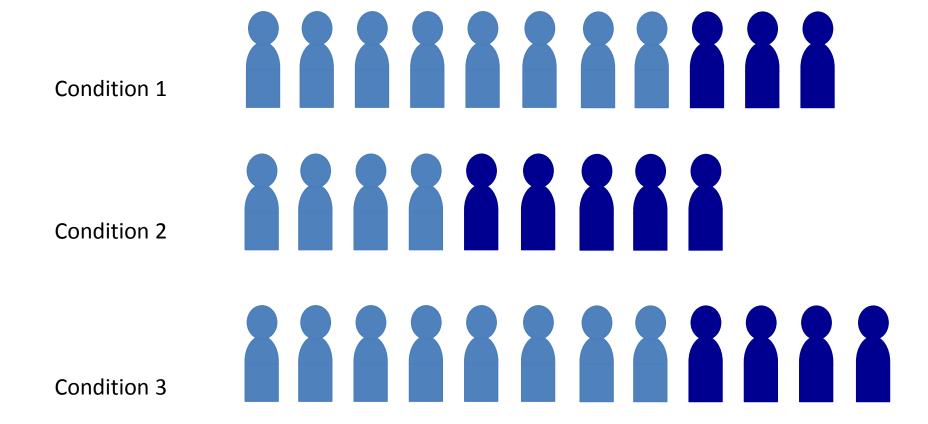Number of people who could potentially benefit from AAC

Number of people who could benefit from AAC and are not accessing AAC services

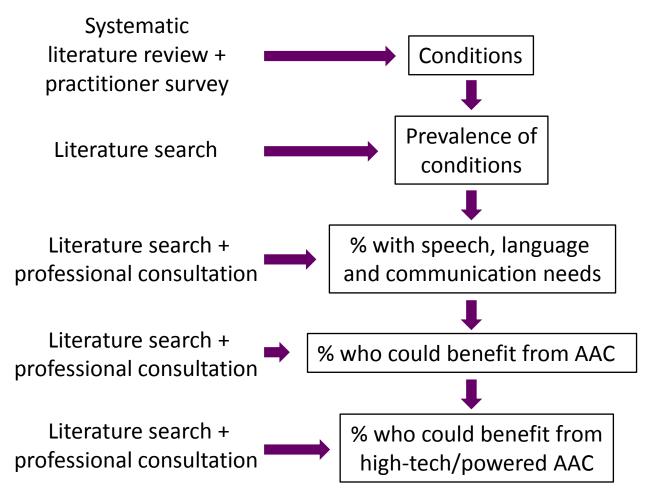Number of people who currently use AAC

People who could benefit from AAC

Condition 1

Condition 2

Condition 3

Calculating need (UK)

Systematic literature review + practitioner survey ➡️ Conditions

⬇️

Literature search ➡️ Prevalence of conditions

⬇️

Literature search + professional consultation ➡️ % with speech, language and communication needs

⬇️

Literature search + professional consultation ➡️ % who could benefit from AAC

⬇️

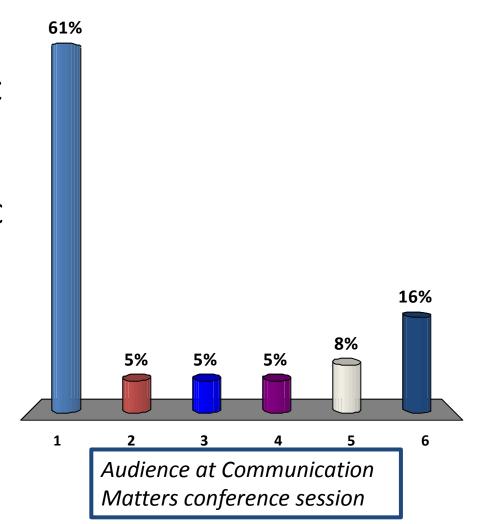Literature search + professional consultation ➡️ % who could benefit from high-tech/powered AAC

Who is here?

1. AAC practitioner
2. Person who uses AAC
3. Family member/assistant of person who uses AAC
4. AAC company employee
5. Researcher in AAC
6. Other interested person

61%

16%

5% 5% 5% 8%

1 2 3 4 5 6

Audience at Communication Matters conference session

What are the top 5 main conditions of people who could benefit from AAC?

1. Autistic spectrum disorder
2. Learning difficulties
3. Profound and Multiple Learning Difficulties
4. Cerebral palsy
5. Motor neurone disease
6. Multiple sclerosis
7. Parkinson's disease
8. Stroke/CVA
9. Alzheimer's/Dementia
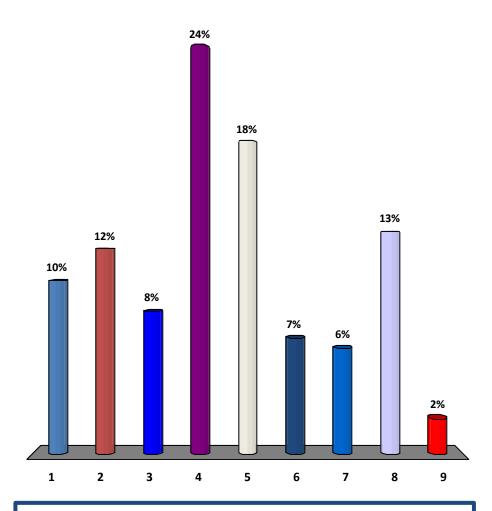
Please rank your top 5 with most common first

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8. Stroke/CVA
9. Alzheimer's/Dementia

Please rank your top 5 with most common first

Responses from audience at Communication Matters conference session

Top 5 main conditions of people that could benefit from AAC: response from literature & expert opinion

	Per 100 000 population
1. Parkinson's	120
2. Autistic Spectrum Disorder	100
3. Learning difficulties	70.5
4. Stroke/CVA	52.4
5. Cerebral palsy	24

As reported at Communication Matters conference session September 2012 – further analysis to be undertaken

Summary

- Continuing to try and establish the number of people who could benefit from AAC
- Difference between expected total of people who use AAC and actual data collected provides an indication of the gap in service provision
  - Some mismatch between those accessing services and expected need
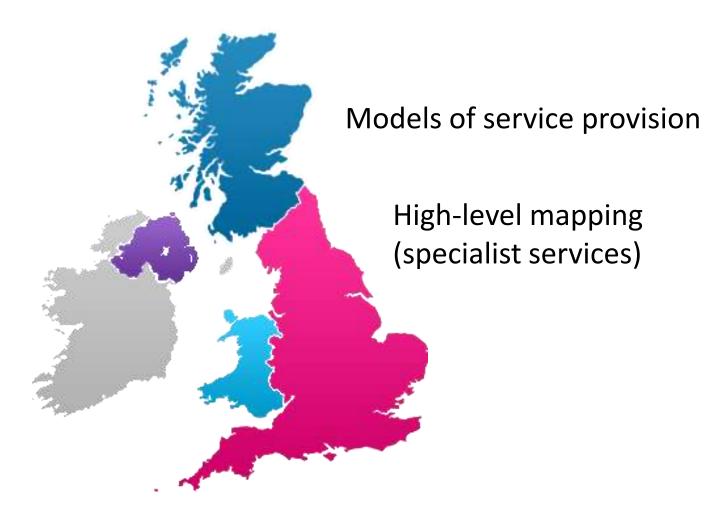- Need further analysis for accurate conclusions

Understanding current AAC service provision in the UK

What mapping?

Models of service provision

High-level mapping
(specialist services)

Key elements of service provision

Manchester Metropolitan University

- Improved access to evidence about AAC

AAC Evidence Base website – Focus Groups

Medical professionals

Charities

People who use AAC

Personal assistants

Researchers

Family members
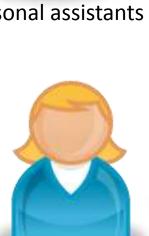
Education professionals

Speech & language professionals

Companies

AAC Evidence Base website - terminology and structure

- Exclusive and confusing

- Medical, legal, social perspectives

Implementation:

- How will we use terminology to help people navigate the site?

AAC Evidence Base website - content

- A glossary of terms, definitions and conditions
- User experiences in the form of case stories
- Published case stories
- Fact sheets
- Technical specifications of AAC systems & devices
- Assessment studies
- Intervention studies
- Service provision, funding and policy studies
- Discussion forum

Prototype: Home Page

Case Stories

different formats to meet different stakeholder needs

look for relevant case stories

Search this site: [ ] [Search]

Home | **Case Stories** | **FAQs** | **Factsheets** | **Summaries** | **Glossary**

Case Stories

case   stories

AAC case stories from different personal and professional perspectives.

- Adam's experiences with different AAC systems
- Bill's experiences after a stroke
- Craig's experiences of getting into work
- Funding a communication aid for my son
- Heidi's experiences with facilitated communication
- Jeff's experiences after leaving school
- Jim with locked-in syndrome, using eye gaze
- Mark's experiences in day centres
- Terry using a communication aid after a stroke
- Tids and the care system

Adam's experiences with different AAC systems ›

Printer-friendly version

Case Story Example

access and equipment
acquired condition
adults advocacy aided
communication
amyotrophic lateral
sclerosis (ALS)
aphasia apraxia Asperger
syndrome aspirations
assessment
augmentative and
alternative
communication
(AAC) autism (ASD)
brain injury / head
injury (TBI) brain tumour
cerebral palsy (CP)
charities children
communication
impairments complex
communication
needs (CCN) congenital
condition dementia
developmental-
learning disability
dysarthria dysphagia
dysphasia dyspraxia
education employment eye
gaze funding government high-
tech Huntington's disease (HD)
laryngectomy locked-in
syndrome low-tech medical
conditions motor neurone(e)
disease (MND) multimedia
multiple sclerosis (MS)

Adam's experiences with different AAC systems

different   AAC   systems

different AAC perspectives

I am a speech and language therapist and want to share the story of a young man with you. 'Adam' is now nearly 19 and I have known him since he was seven. He has always been a friendly young man who likes to help. He gets his message across to you by taking you by the hand to something he wants, or by pulling at your jersey and pointing to things. He uses his voice well and by that you can tell when he is happy, concerned, uncertain, angry and a range of other emotions.

Over the years we have tried lots of different AAC systems with Adam and to begin with they all seem to be good and people are interested in them. He has used picture symbols on cardboard or in books; he has used light tech devices with recorded words and sounds associated with activities. One thing that does happen quite a bit is that if Adam gets upset he tends to throw things. This is one of the reasons why we moved away from using light tech AAC – not because of fear of it getting broken or potentially hurting someone but that when this happens it makes Adam inconsolably upset for a considerable period of time after the incident.

Recently, we have found that what works best for him is to use digital photographs which he helps to take, print off and then put in his communication book. He takes great delight in sharing his book with people and recently has used it spontaneously to ask to do something, or see someone. This is a huge leap forward for Adam. What is slightly sad though, is that I think we (Adam's family, Adam, me and his class teacher) are coming under pressure to go for a technological solution again. Perhaps that may be helpful in the future but for now I do wish 'low tech' was seen to be as valuable as high tech!

Things you may want to look into: picture symbols, communication book

easy to find same-format resources

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easy to find content-related resources

tags: assessment   training   high-tech   low-tech   augmentative and alternative communication (AAC)

‹ Case Stori   up   Bill's experiences after a stroke ›

there is a vast array of AAC equipment which mirrors the individual needs of people who may use AAC and to determine the right specification for an individual they should have a specialised assessment which considers a number of equipment options
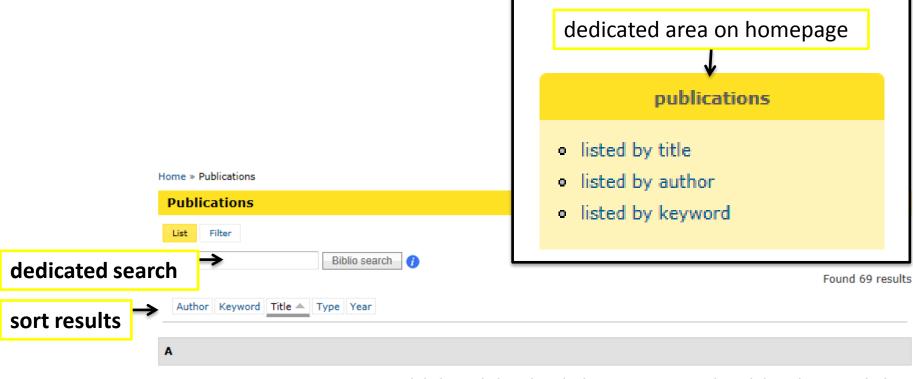
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LOTTERY FUNDED

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- listed by author
- listed by keyword

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AAC and ICF: A good fit to emphasize outcomes, Fried-Oken, Melanie, and Granlund Mats , AAC: Augmentative and Alternative Communication, Mar, Volume 28, Issue 1, p.1-2, (2012) Abstract

AAC for adults with acquired neurological conditions: a review, Beukelman, David R., Fager Susan, Ball L., and Deitz A. , Augmentative and Alternative Communication, Volume 23, Issue 3, p.230-242, (2007) Abstract

An AAC personnel framework: Adults with acquired complex communication needs, Beukelman, David R. , Augmentative And Alternative Communication, 2008, Vol.24(3), pp.255-267, Volume 24, Issue 3, p.255-267, (2008) Abstract

AAC strategies for people with primary progressive aphasia without dementia: Two case studies, Cress, Cynthia J., and King Julia M. , AAC: Augmentative and Alternative Communication, Dec, Volume 15, Issue 4, p.248-259, (1999) Abstract

Summaries

Summary: AAC for adults with acquired neurological conditions

AAC,   adult   acquired   conditions

This article is about people who have grown up with typical speech and language skills. They have lost those skills for a number of reasons, as detailed below.

It is a summary of **AAC for adults with acquired neurological conditions: a review** (2007)

Authors:	Beukelman, D.R., Fager, S., Ball, L., & Deitz, A.
Published:	Augmentative and Alternative Communication Journal
Bibliography:	http://www.aacknowledge.org.uk/biblio/aac-adults-acquired-neurological-conditions-review

Why was the review carried out?

It aimed to provide an update on the use of AAC technologies associated with a range of acquired medical conditions that impact on speech and communication. This review was based on USA statistics, research studies and service provisions, although it refers to studies completed in other parts of the world.

What did they look at?

They looked at the typical use of AAC systems in people with medical diagnoses of: ALS (a form of motor neuron disease, a condition that gets worse over time); TBI (a range of brain traumas); Brain Stem Trauma (an aspect of the brain that is involved in control of reflexive (e.g. breathing) and voluntary movement). This may be called 'Locked-in-Syndrome' in many individuals. This often means that people are anarthric – cannot say anything, rather than dysarthric – produce slurred and distorted speech; and Dementia (a progressive loss of thinking and language skills). They also looked at speech and language diagnoses: Aphasia (a speech and language difficulty usually following a stroke); and PPA (a form of aphasia that gets worse and may eventually be related to dementia).

What did they find out?

ALS: This has several characteristics that can make communication more challenging. These include: slurring of speech with eventual loss of the movement control to produce speech, breathing co-ordination difficulties and low volume of speech. They found that as things progress there is evidence that ventilation support and nutrition support can have a positive impact on quality of life experiences including both life expectancy and the length of time that AAC might be used. Research suggests a good uptake of AAC (95%) when recommended; and in those who rejected it there were often additional difficulties, e.g. dementia. One study suggests that 100% of those with ALS used AAC to within weeks or days of their death. It is reported that AAC supports offered to the individual with ALS and their family members gave a greater sense of social closeness and understanding.

different formats to meet different stakeholder needs

link to article in Publications

Glossary

medical conditions

diagnosed diseases and disorders

acquired condition – a disease or condition/characteristic that is not congenital but develops after birth; common adult-acquired conditions include stroke/CVA, brain injury/brain tumour, MND, MS, Parkinson's disease and Huntington's disease: see also congenital condition

congenital condition – a disease or condition/characteristic that is present at birth developmental condition: see also acquired condition

amyotrophic lateral sclerosis (ALS) – the most common degenerative disease of for the form of MND that involves upper and lower motor neuron(e)s: see also motor

- http://www.hawking.org.uk/living-with-als.html
- http://www.mndassociation.org/
- http://www.mndscotland.org.uk/

Asperger syndrome – Asperger syndrome is a form of autism, where people have difficulties with understanding and processing language: see also ASD

- http://www.autism.org.uk/

autism (ASD) – a congenital condition that affects people in a spectrum of ways (a inability to understand how to interact socially: see also Asperger syndrome

- http://www.autism.org.uk/

core AAC terms

core AAC terms

These core terms are defined on the main Communication Matters website: http://www.communicationmatters.org.uk/page/resources/glossary

- aided communication
- augmentative and alternative communication
- ISAAC
- person who uses AAC
- unaided communication
- voice output communication aid

tags: aided communication   VOCA   unaided communication

Looking forward

- Launch the AAC Knowledge website
- Publish & disseminate final research report (April 2013)
- Report to the Big Lottery Fund
- Influence policy & decision-makers
- Continue to support AAC research in the UK

Supporting AAC research

- AAC Knowledge website

- Case study database

- Research Involvement Network

Communication Matters

Research

- Contents
- ▾ Communication Matters Research
  - ▸ AAC Evidence Base Project
- Research Involvement Network
- UK Research

Turn Point symbols off

Research Involvement Network

Research   Involvement   Network

How can I get better help and support for people who use AAC? Take part in research!

Communication Matters has set up the Research Involvement Network to support and encourage research into Augmentative and Alternative Communication (AAC) in the UK by building a list of people who are interested in taking part in research. The Network was launched in September 2011.

Research is a process of gathering information and analysing it to increase our understanding of a topic or problem. Research can establish facts, solve problems or develop new theories. Findings from research into AAC could help the Government, the NHS and local authorities to understand better what services are needed. Research evidence could help practitioners to improve services and support for people who use AAC to communicate. Communication Matters believes it is important that more people who use AAC are involved in research as this will make research more relevant and more likely to be used.

You can help to ensure that our research will be directly relevant to the people who can benefit from it most, by sharing your knowledge and experience.

We are currently recruiting members in the UK. We are particularly keen to recruit more people who use AAC and family members and carers of people who use AAC. The first person who uses AAC to become a member of the Research Involvement Network was Simon Stevens (pictured right).

Read on to find out how you can join...

Who can join the Network?

- People who use AAC, both adults and children
- Family members and carers of people who use AAC
- Practitioners from the fields of health, education and social care

Questions

THANK YOU

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/research

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