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# Communication Matters – Research Matters: an AAC Evidence Base

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## Beyond the Anecdote

Examining the need for, and provision of, AAC in the United Kingdom.

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This report details research carried out by the University of Sheffield in collaboration with Barnsley Hospital as part of the AAC Evidence Base project. The project was commissioned and led by Communication Matters, the UK charity for augmentative and alternative communication. It was funded by the National Lottery through Big Lottery Fund.

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## Contents

- 1    **Chapter 1: The background to AAC service provision**
- 13   **Chapter 2: Quantitative data**  
Collecting data on the need and use of AAC
- 51   **Chapter 3: Provision and use of services for augmentative and alternative communication**
- 104   **Chapter 4: Examining the Need for and Provision of AAC in the United Kingdom**
- 115   **Appendix 1**  
Information sheets for potential research participants
- 126   **Appendix 2**  
Study protocol
- 135   **Appendix 3**  
Scoping study example data
- 136   **Appendix 4**  
Study participants
- 136   **Appendix 5**  
Topic sheets - interviews and focus groups
- 139   **Appendix 6**  
Example service component map (regional communication aids service)
- 141   **Appendix 7**  
Summary of data from RCSLT Focus Groups
- 145   **Appendix 8**  
AAC industry/supplier and charity surveys
- 148   **Appendix 9**  
Practitioners' survey
- 156   **Appendix 10**  
Mapping AAC provision: 2012-13 v8.3.1 (22/11/12)

# Chapter 1: The background to AAC service provision.

## Introduction

People of all ages with severe speech and language impairments use a range of Augmentative and Alternative Communication (AAC) methods to assist them to communicate their views and needs. AAC includes non-technological systems such as signing, use of symbols and picture charts as well as sophisticated technology including dedicated computerised systems and voice output communication aids. Without support people with communication difficulties are unable to realise their potential and face social isolation, dependency, a decreased quality of life, and increased care costs.

The project detailed in this report was commissioned and led by Communication Matters, the UK charity for augmentative and alternative communication, and funded by the National Lottery through Big Lottery Fund. Communication Matters is committed to the advance of research in the AAC field and in particular research that:

- promotes understanding of the need for provision of AAC and ongoing support services
- improves the quality of life for individuals and groups of individuals by understanding their needs
- influences local and national policy and practice and leading to better services and interventions for people who use AAC
- promotes community learning and creates opportunities for people who use AAC and their families

The objective of this programme of work was to provide fundamental evidence to support the appropriate development of AAC services and improve provision of aided communication and other AAC strategies. The research, building on the literature, aimed to: provide an improved picture of the need for AAC and aided communication to support commissioning and planning of services; provide a better understanding of the current picture of AAC service provision to help inform the development of aided communication and other AAC services to meet the needs of people who use AAC; and to contribute to the knowledge about the use of AAC in the UK and the factors that may contribute towards successful use. There were two overarching research questions that this work aimed to address:

- 1 How many people are using AAC?
- 2 What are the routes to provision of AAC?

## AAC

Communication is more than giving someone a message, but needs to allow a person to initiate and end interactions, maintain different topics of conversation, make requests, relate information and allow a historical narrative to be maintained.

AAC strategies can help a person communicate wants, needs, thoughts, and ideas and express their personality when they are unable to use speech.

Augmentative or alternative communication (AAC) systems may be of several types. The term encompasses unaided modes that rely on a user's body to convey messages; for example gestures, signs and facial expressions. Also, it includes aided communication modes that require additional materials or devices.

Within the category of aided AAC there is a commonly-used further sub-division of high-tech and low technology aided options as listed in Table 1.1.

**Table 1.1: Summary of commonly defined types of AAC**

Augmentative & Alternative Communication	Unaided		E.g. eye pointing, facial expressions, signing
	Aided	"Low-tech"	E.g. symbol/pictures/charts/books, Eye Pointing frame, paper and pencil
		"High-tech"	E.g. dedicated AAC devices (mostly computerised), AAC software for computers and mobile devices

During the course of this project it became clear that the definitions used within the field of AAC were not consistently used around the country. A process of agreeing definitions was undertaken, explained later in this report. These agreed (UK) definitions are in Table 1.2.

Table 1.2: AAC definitions developed during the study

Augmentative and Alternative Communication (AAC):
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. It can include use of eyes, facial expression, gesture, signing, symbols, communication boards or books and technology based systems such as voice output communication aids." AAC may incorporate the integration of different systems
Unaided communication:
Unaided communication is a subset of AAC which refers to those methods of communication which do not involve additional equipment, such as signing, body language, eye pointing, facial expression and gesturing.
Aided communication:
Aided communication is a subset of AAC which refers to 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 which 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 aided communication:
These technology based systems are those which require some power to function, ranging from systems such as single recorded message output devices to more complex systems which take text or symbol input and produce a speech output.
Communication aid:
A communication aid is a piece of equipment which 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.

## Existing evidence around AAC

A literature review was undertaken in order to examine published work regarding the effectiveness of high-tech aided communication; to provide evidence-based information for potential users and service providers; and to provide context related to the need for AAC and the requirements for service provision. The aim of the review was to investigate: the technologies in use; the populations described as benefiting; the outcomes reported following provision; and the barriers and facilitators to use.

## Systematic literature review

### Method

#### Identification of studies

Relevant published literature reporting high-tech AAC intervention was identified via searching of the CINAHL, Cochrane library, EMBASE, MEDLINE, PsychINFO, CSA, and Web of Science electronic databases. Search terms used related firstly to conditions (for example learning disability, cerebral palsy, Parkinson's Disease), secondly impairment terms (such as language disorder, communication impairment), together with AAC terms (such as speech generating device, assistive aids) and in addition, commonly used devices (such as Canon Communicator, Minspeak, LightWriter). The full search strategy is available from the authors. In addition to this electronic database searching, we scrutinised the reference list of included papers and review papers for any additional citations of potential relevance.

The review considered studies published in peer-reviewed journals between 2000 and 2010 that were reported in English. This time period was chosen given the rapidly expanding and changing nature of the technological developments. We intended to complete a "state of the art review" to provide evidence regarding the current level of knowledge in the field, and therefore aimed to be inclusive regarding the literature examined. Any studies that reported the effectiveness of an intervention were therefore eligible for inclusion. In view of the inclusion of studies across the hierarchy of evidence, quality was assessed via noting key aspects: the appropriateness of study design; choice of outcome measures; quality of reporting; quality of intervention; and generalisability; rather than using a formal critical appraisal tool.

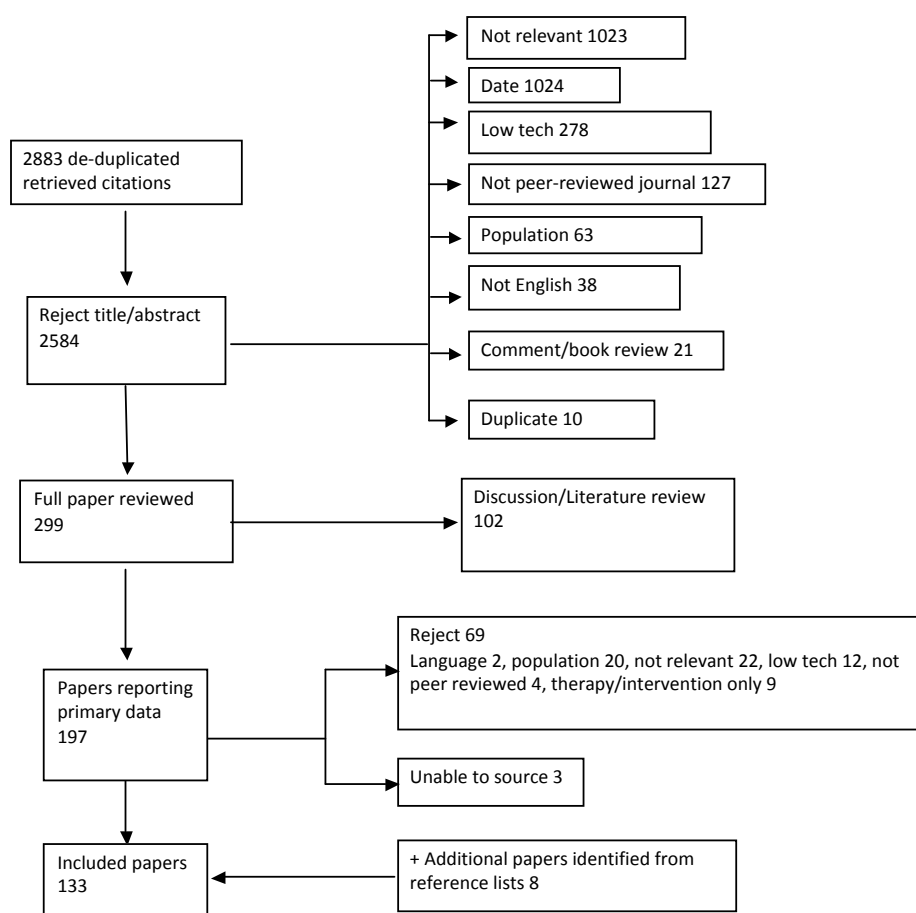
The population under consideration was any person who has an impairment of communication not resulting from a primary auditory or visual impairment. All age groups were included. The review also encompassed studies reporting data from relatives/significant others of people with communication difficulties, together with staff delivering AAC services to this population. Studies carried out in non-communication impaired populations were outside the remit of this review, although work reporting findings from mixed populations was considered.

The review encompassed “high technology” communication interventions only. For the purpose of this work high technology (high-tech) devices were defined by exclusion as those acquired and augmentative communication methods or devices which cannot be described as low technology and are not powered. Thus signing, gesture, communication books, communication boards, alphabet boards, writing and drawing, and pictures/symbols not used with a computer were outside the remit. Papers which reported both high and low technology were included, with the data relating to high tech only extracted. Software that could be used only as a treatment tool during therapy sessions was excluded. Technology which provides access to computers/switches to overcome physical disabilities (rather than for communication needs) was also outside the scope of this review.

### Selection of publications for review

The initial search retrieved 2883 duplicated citations. All the retrieved literature was screened at title and abstract level for relevance, and those that had potential for inclusion were taken through to full paper appraisal and extraction of data. Following the initial sifting 299 papers were examined as full papers with inclusions and exclusions checked by a second member of the research team. Figure 1.1 provides a summary of the process of inclusion and exclusion, indicating how papers of relevance to this review were identified and selected.

**Figure 1.1: Flow chart illustrating the inclusion and exclusion process**



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## Overview of papers identified

### Study characteristics

The review identified 65 papers. The reasons for exclusion are detailed in the figure above with more than 1000 being deemed not relevant to the questions of this research and more than 100 being published non-peer reviewed journals. Most of the papers retained had small numbers (1-5) of participants. Only three of the included articles (Fink et al. 2008; Fried-Oken et al. 2009; Schlosser et al. 2007) described data from more than ten individuals. The studies encompassed work from 10 different countries with the highest proportion of papers originating from North America. The inclusion criteria stipulating that papers should be published in English was an obvious limitation to achieving an overview of work taking place worldwide, and the papers had the expected bias towards English-speaking countries. Studies reported interventions using the full range of high-tech devices encompassing VOCA/SGDs, computer software enabling output, and input systems such as speech recognition technology and brain-computer interfaces.

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#### Key Point 1

only three studies identified included more than ten individuals.

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### Participant characteristics

The study participants included people with acquired non-progressive neurological disorders, acquired progressive neurological disorders, autism/autistic spectrum disorder, and other developmental disorders. There was considerable heterogeneity of participants in some studies, with diversity in terms of age, diagnosis, or pattern of communication difficulties.

### Study quality

The searches found no papers reporting studies with an experimental design. The papers were all of a case study or case series design. Quality issues noted amongst the set in addition to a lack of experimental studies were: short follow up periods; limitations in the choice of outcome measures; limited reporting of the intervention; and use of descriptive data rather than detailed or statistical analysis.

### Outcome measures

There was a vast range of measures across the papers evaluating outcomes of high-tech AAC intervention. Many authors used multiple measures within a single study. The outcomes included those that measured the frequency of communications made using a device, amount of information provided, or the number of correctly identified target items in a structured situation. Some authors commented on the limited nature of these measures in terms of use for functional communication, with some studies endeavouring to address this limitation by using measures relating to the duration or degree of usage of the device.

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## Overview of the AAC literature

We reviewed the literature on the efficacy of high-tech augmentative and alternative communication aids and identified 65 papers published in the last 10 years. The findings suggest that these devices may be beneficial to enhance communication across a broad range of diagnoses and age ranges including acquired progressive and non-progressive neurological conditions, and other developmental disorders.

Papers were found reporting the use of all three types of technology: (i) speech generating devices/voice output communication aids; (ii) speech generating device software on personal computers or laptops used as a communication aid; and (iii) technology which provides access to personal computers or laptops enabling them to be used as communication aids.

There seemed to be no evidence of different levels of effectiveness between devices, with variable outcomes within groups of individuals using the same system. The different devices enabled communication at very different levels, ranging from indicating a yes/no response to sentence generation.

In the last 10 years high-tech communication devices have become more commonly available however funding for these devices for those with special needs is still reported as being problematic. Whilst most of the papers prior to the 10 years presented here refer to AAC with clients with motor speech problems more recently technological developments have facilitated access by those with language and pragmatic disorders e.g. aphasia and autism.

Key Point 2

there are many references in the literature related to funding difficulties for the provision of powered communication aids.

Key Point 3

the range of powered communication aids available and used for persons with language rather than motor speech disorders is increasing.

Literature quality

It is important to note that the included literature was all of a case series or case study design representing only level IV evidence. The review is thus unable to conclude that there is high quality evidence of effectiveness. There is currently a lack of work using experimental rather than observational designs in this field, which will be difficult to undertake but must be a future priority if the evidence base for AAC is to be strengthened.

While considered to be the design most subject to bias, case studies are commonly used and reported in the medical literature. It has been suggested that they can be a helpful source of information about adverse events, can be a useful means of generating hypotheses, and are likely to provide more participants, longer follow up and more generalisable data than controlled trials. However, they have significant limitations in terms of providing conclusive evidence of effectiveness as they are prone to publication bias. The evidence from these case studies should be used to underpin stronger designs in future research. In particular consideration needs to be given to controlling for attention as many of the studies cited above provided fairly intensive teaching and support of communication in general which may have affected the outcomes whether with or without AAC.

Many studies described their limitations in terms of being undertaken in a highly controlled context with lack of consideration of functional use and environmental factors. Issues relating to fidelity of the intervention regime may adversely impact on outcomes outside these research environments. Some authors highlighted the challenges associated with carrying out interventions in an educational context, or where intensive training is required. A minority of the papers evaluated use in a home context, and only one in a community setting. Further work exploring how effective the technology is in aiding communication in a functional setting is needed.

Much of the work while describing generally positive outcomes, which may be attributed to publication bias, reports variability in response to intervention amongst participants.

Key Point 4

whilst limited, the evidence of benefit to individuals of providing AAC is clear.

There is currently considerable debate within the field regarding what the consideration of a successful outcome should be. The literature examined in this review used a wide variety of measures, however many were frequency counts. It is recognised across the field of communication impairment that outcome measures need to cover a range of communication tasks and purposes, and that the individual's own views are important. In response to this measures to evaluate communication effectiveness and explore the functions of communication have been developed for some client groups such as post-stroke. There has also been the suggestion that it may be important to evaluate the perception of caregivers and the impact that technology has on them as communication partners in everyday life. As a primary focus of rehabilitation is to promote functional living skills, a greater emphasis on developing functional measures of high-tech AAC intervention effectiveness seems warranted.

Key Point 5

outcomes are not consistently reported making the pooling of data difficult.

What high-tech communication aids are used?

The review found a wide range of VOCAs/SGDs, software and access systems reported. A small number of studies were available which evaluated and compared systems.

There seems a need for further work in particular to compare different types of VOCAs, with a large array of devices available, yet there is a dearth of papers providing information on which may be more successful for which type of client.

While outcomes of interventions using high-tech AAC were generally positive there were also a few papers which compared high versus low tech devices and found that low tech were preferable for some clients. Further evidence regarding when one type of technology may be more effective than another is also required.

There was the suggestion for example that children and adults of a younger age may respond better to high-tech AAC intervention, although this finding was not universal across all studies.

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**Key Point 6**

the evidence of the impact of AAC is mostly limited to low-tech devices and provides little information which would facilitate generalisation or knowledge or maintenance of use.

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**Key Point 7**

more evidence is required to underpin recommendations by practitioners regarding choices between devices or features of AAC devices.

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### What may be the outcomes from AAC interventions?

The review found that a wide range of outcomes have been used to evaluate AAC interventions. These outcomes included increases in narrative, word flow, longer utterances, requesting, responding, communication effectiveness, engagement, spelling a target word, and yes/no indication. In addition to these evaluations of the content of communication, authors considered take up of devices, degree of usage, use in a functional setting and views of users and families of users. The studies reported mostly positive outcomes from intervention. Five of the six papers using linguistic analysis found benefits, 21 of the 27 using number of initiations or communications, both papers using communicative effectiveness, and all twelve using percentage correctly selected. Studies which used outcomes of verbal comprehension/correct selection, standardised language measures and intelligibility/use of speech generating software each reported mixed outcomes. Papers which reported usage/take up suggested that 30-50% of devices offered were accepted and used successfully. As highlighted previously, individual variation was apparent within these positive outcomes.

A range of benefits were identified by users and their families including increased social and educational opportunities, independence and employment, a means of participation and enabling choice. Several authors made reference to the complexity of evaluating success in regards to AAC, for example it was argued that the view of the user should be paramount in a successful outcome, or alternatively that use in an everyday setting is a more appropriate measure rather than in a controlled communication exchange.

The minority of papers not reporting successful outcomes reported that in some instances low tech devices were more successful than high-tech. Some papers also described a lack of generalisation from a controlled situation, or limited continuance of use or progress at follow up. In any review of published work, the potential impact of publication bias on evidence of positive versus

negative outcomes should be considered.

Limitations in study quality currently impact on the evidence base regarding intervention outcomes. The field is dominated by studies with small samples, many of which are case studies. Even within these small samples there were examples of considerable heterogeneity of participants, with a need for future studies to endeavour to recruit using closer matching of individual communication levels rather than the seeming tendency towards convenience sampling. There is currently a lack of work using controlled designs which must be a future priority, if potential sources of bias in intervention study outcomes are to be overcome.

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**Key Point 8**

case and group studies indicate that AAC interventions have been found to be useful in expanding the communication of many individuals with a broad range of underlying conditions affecting their communication potential. The complexity of the multi-factorial impairments and frequently associated cognitive, sensory and environmental situations has an impact on study design and limits the wider application of the findings.

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**Key Point 9**

the majority of studies have indicated the importance of identifying the right AAC approach within the context of a service offering a programme of support and teaching for users and carers to maximise usage.

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### How are AAC Services Delivered?

Beyond the studies reporting training of educational staff, no research was found that evaluated alternative models of service delivery, thus this review is unable to comment on effective versus less effective delivery options. This might be expected as the review excluded studies that were not published in peer-reviewed journals. Evaluations of service delivery may be more apparent in grey literature or perhaps considered to fall within the scope of audit rather than research which may account for the paucity of published work.

Evidence regarding service delivery models is limited. Studies suggested that the training of staff in schools may be influential, together with the degree of team working. It was reported that speech and language therapists perceive that they have limited knowledge and skills regarding high-tech AAC which may indicate a need for greater training.

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**Key Point 10**

There is little existing evidence around the efficacy of different service models.

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## Output (2.2) Establishing existing data on provision of AAC

### Which people with communication impairments would benefit from AAC intervention?

The literature currently has a tendency to report by diagnosis rather than by type of communication difficulty, with considerable individual variation in outcome reported in many studies. This variation may possibly be linked to varying patterns and levels of communication needs within any single diagnostic category.

The review found use of high-tech AAC across a range of diagnoses including aphasia (resulting from CVA and TBI), Amyotrophic Lateral Sclerosis/MND, head and neck cancer, locked in syndrome, progressive aphasia, Alzheimer's Disease, Parkinson's Disease, autistic spectrum disorders, cerebral palsy, complex/multiple developmental disabilities, syndromes such as Down and Angelmann, developmental apraxia of speech, and other developmental neurological disorders. The papers reporting demographics of service users echoed these wide-ranging client groups. Multiple Sclerosis was also identified as a significant client group, however only one study had a single participant with MS amongst others with cerebral palsy.

Only one paper was identified reporting high-tech AAC use with people who have Alzheimer's Disease and this work suggested that voice output could adversely impact on communicative responses. Similarly, the one paper reporting a client with progressive aphasia reported a negative outcome.

The largest group of papers (26) reported work with people who have CP, one more than the papers outlining work with people who have aphasia. There were 14 papers each for autistic spectrum disorders, ALS, and non-CP developmental disorders. The high number of papers investigating use in people with CP is perhaps explained by the service demographic data indicating that high-tech AAC is used more by clients with CP than other diagnostic categories.

Examination of study populations in published work can provide only limited information regarding the groups that may benefit from AAC, and may not relate closely to the state of practice in the field. A small number of papers (7) were identified during the review that provided demographic data regarding users of AAC services.

In addition to demographics, four papers analysed data to provide prevalence estimates which may provide some indication of level of need.

#### Key Point 11

the few papers reporting demographics provide different figures suggesting variation in access to services.

#### Key Point 12

none of the papers reporting an indication of the level of need were relevant to estimating the need within the UK population.

## Output (2.2) Establish existing data around background conditions.

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## Context

### UK AAC service provision

The commissioning and provision of AAC services across the UK have developed over the last 20 years and led to different arrangements in different parts of the country. In some areas specialist AAC services have been jointly commissioned (with separate or pooled budgets). In other areas AAC budgets have been combined with broader equipment budgets receiving funding from local authorities and health authorities. Other models have incorporated funding for AAC within broader service specifications which have not identified the services separately. The funding for equipment in some areas has been in addition to or omitted from funding of the service.

This project cannot be seen in isolation from the policy and service delivery climate. The initial planning (2009) of this project was, in part, a response to the Bercow Report (July, 2008) "A Review of Services for Children and Young People (0–19) with Speech, Language and Communication Needs". Policy has been developing from this throughout the duration of the project and there has been an unprecedentedly high level of policy and campaigning activity during this period. This has culminated in significant changes in the proposed commissioning of services delivering AAC.

### UK policy context

#### Bercow review

In 2007 the Labour government commissioned John Bercow to investigate the system for providing support to children and young people with speech, language and communication needs (SLCN) in England which was routinely being described by families as a 'postcode lottery', particularly in the context of their access to speech and language therapy (SLT). His report (Bercow 2008), which followed 10 months of evidence gathering and consultation with a wide range of stakeholders, concluded that the needs of many children and young people were still not being met and that 'children and young people who require AAC face a particular struggle to have their needs met under the current commissioning arrangements'. The review found no consistent or equitable system (locally, regionally or nationally) for ensuring that those who needed communication aids received them.

#### Better communication action plan and communication champion

The Government's action plan (December 2008), responding to the Bercow Report, established the role of the Communication Champion which was to include reviewing the effectiveness of augmentative and alternative communication provision in different areas of the country and to identify good practice to inform the development of future initiatives with the aim of improving services. Jean Gross published a final review of her Communication Champion role (Gross 2011b) and also a specific report on AAC (Gross 2011a). The review conducted by Gross focused on high technology communication aids, rather than devices such as charts and communication books with pictures, symbols or photos, since it is in this 'high-tech' area that learners experience the greatest difficulty in securing appropriate provision.

The report identified much good practice in local areas. This included detailed assessment, the opportunity to trial aids until the right match to needs could be found, adaptations to fit the aid to a wheelchair and/or to integrate it with environmental control systems, ongoing training for users, the adults they live with and the adults who work with them at school and in other settings, rapid technical help if the aid ceases to function, and regular review to check that goals are being met and defined outcomes achieved.

To fulfil these functions, the effective PCTs and local authorities visited provided local multi-agency specialist teams, supported by regional centres of excellence. A budget was identified for communication aids and allied services, to plan multi-level training for the children's workforce, and to attend to the issues that can arise at the transition between child and adult services.

However, Jean Gross found that many local areas failed to make effective provision. One in five of the areas visited lacked local specialist expertise, and many were struggling to fund AAC. Data from AAC suppliers also indicated that the estimated level of need was not being met.

At the time, NHS guidance in the form of the Specialised Services Definition Set Number (NSSDS) 5 - "Assessment and provision of equipment for people with complex physical disability". Communication aids services were included in this definition set which stated that "the 10 Specialised Commissioning Groups, acting on behalf of their member PCTs, are responsible for the commissioning arrangements for specialised services." However, Jean Gross' report concluded that only one of ten specialised regional commissioning teams was fulfilling this function.

The report from the Communication Champion recommended that:

- government ask the new NHS Commissioning Board, once established, to take forward the commissioning of regional AAC 'hubs' as a matter of urgency;
- government consider commissioning regional AAC hub services on an all-age basis, that also includes the full range of high technology assistive technology as well as communication aids;
- government ask NICE to review and if appropriate adopt quality standards for AAC which are currently being prepared;
- quality standards include better signposting of services for individuals, parents and professionals working with children and adults who would benefit from AAC;
- government grants to providers of AAC services are maintained until the end of March 2012, as originally planned in the Better Communication Action Plan, or until such time as the NHS Commissioning Board has completed the process of commissioning regional hub AAC services, whichever is the earlier;
- commissioning tools for speech, language and communication needs, currently being developed within the Better Communication Action Plan Pathfinder programme, should include a description of how the local need for a 'spoke' AAC service should be assessed, what an effective service should look like (based on the quality standards that are in preparation), and how its impact could be measured;
- government work with Communication Matters to develop outcome measures that effectively capture the impact of AAC on users' quality of life and social participation;
- the special educational needs and disability review being undertaken by government considers changes to the current Statementing system so that Statements (or any mechanism that replaces them) specify the levels of competence in AAC required by teachers and teaching assistants in regular contact with the child.

This report suggested that the annual cost of providing communication aids to every child or young person in England who needs one is in the order of £6.5 million per annum, but benefits, in terms of an increase in the numbers of economically productive adults, can be large. If even one in ten children provided with aids and associated services were as a result able to enter permanent employment, this would realise estimated benefits of £310m to the economy over those individuals' working lives.

### NHS reforms

During the period of the Communication Champion's post, a new coalition government came to power (May 2010) and almost immediately implemented a process of overarching reform of the NHS. At the same time, cost improvements of 4% were being expected of the NHS.

The NHS White Paper 'Equity and Excellence: Liberating the NHS' was published in July 2010. This white paper proposed fundamental changes to the commissioning of all NHS services. These changes included specialised services (as defined, at the time, by the Specialised Services Definition Sets). The AAC community carried out significant campaigning and response to the White Paper consultation aimed at using the opportunity of these changes to improve the provision of AAC and AAC equipment.

The legislation was passed into law as the 'Health and Social Care Act 2012'. This has been described as "the most extensive reorganisation of the structure of the National Health Service in England to date."<sup>1</sup> The legislation takes effect from April 2013.

The Act created a new national NHS Commissioning Board (NHS-CB) to oversee commissioning of all NHS services. The NHS-CB directly commissions a very small number of highly specialised services and holds a budget 'top sliced' as a percentage of the whole NHS budget. The commissioning of the next 'layer' of specialised services - now known as 'Prescribed Services' - is overseen by the NHS-CB, but managed through 10 of the new 'Local Area Teams'. All other services will be commissioned through Clinical Commissioning Groups - consortia of GPs.

### Specialised Services

A process of evaluation of the current NSSDS was carried out in order to confirm the commissioning route of all of the listed specialised services. This process consisted of the creation of a clinical advisory group for prescribed services. This group consulted 60 further clinical reference groups and recommended which health services for interventions for people with complex conditions should be included in the Commissioned Services list from April 2013. This 'Manual for Prescribed Services' includes the recommendation that "Specialist Augmentative and Alternative Communication Aids" services and equipment should be commissioned by the NHS Commissioning Board via 10 Local Area Teams.

In June 2012 the Department of Education commissioned 4 regional groups to work to support the transition to the new commissioning model.

1 "Dr Lansley's Monster", BMJ 2011; 342. <http://www.bmj.com/content/342/bmj.d408>

## Local AAC services

While the legislation has potentially improved the picture for commissioning of specialised AAC services (dependent on implementation), the commissioning of local AAC services remains unclear. Much AAC provision occurs through local NHS services - i.e. Speech and Language Therapy services, as well as via Education, Council and Social Care services. NHS components of this provision will be commissioned through CCGs, however there appears to be no guidance on CCGs on commissioning these local AAC services and local variation may well continue.

There is a highly dynamic policy and economic background to the data collection carried out in this project. This undoubtedly affected the data collection. However, it also allowed for a direct and dynamic link between the research, policy and campaigning activity.

## Study overview

### Introduction to the research data

The data collected during this project is presented in this report, structured by the overarching themes and research questions related to need, service provision and use.

The overall potential need for AAC has been defined by epidemiological investigation and this potential need has been put into context by the extensive information gathered from over 150 users, professionals and others.

Existing service provision was investigated through an analysis of the qualitative data which generated a framework of potential AAC service components. This set of components represents the range of possible activities associated with the provision of AAC and aided communication services. As well as a summary of the participants' perceptions of each component, each component has been defined using a Delphi methodology to reach consensus.

The picture of current UK AAC service provision is reported through analysis of data returned from wide-ranging surveying of UK services. This analysis allows identification of variances in service provision and models in the UK.

Data on the current level of use of AAC and, in particular, aided communication, is provided through analysis of data returned from AAC services in the UK. Qualitative data from participants gives context to this potential gap between current service provision and the potential for AAC use.

## Approvals

Ethical approval for the project was granted by the Leeds NHS Research Ethics Committee for those aspects of the project involving recruitment (of professionals and patients) through the NHS. The School of Health and Related Research Ethical Panel granted Ethical approval for those elements not involving recruitment through the NHS. A single protocol was developed for all aspects of the project.

Barnsley Hospital NHS Foundation Trust acted as the research study sponsor NHS site and the study was placed on the CLRN portfolio.

Research governance approval was obtained for all areas in which patients or professionals were recruited.

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# Chapter 2: Quantitative data

## Collecting data on the need and use of AAC.

There are five sections within this chapter. The first describes an epidemiological approach to deriving the number of people who could benefit from the use of powered aided communication. The second presents service data gathered from AAC services across the UK. The third section takes the data gathered and attempts to match it against criteria for defining specialised services to categorise the services in their degree of specialism. The fourth section derives the number of people who are currently using powered aided communication across the UK and the fifth section validates this derivation using data from other sources which contribute to the provision of AAC and related services.

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### Epidemiology

#### Introduction

It is important to clarify why it is necessary to establish the numbers of individuals requiring AAC and aided communication. Having an estimate of the numbers of individuals requiring services is necessary for the development and commissioning of services. These numbers will also assist in identifying unmet need and benchmarking of provision.

The literature review in chapter 1 of this report provides information on prevalence of users of AAC services. The lack of clarity on the prevalence of need for AAC is due, in part, to the fact that the provision of services is determined geographically and not on need i.e. some services provide services to children alone, others provide for adults with acquired conditions.

There are several reasons why it is difficult to make precise estimates of need. The numbers of disabled children surviving longer is growing, the numbers of individuals living with complex neurological conditions is increasing, and there is increasing sophistication of AAC strategies and equipment which can be accessed by persons with a greater range of difficulties. For example, one study (Parrott, Tilley, & Wolstenholme, 2008) reported that the numbers of young people aged 15 – 19 years who had severe or complex needs had increased by 70% in the period 1998 to 2008. Furthermore, the expectations of individuals and their families along with greater realisation of untapped potential may contribute towards an increased demand on services and uptake of AAC.

It is hypothesised that the prevalence figures used in the past are likely to be an underestimation and figures need to be reviewed on a regular basis because of these changing contexts. A report on AAC use in children aged 0 – 19 years in England identified an under-identification of children who could benefit from using AAC (Gross, 2010). The population requiring and benefitting from AAC systems is likely to increase with the increased survival rate of people with complex difficulties and the development of new AAC systems that can help a wider population, such as in Autism and Dementia.

Estimating need for services is important for service planners in local authorities, education and health services. Recent changes require more explicit commissioning and are encouraging greater clarity regarding integrated services for those with complex needs. Basic data on prevalence and needs of service users is required at the starting point for many of these important discussions and is necessary to ensure equity of provision.

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### Existing data on prevalence of AAC need

#### Method

The research reported here has considered the issue of prevalence of the need for AAC by examining information from many different sources in order to triangulate the data and determine a more informed estimate.

Searches were performed on The NHS Information Centre for Health and Social Care<sup>1</sup> and the UK National Statistics Publication Hub<sup>2</sup> to identify potential sources of useful data for the identification of numbers of people with speech, language and communication needs which could lead them to need to use AAC. Data sources were identified as the General Practice Research Database (GPRD) (now the Clinical Practice Research Datalink) and the English Health Survey. These sources were searched to provide information about statistics relevant to the need for AAC.

1 <http://www.ic.nhs.uk/>

2 <http://www.statistics.gov.uk/hub/>

### General Practice Research Database (GPRD)

The GPRD is taken from UK primary care data, covering approximately 8.32% of the population and containing data from over 600 practices (July 2011 – 629). The database provides research standard information on 11.39 million patients, of which 5.14 million are currently active (July 2011). Research standard records are those which have been accurately completed where the content does not reveal any inaccuracies that raise an issue of validity of information provided. Inactive patients are those who have either died or who are currently no longer at a primary care practice where data is collected for the GPRD.

Data for the GPRD is collected through the Vision (INPS) local clinical system. The Vision interface and guidelines are provided for the practices involved in collecting the data. The guidelines state that the GP should record any prescriptions, consultations or clinical contacts, episodes of illness, referrals, hospital admissions, surgery, pregnancy, childbirth, date and cause of death, diagnoses, test results, immunisations and lifestyle information (such as smoking or drinking). These records are Read coded, a system of codes by which patient findings and procedures are recorded, which allow systematic extraction of data from the patient's clinical record.

Initial searches of the Read codes were examined (using both the GPRD medical browser and the Read code browser available from the Technology Reference Data Update Distribution Service) and the following information was found:

- There are no specific Read codes for AAC services or referral to AAC services
- There are no specific Read codes for particular equipment relating to communication
- There are Read codes for "Provision of communication aid", "Communication aid" and "Keeping communication aid by patient"
- There are codes which indicate that the patient could benefit from communication support: "Unable to speak", "Does not speak", "Unable to speak intelligibly", "Does not speak intelligibly"

Searches were performed on these Read codes as an initial feasibility study for whether this search would yield useful results for the project using the GPRD.

### Health Survey for England

The Health Survey for England is a series of annual surveys commissioned by the Department for Health. It has a set of core questions and additional module questions which vary every year that the survey is distributed. The questions are asked to approximately 16,000 adults and 4,000 children (1995) although this is variable dependent on the year.

In 1995, 2000 and 2001, the questions included modules on aspects of disability, specifically including questions on communication impairment. Questions on sight and hearing were asked separately. The questions relevant to providing information about the sample's need for AAC were:

- Has difficulty speaking?
- Level of difficulty communicating?
  - moderate – difficulty communicating with other people
  - severe – difficulty communicating with close relatives
- Has a communication disability?

Responses to these questions were extracted from the database via the Economic and Social Data Service<sup>3</sup> for each available year.

### Results

Existing data extracted from the GPRD using the identified Read codes are shown in Table 2.1. The total number of patients identified as using or could need AAC is 55 out of a total of 5.14 million. This translates to 0.001% of the population or 1 per 100,000 population.

**Table 2.1: Results of the GPRD search of patient records for detail on number of people who use or could benefit from AAC from a sample of 5.14 million records**

Code	Number of patients
Provision of communication aid	9
Provision of communication aids	6
Keeping communication aid by patient	0
Unable to speak	28
Does not speak	11
Unable to speak intelligibly	1
Does not speak intelligibly	0
<b>Total</b>	<b>55</b>

Table 2.2 shows the results of the Health Survey for England extraction to estimate the numbers of people in the sample who could benefit from AAC. The definitions of moderate and severe are: those people who have difficulty communicating with others (moderate) and those people who have difficulty communicating with those familiar to them (severe) (correct to 1 decimal place).

**Table 2.2: Results of the Health Survey for England extraction to estimate the numbers of people in the sample who could benefit from AAC**

Question	Answer	1995 <sup>4</sup>	2000 <sup>5</sup>	2001 <sup>6</sup>
Has difficulty speaking?	Yes (%)	0.6	3.5	0.4
Level of difficulty communicating?	Moderate (%)	0.5	2.5	0.5
	Severe (%)	0.4	3.9	0.4
Has a communication disability	Moderate (%)	0.9	3.2	0.7
	Severe (%)	0.4	3.9	0.4

## Discussion

The results from the GPRD and English Health Survey database searches suggest that there are very few people in the UK who have severe communication impairments and who have been reported to use AAC. These are unfeasibly low numbers which are so significantly different from the best estimate figures on people who could benefit from or use AAC (1% of the UK population, (Scope, 2008)), that the results suggest that this database is not suitable for extracting this type of information.

The guidelines for filling in the records place emphasis on recording drug prescriptions and significant morbidity events along with a summary of previous medical events that occurred before the patient registered with the practice. The guidelines state that:

“Any information which is required for the clinical care of the patient may be recorded in the computer record” (GPRD, 2004, p11)

There is, however, no requirement to record information that could contribute to clinical care or the way that care is delivered, including primary mode of communication or other communication skills. Data can only be extracted if it is entered into the system. If there is no requirement for status or disability information, the only access is through data that is collected consistently throughout the database, which in this case is primarily diagnosis, episodes of illness or prescribed drugs.

The English Health Survey data shows some discrepancy in the results for 2000. This can be attributed to the survey sample being biased towards older people who were the focus of the survey in that year. The results of information gathered from that year show that for those over 65 and over who lived in care homes there was 34% prevalence of people who had a communication disability which contrasts with 2% of people of the same age in private households who have a communication disability. The other years which have asked these questions surrounding communication (1995 and 2001) show some consistency, indicating that there are approximately 0.4% of the population who both have difficulty speaking and have a severe communication disability.

The existing data suggests a need for more accurate and up to date information to capture the need for AAC in the UK.

- 4 Joint Health Surveys Unit of Social and Community Planning Research and University College London, Health Survey for England, 1995 [computer file]. 4th Edition. Colchester, Essex: UK Data Archive [distributor], April 2010. SN: 3796 , <http://dx.doi.org/10.5255/UKDA-SN-3796-1>
- 5 National Centre for Social Research and University College London. Department of Epidemiology and Public Health, Health Survey for England, 2000 [computer file]. 4th Edition. Colchester, Essex: UK Data Archive [distributor], July 2011. SN: 4487 , <http://dx.doi.org/10.5255/UKDA-SN-4487-1>
- 6 National Centre for Social Research and University College London. Department of Epidemiology and Public Health, Health Survey for England, 2001 [computer file]. 3rd Edition. Colchester, Essex: UK Data Archive [distributor], April 2010. SN: 4628 , <http://dx.doi.org/10.5255/UKDA-SN-4628-1>

**Key Point 13**

existing data stored in the UK regarding the need for AAC is limited. The English Health Survey data suggests that 0.4% of the population have both difficulty speaking and a severe communication disability.

**New data on the prevalence of AAC need**

Estimates of need for AAC cannot be determined from the existing data searches therefore an approach was taken to estimate the prevalence of need for the entire population of the UK derived from literature and using a full set of conditions identified as causing speech, language and communication needs to the extent that the individual could benefit from using AAC. Validation of the results was performed through consultation with professionals who work with the target populations who helped to inform the numbers of people with each condition who could benefit from AAC.

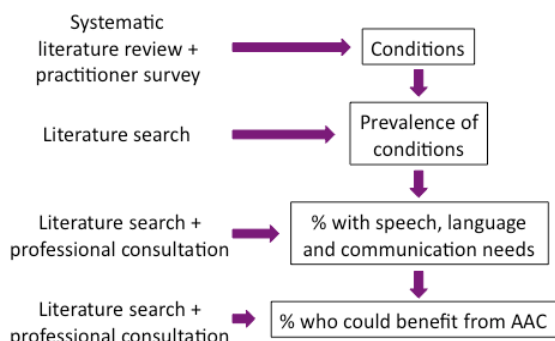
**Method**

The conditions were initially identified using the systematic literature review (see chapter 1) and expanded upon using the practitioner survey which requested information on numbers of individuals using powered aided communication known to the service split by condition. A request was made for the services to indicate any other conditions not listed for individuals that were known to the service. Literature searches provided the prevalence of this set of conditions taking numbers based on research in the UK where possible. Databases including MEDLINE were used to access medical literature to search for individual condition prevalence data published in journals and the NHS Information Centre provided links to other literature not accessed through MEDLINE.

Literature was searched to provide a list of aetiologies of people who use AAC. The percentage of that population who had speech, language and communication needs was deduced and finally a percentage of people who could benefit from AAC was attributed to that population. The staged process to collecting this data is summarised in Figure 2.1.

To complete the set of data, experienced and specialist speech and language therapists involved in the treatment of people with the conditions on the list were consulted to assist with providing estimates of percentages of people with speech, language and communication needs and those who could benefit from AAC. This provides an overall estimate of the need for AAC specific to the UK population.

**Figure 2.1: the staged process to derive the figures for the percentage of people who could benefit from AAC.**

**Results**

The data collected across all conditions is displayed in Table 2.3. These conditions represent the most common conditions identified for people who use AAC. There are a large number of other more rare conditions which may result in people having AAC needs but we have insufficient information to arrive at a reliable estimate. It should also be noted that people often have co-occurrences of some of these conditions, for example cerebral palsy with learning disabilities.

Table 2.3: prevalence of conditions associated with use of AAC (correct to 1 decimal place).

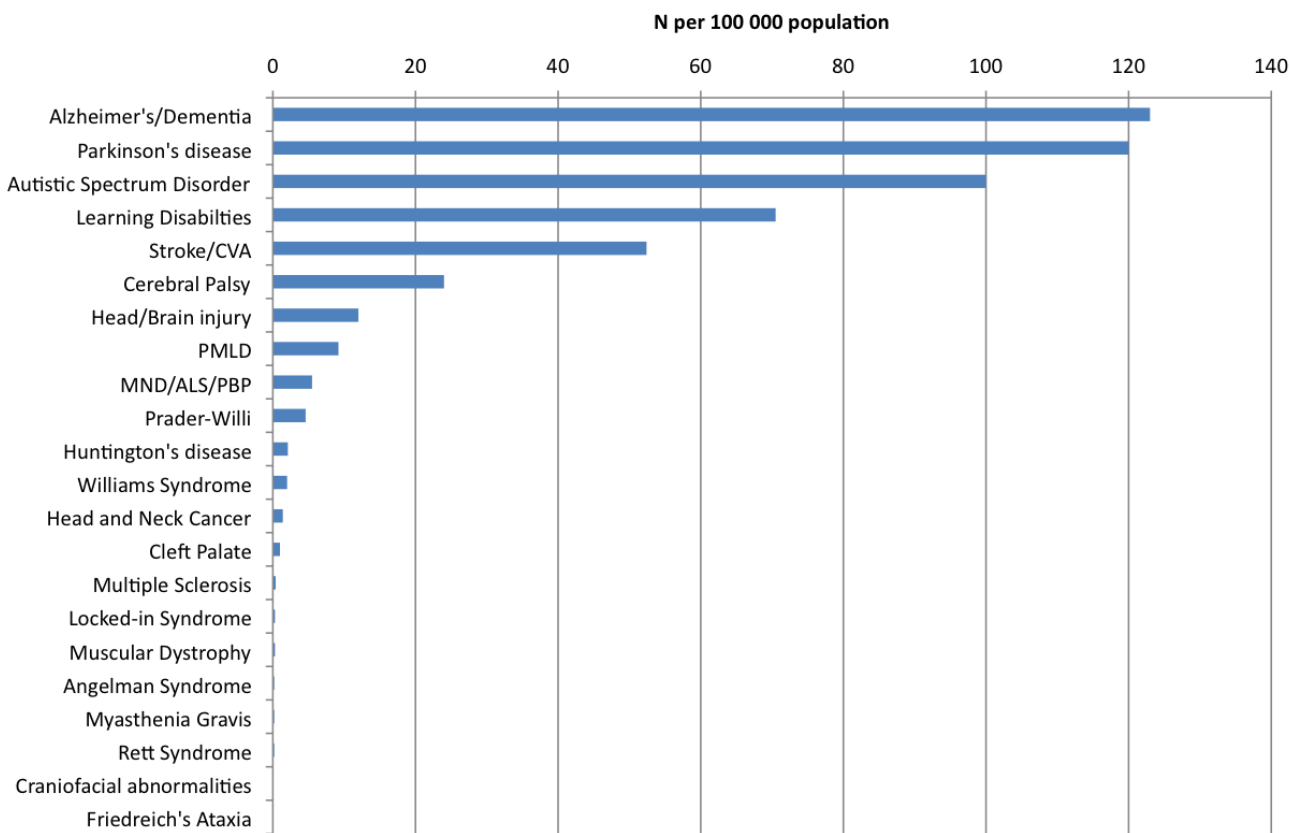
Condition	Per 100,000 population	Language or communication needs %	Language or communication needs (Per 100,000 population)	Who could benefit from AAC %	AAC (Per 100,000 population)
Autistic Spectrum disorder	1000	100	1000	10	100
Learning disabilities	469.9	100	469.9	15	70.5
PMLD	36.7	100	36.7	25	9.2
Cleft Palate	145	68	98.6	1	1
Craniofacial abnormalities	0	0	0	0	0
Cerebral palsy	200	60	120	20	24
Muscular Dystrophy	12.5	25	3.1	10	0.3
Williams syndrome	13	60	7.8	25	2
Myasthenia Gravis	8	25	2	8	0.2
Rett syndrome	0.4	100	0.4	50	0.2
Huntington's disease	7	60	4.2	50	2.1
Angelman syndrome	10	100	10	2	0.2
Prader-Willi	10	91	9.1	50	4.6
Stroke/CVA	874	30	262.2	20	52.4
Head/brain injury	300	20	60	20	12
Locked-in Syndrome	2	100	2	16	0.3
Head and neck cancer	6	90	5.4	25	1.4
Multiple sclerosis	150	23	34.5	1	0.4
MND/ALS/PBP	8	95	7.6	72	5.5
Parkinson's disease	200	80	160	75	120
Alzheimer's/Dementia	1230	100	1230	10	123
Friedreich's ataxia	2.5	0	0	0	0
<b>Total</b>	<b>4685</b>		<b>3523.5</b>		<b>529.3</b>
<b>% of UK population</b>		<b>3.5%</b>		<b>0.5%</b>	

Key Point 30

We estimate that 0.5% of the UK population require AAC. This equates to 529 people per hundred thousand population. The population of potential AAC users has a broad range of complex conditions with different underlying medical diagnoses

Figure 2.2 shows the number of people who could benefit from AAC per condition per 100,000 population.

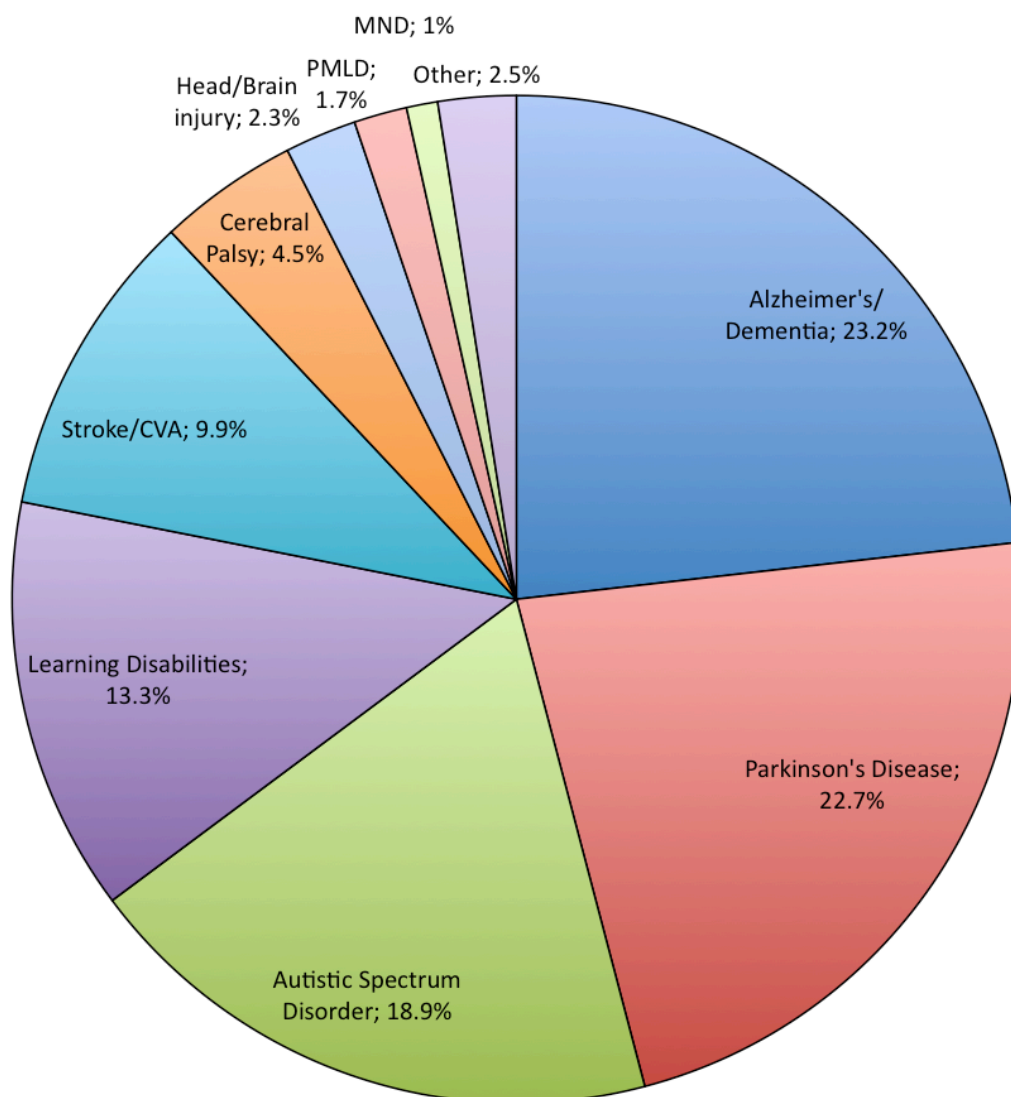
Figure 2.2: the number of people who could benefit from AAC per condition per 100 000 population.



From this analysis, the largest population of people who could benefit from AAC are those with dementia, with large populations of people with Parkinson's disease, Autistic spectrum conditions, Learning disabilities, Stroke/CVA, Cerebral palsy, Head/brain injury, Profound and Multiple Learning Difficulties and Motor Neurone Disease.

**Figure 2.3: the percentage of the total number of people who could benefit from AAC in terms of the individual conditions. Conditions comprising "other" are: Prader-Willi, Huntington's disease, Williams Syndrome, Head and neck cancer, Cleft palate, Multiple Sclerosis, Locked-in syndrome, Muscular Dystrophy, Angelman syndrome, Myasthenia Gravis, Rett syndrome, Craniofacial abnormalities, Friedreich's ataxia.**

Figure 2.3 shows the profile of the total population of people who could benefit from AAC as derived from the literature searching and professional consultation. 97.5% of the total number of people who could benefit from AAC have 9 conditions. The 2 conditions that represent 45.9% of that population consist of Alzheimer's/Dementia and Parkinson's disease, conditions associated with an ageing demographic of the population.



**Key Point 31**

nine conditions account for 97.5% of the total number of people who could benefit from AAC. Just two of these conditions, Alzheimer's/ Dementia and Parkinson's disease, account for nearly half of the total (45.9%). These are conditions associated with an older population.

The difficult addition to the table is to assign the number of people who could benefit from powered aided communication. Powered communication aid use involves more complexities than other aided communication or AAC and appropriate use depends on the condition of the individual and their physical, cognitive, sensory and communication skills and abilities. The best estimate available used by the Communication Champion is that 10% of the population who use AAC could benefit from using powered communication aids. Applying this assumption to the above results for the prevalence of conditions data, the overall percentage of the population who need powered aided communication is 0.05%, 52.9 people per 100,000 and a total of 31,616 people in the UK.

**Key Point 32**

approximately 0.05% of the UK population are estimated to require powered communication aids.

**Discussion**

The new data collated based on prevalence of conditions provides indicators of the size of the expected population who need AAC. The overall expectation is that 0.5% of the population could benefit from AAC, which equates to 529.3 people per 100,000 population and (based on population estimates in mid-2011, 63,232,800 people in the UK (Office for National Statistics, 2013)), 316,164 people in the UK. This fits closely with the data gathered by the English Health Surveys calculations of people with a severe communication disability, which rises to 1% of the population when combined with those people with a moderate communication disability.

The majority of people (97.5%) who could benefit from AAC, from the list of conditions derived, are those who have one of nine aetiologies. There is a large proportion of this number with conditions associated with older populations.

**Limitations**

This data may be considered an under-estimate of need as it relies on having identified the full set of conditions that may result in the potential need for AAC. However it is suggested that the majority of the populations have been covered in this analysis (as validated against the reported service data) and that any additional conditions are likely to add only marginally to the total estimate.

Other possible limitations to the data may arise from 'double counting' within the conditions where populations of people with secondary conditions are included in both of the epidemiology statistics. However, the data reported above is for primary diagnosis so this effect should be minimal.

The estimates of the % of the populations that may benefit from AAC are based on expert professional opinion. This may be subject to a level of error. For the high incidence populations, such as Alzheimer's or ASD, small variations in this estimate can have relatively large effects on the total estimate.

**Validation exercise: perspectives of use from services**

To assess the overall validity of these figures in terms of what target population was perceived as being seen by AAC services, the views of individuals involved in AAC were gathered during a conference presentation of this data. This could provide an indication of where there might be gaps in service dependent on condition.

**Method**

A conference presentation was given at Communication Matters conference 2012 (titled Catching up with the numbers) as part of the overall project dissemination. The approach to estimating the need for people who use AAC was presented and followed by an interactive session with the audience participating in voting for answers to questions. The Turning Point electronic voting system was used which took input from handheld key pads and once voting was closed, the results were displayed on the screen.

An initial non-related question was asked which allowed the participants to gain familiarity with the electronic voting system. The first question asked was to establish their role or relationship to AAC.

Secondly, a list of 9 conditions which had been identified as containing the most common conditions of those who use AAC and powered aided communication were provided from which the attendees could choose to rank 1-5 as answers to the following questions:

- What are the top 5 main conditions of people who could benefit from AAC?
- What are the top 5 most common conditions of people who use powered aided communication?
  - Choice of: Autistic spectrum disorder, Learning difficulties, Profound and Multiple Learning Difficulties, Cerebral palsy, Motor neurone disease, Multiple sclerosis, Parkinson's disease, Stroke/CVA, Alzheimer's/Dementia

The results were collected automatically and presented in graphical form back to those attending the workshop. These results were then compared to the figures gathered from literature and professional consultation.

## Results

The results of the validation exercise were submitted by between 35 and 39 people for each question. The inconsistency is attributed to either where people have not answered the question within the allotted time or chosen not to answer that particular question.

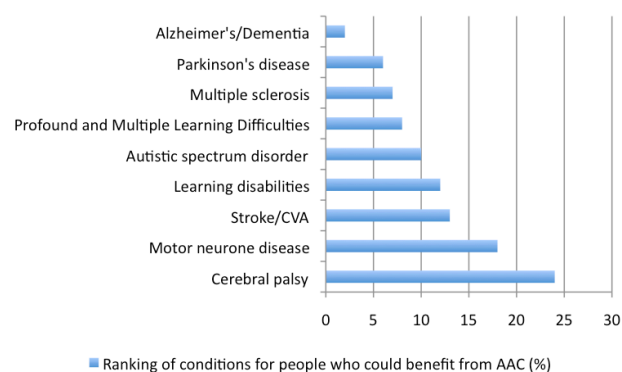
The response to the initial question: "Who is here?" asking who was attending the presentation and held the keypads is shown in Table 2.4. There was a total of 38 people responding with the majority being AAC practitioners.

**Table 2.4: Response to 'Who is here?' question.**

Role	Response (N)
AAC practitioner	23
Person who uses AAC	2
Family member/assistant of person who uses AAC	2
AAC company employee	2
Researcher in AAC	3
Other interested person	6
<b>Total</b>	<b>38</b>

Figure 2.4 shows the results of the question asked "What are the top 5 main conditions of people who could benefit from AAC?". The % ranked shows the overall ranking of that condition by the participants.

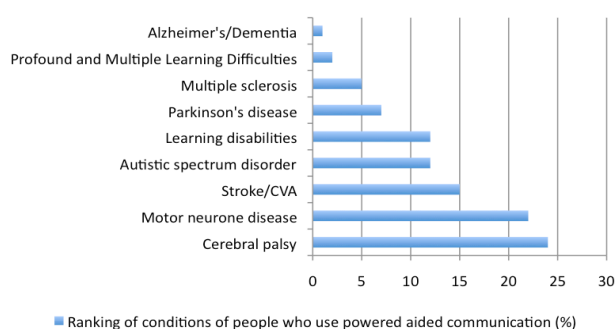
**Figure 2.4: The results to the question "What are the top 5 main conditions of people who could benefit from AAC?" as answered by an audience of approximately 60% AAC practitioners. The % represents an overall ranking of that condition by the participants.**



The results show an overall ranking of the most common conditions of people who could benefit from AAC as being: Cerebral palsy, Motor Neurone Disease, Stroke/CVA, Learning disabilities, Autistic Spectrum. The lowest ranked conditions were Alzheimer's/Dementia and Parkinson's disease.

The results to the second ranking question "What are the top 5 most common conditions of people who use powered aided communication?" are displayed in Figure 2.5.

**Figure 2.5: The results to the question “What are the top 5 most common conditions of people who use powered aided communication?” as answered by an audience of approximately 60% AAC practitioners. The % represents an overall ranking of that condition by the population.**



The results show an overall ranking of the most common conditions of people who use powered aided communication as being: Cerebral palsy, Motor Neurone Disease, Stroke/CVA and Learning disabilities and Autistic Spectrum with equal ranking. The lowest ranked condition was Alzheimer's/Dementia. Parkinson's disease has moved higher up the rankings for powered aided communication than its position for AAC in general.

### Discussion

The validation exercise showed that there was some difference between the perception of AAC use and the estimated need calculated from conditions. The main disparities are the results for Alzheimer's/Dementia and Parkinson's disease. These conditions account for the highest expected number of people who could use AAC, but did not feature highly in the list of conditions as ranked in the validation exercise. Alzheimer's/Dementia features 9th in the ranking for AAC and powered aided communication. Parkinson's appears 8th in the ranking for AAC and 6th in the ranking for powered aided communication. This increase in ranking between AAC and powered aided communication could be indicative of the prevalent use of voice amplifiers for people with Parkinson's disease.

The prevalence data exercise also puts Cerebral Palsy and Motor Neurone Disease lower in the expected number of people who could benefit from AAC and powered aided communication compared to the ranking exercise where they are placed 1st and 2nd.

There are a number of potential causes for this discrepancy in the data:

- 1 The cohort completing the validation exercise were biased towards services providing (electronic) aided communication. The epidemiology of this population may be significantly different to those who need AAC more generally.
- 2 The cohort completing the exercise may have skewed the data towards indicating that there were more people accessed who have conditions more associated with a younger population such as Cerebral Palsy.
- 3 Services providing AAC have not adapted to meet the potential demand from these populations. Many of those with Alzheimer's/Dementia and Parkinson's disease are not being reached by AAC services.
- 4 The estimates of potential need for AAC within the data are too high due to reliance on some estimates.

The results of this exercise indicate that it may be unlikely that a simple 10% of those people who could benefit from AAC is an accurate estimate of the population who use, or could use, powered aided communication devices due to the potential differences in epidemiological profile between the two populations.

#### Key Point 33:

the validation exercise showed that there was some difference between the perception of AAC use and the estimated need calculated from conditions. Of particular note is the discrepancy relating to Alzheimer's disease and Parkinson's disease.

#### Key Point 34:

there may be a large unmet need for AAC within the population of people with Dementia and Parkinson's Disease. This may be as the result of amenable technologies becoming available but distribution, practice and use are lagging behind. This discrepancy may be caused by other factors and warrants further investigation.

## Overall analysis

This section has shown that there are few existing primary sources from which an estimate of need for AAC based on evidence can be obtained. Existing sources have been shown to be unsuitable or lack data. The only source of some use, the Health Survey for England, can only be used to validate the scale of the estimates of need.

The estimate of need resulting from this data has suggested a potential need for AAC of 0.5% of the UK population. The estimate depends on a range of factors, including that this is a full identification of the set of relevant conditions and therefore it is suggested as an indication of the need for AAC.

There may be a discrepancy between the profile of people currently using AAC and those that could benefit. This may be for a number of reasons, potentially including problems in accessing AAC services for older people.

If accurate figures on the potential need for and use of AAC are to be achieved, data needs to be consistently recorded at a community level. We would suggest that GPs should collect this data on the established systems as part of the increasing requirement for them to collect population and public health information to inform commissioning.

## Service models

### Introduction

The provision of services for aided AAC has previously been described as 'varied' (Gross, 2010), however there has been little work to understand the differences in provision in depth. There were no studies identified in the systematic review undertaken and reported in chapter 1 that dealt with descriptions or evaluations of service models.

It has also been highlighted that little data exists around the current provision of aided AAC services. Such information could contribute to the understanding of the current use, equity of provision and potential need for aided AAC. The focus for this part of the study was on those services, teams or departments which provided services for aided communication. Focussing on a smaller set of specialised services which have been accessed by a high proportion of the number of people who use powered aided communication in the UK allows more accurate estimates to be made.

The aim of this study was to define the types of services offered by AAC practitioners across different services in the UK and the routes to provision of services, and to understand better how to characterise and describe service provision in this area. With no current standardised method for describing services, a survey would need to be developed which was flexible enough to capture all the possibilities of the services but constrained enough to provide options for categorisation standardised across all services.

Practitioners were consulted to provide data on their own service provision and how it relates to other related providers, such as suppliers and charities.

## Service data using Practitioners' survey

### Method

To quantify use of AAC and collect data on service provision, a survey was developed informed by the literature discussing service provision of AAC services and based on the knowledge and experience of an expert group of researchers and clinicians in the area. The survey was developed to capture information from all types of services for AAC whether they were commissioned specifically for that purpose or whether providing AAC resources was included as a small part of the service's remit. The survey was designed to allow data to be gathered from all practitioners based across all areas of health, education, social services and those in independent practice.

The aim was to collect data from both specialised centres to focus on those services with a large volume of people who use powered aided communication and as many local services involved in AAC as possible to capture information about the types of service models available.

The survey was developed in paper and online formats (Word form and online survey, using LimeSurvey software).

The Practitioner's survey was distributed initially for piloting with delegates attending the Communication Matters conference 2011. It was distributed in paper format to all practitioners attending and contained a link to an online version.

Modifications were made based on discussions with those who had completed the initial surveys to resolve ambiguities or difficulties encountered.

The Practitioner's survey was then distributed across all known services identified through the Communication Matters assessment centre list, those services identified by a scoping survey (as detailed in chapter 3) and any other AAC practitioner who was fortuitously encountered throughout the project. There were five sections to the survey, which is included in Appendix 9:

- 1 Information about you: information to allow identification of the service, team or department and individual completing the survey for further contact
- 2 Information about your service: information about the type of service, access to the service in terms of client groups, geography, settings and eligibility to access. Information is collected to detail the service skills and resources available.
- 3 Services offered: information about what services are offered by the team.
- 4 Care pathway: information about how people get access to the service and what other services are involved in the provision of AAC.
- 5 Information about your clients: information about the number of people who are seen in the service, conditions of people who are seen by the service and the devices that they use.

From the pilot stage it was clear that not all the services were able to fill in the survey completely. Many services did not collect or were unable to access all the data requested in the survey. There was therefore a request attached that the services should return the survey even if it was partially completed to maximise returns.

Once a survey was returned, the more specialised services were asked whether they could provide any further information about their caseload, such as the first half of the clients' postcode (for identifying the reach of the service and average distance travelled), ages of their caseload or other information that could reveal any information about people who use AAC that could be relevant to the study aims.

In total 200 questionnaires were distributed to individual practitioners (not necessarily distinct services) at the pilot stage and a further 155 distributed to services post-pilot stage, targeting those services identified as being involved in provision of AAC services. In total 92 surveys were returned giving a maximum response rate of 59.4%, taking into account that those surveys distributed could have been distributed to teams that had previously received the survey or where multiple copies were received by different individuals in the same service.

A further more targeted stage of data collection was carried out to attempt to gather as detailed a data set as possible from those services that may be defined as 'specialised services'. These services were requested to provide data many times over the period of a year, including the submission of Freedom of Information requests to some.

It is likely – due to the distribution method of this survey – that these services represent specialist tertiary AAC services, and also relatively specialist local AAC services. These services are all likely to categorise themselves as 'AAC services' – as opposed to other local services who occasionally deliver some AAC provision. The categorisation of services is discussed in more detail later. The data set contains as complete as possible a record of specialised services provision and an incomplete, opportunity sample, of other AAC services.

## Results

### Type of organisation

The AAC teams/services are based in organisations within health, education, social services and the voluntary sector. The breakdown of where the teams are based and function within are shown in Table 2.5 below.

**Table 2.5: The types of organisations and number of AAC services across each sector**

Organisation	Number of teams	% of total returns
<b>Charitable organisation</b>	<b>7</b>	<b>7.6</b>
Local authority	12	13
Higher or Further education	2	2.2
Independent school	1	1.1
State school	1	1.1
<b>Education total</b>	<b>16</b>	<b>17.4</b>
NHS Community Trust	24	26.1
NHS Foundation Trust	18	19.6
NHS Hospital/Acute Trust	10	10.9
NHS Social Enterprise	4	4.3
Other NHS	4	4.3
NHS Community Trust/Hospital Trust/Primary Care Trust	1	1.1
<b>Health total</b>	<b>61</b>	<b>66.3</b>
NHS Primary Care Trust and Local Authority	1	1.1
NHS Foundation Trust and NHS Hospital/Acute trust and Local Authority	1	1.1
<b>Combined health and education total</b>	<b>2</b>	<b>2.2</b>
NHS Social Enterprise (Health and Social services)	1	1.1
<b>Health and social services total</b>	<b>1</b>	<b>1.1</b>
NHS Community Trust and Local Authority and Social services	1	1.1
Health and education and social services total	1	1.1
Independent practice	3	3.3
<b>Other</b>	<b>1</b>	<b>1.1</b>
<b>Totals</b>	<b>92</b>	<b>100</b>

Of those 92 surveyed, 88 (95.7%) employing organisations were reported as single sector (e.g. charity, NHS, local authority). 4 (4.3%) were jointly organised. However, this may be an artefact of the survey where participants were likely to select one answer only.

### Key Point 23

Up to 70% of AAC services responding were health funded with over 66% solely health funded. Less than 5% of services responding to the survey reported joint service funding arrangements.

The majority of those surveyed were based singly within the NHS (61/92 66.3%). The range of NHS organisations involved in AAC service provision are: NHS Community Trusts, NHS Foundation Trusts, NHS Hospital/Acute Trusts, NHS Primary Care Trusts, NHS Social Enterprise, NHS boards (Scotland), NHS Health and Social Care trust (Northern Ireland). NHS Community Trusts (24/92 26%) and NHS Foundation Trusts (18/92 20%) were the most common types of NHS Trusts involved in AAC service provision. The NHS contributes to 65 of the services surveyed (70.6%) including those jointly organised.

Overall, education singly provides 16/92 (17.4%) of the AAC services surveyed, overall contributing to 19/92 services (20.7%) when including those jointly provided. Other organisation types are charitable organisations and independent practice.

### Access to the service: target population (age)

Table 2.6 shows the number of services that are targeted at each client age groups from the services that responded to the survey.

**Table 2.6: the number of services that are targeted at each client age groups who returned data in the Practitioners' survey.**

	Services (N)	Services (%)
Adults	28	30.4
Children	33	35.9
Both adults and children	31	33.7
<b>Total</b>	<b>92</b>	<b>100</b>

**Key Point 27**

Only 33.7% of services responding were accessible to both children and adults.

Figure 2.6 shows the geographical location of the 92 services that responded to the practitioners' survey and whether they provide services for adults, children or both adults and children.

**Figure 2.6: the location of the 92 services that responded to the practitioners' survey and the client age group they provide services for: adults, children or both (adults and children). The map has been generated using ArcGIS online (Map attribute: National Geographic, Esri, DeLorme, NAVTEQ, UNEP-WCMC, USGS, NASA, ESA, METI, NRCAN, GEBCO, NOAA, IPC).**



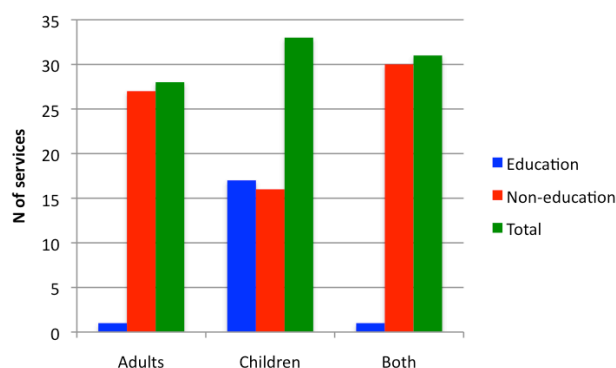
Table 2.7 below shows the number of AAC services by type of organisations and target population by age.

**Table 2.7: the number of AAC services by type of organisations and target population by age.**

Organisation	Adults	Children	Adults and Children	Total
Charitable organisation	1	0	6	7
Education total	1	14	1	16
Health total	25	16	20	61
Health and education total	0	2	0	2
Health and social services total	1	0	0	1
Health and education and social services total	0	1	0	1
Independent practice	0	0	3	3
Other	0	0	1	1
<b>Total (N)</b>	<b>28</b>	<b>33</b>	<b>31</b>	<b>92</b>
<b>Total (%)</b>	<b>30.4</b>	<b>35.9</b>	<b>33.7</b>	<b>100</b>

Figure 2.7 shows the number of AAC services that are organised totally or partially through education against those that are not organised through education. It shows that children's services are organised with a relatively even distribution through education and health and other sources, whereas adult services or those for both adults and children are organised almost exclusively through routes other than education (94.6% and 96.8% respectively). 89.5% of services organised through education have a target population of children.

**Figure 2.7: number of services that are organised through education and through other routes across all age groups.**



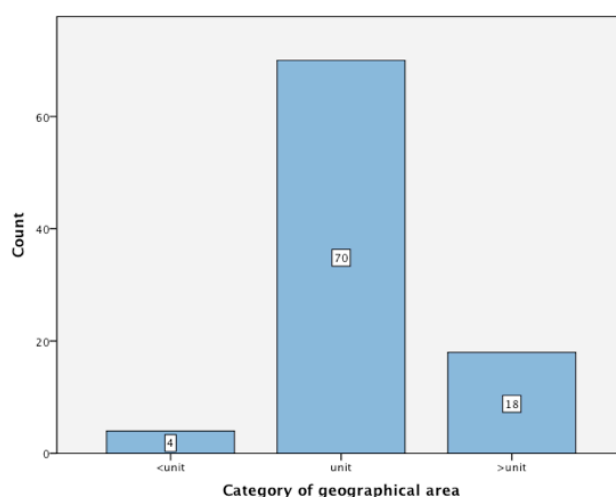
### Access to the service: geographical coverage

The Practitioners' survey asked for the service to describe the geographical area that they covered. The larger the area that would be covered would indicate an increased average distance to travel to get access to the service.

The results were collected and categorised for whether they were an area covered by the trust or health board, the local authority, within an organisation (such as a school or hospital), a county (usually where the service is independent of a health or education authority), a wider region or national coverage. These categories were then combined using a trust, local authority or within an organisation as a basic unit of area. Any coverage which was below this size was categorised as <unit or >unit. The results of this collation are shown in Figure 2.8.

The majority of services cover an area equivalent to a local authority or NHS trust or board area with 18 services (19.6%) of those surveyed covering wider areas such as more than one trust area, regional or national coverage.

**Figure 2.8: The area of geographical coverage categorised for each service respondent. A unit is defined as an area coverage equivalent to that of a NHS trust, local authority or within an organisation with a defined population such as a school, college or in patient hospital.**



### Key Point 25

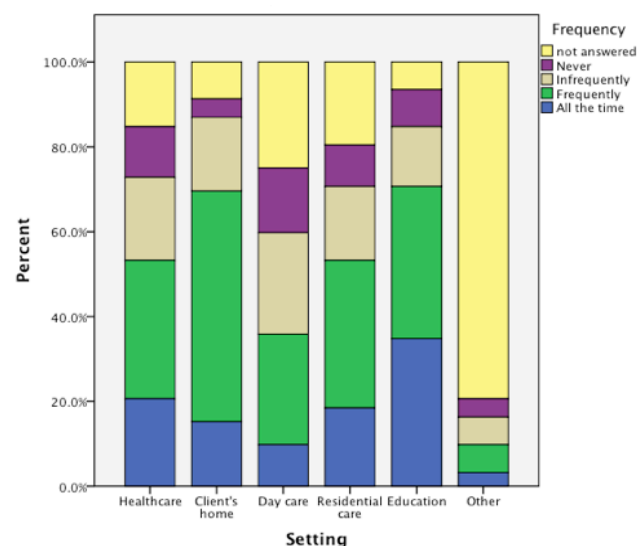
the majority of AAC services responding cover an area equivalent to a local authority or NHS trust/board area with less than 20% of those surveyed covering a wider area.

**Table 2.8: % and frequency of service in different types of settings (correct to 1 decimal place)**

	Healthcare	Clients' own homes	Residential care	Day care	Education	Other
All the time (%)	20.7	15.2	18.5	9.8	34.8	3.3
Frequently (%)	32.6	54.3	34.8	26.1	35.9	5.4
Infrequently (%)	19.6	17.4	17.4	23.9	14.1	6.5
Never (%)	12.0	4.3	8.7	15.2	8.7	4.3
No data (%)	15.2	8.7	20.7	25.0	6.5	80.4
Total	100	100	100	100	100	100

### Access to the service: setting

In addition to other information about types of organisations, the Practitioners' survey aimed to find out in what settings services were offered and how frequently practitioners worked in those settings. The question asked practitioners to define how frequently they worked in the following settings: healthcare, clients' own homes, residential care, day care, education or other. The results are shown in Table 2.8 and Figure 2.9.

**Figure 2.9: Frequency of service in different settings**

The results show that services are most frequently available in clients' own homes and in educational settings. Services are least available in day care settings.

#### Key Point 20

AAC services are commonly delivered in individuals' own settings e.g. either at home or school. This may reflect practitioners' belief in the efficacy of AAC being assessed and used in context.

### Access to the service: eligibility criteria

The practitioners' survey asked the respondents what the eligibility criteria were used for access to their service. 17/92 services stated "none". Age as an eligibility criteria had been collected in an earlier question, with the results shown in Table 2.9. The majority of the services were split into those dealing with all age groups, adults and those of pre-school – secondary school age.

10 (10.9%) of the services deal explicitly with people who have learning disabilities.

Other eligibility criteria varied but could be categorised into issues relating to condition, geography, funding, equipment required, procedure or adherence to the care pathway and abilities of the individual. The range of criteria is detailed in Table 2.10.

**Table 2.9: eligibility criteria relating to age for access to the services**

Age criteria	Number of services
All	26
Adults	24
Pre-school age – Primary school age	1
Pre-school age – Secondary school age	22
Pre-school age – Further education	5
Primary school age – Secondary school age	4
Primary school age – Adult	1
Further education – Adult	2
Other:	
18-22	1
0-19	4
16+	1
No data	1

**Table 2.10: eligibility criteria for access to the services grouped into criteria relating to condition, geography, funding, equipment, procedure and requirements relating to the individual's abilities**

Condition	<ul style="list-style-type: none"> <li>• Acquired neurology disorders in acute hospital setting/ community</li> <li>• Acquired Neurological Disorder</li> <li>• A neurological condition or stroke</li> <li>• School age developmental physical disabilities</li> <li>• Must not have learning disabilities</li> <li>• Must have learning disabilities</li> <li>• Must have a physical disability</li> <li>• Where the medical condition affects their ability to access the curriculum or environment</li> <li>• Lifelong conditions only</li> </ul>
Geography	<ul style="list-style-type: none"> <li>• Have a GP within area</li> <li>• Must live in the area</li> <li>• Must attend that school</li> <li>• Must attend a school within the area</li> <li>• Must be an inpatient in the hospital</li> </ul>
Funding	<ul style="list-style-type: none"> <li>• Secured LEA funding</li> <li>• Service level agreement in place</li> </ul>
Equipment	<ul style="list-style-type: none"> <li>• Referral should be for VOCA use</li> </ul>
Procedure	<ul style="list-style-type: none"> <li>• Statement of Educational Need</li> <li>• Support and commitment from school or other supportive environment</li> <li>• Where all other standard solutions have been tried and are deemed inappropriate</li> <li>• Service can meet their needs</li> <li>• Referral must be agreed (via a signature) by their local Consultant Community Paediatrician</li> <li>• Appropriate postural support is in place</li> <li>• The local therapy team and the client's team are prepared to work jointly with the service throughout the process</li> <li>• In education</li> <li>• Not in full time education</li> <li>• Unable to access outpatient therapy services</li> <li>• Parental permission</li> </ul>
Requirements relating to individual's abilities:	<ul style="list-style-type: none"> <li>• People who are physically unable to access a standard keyboard layout (on a VOCA) or physically able to access a keyboard, and have an additional impairment e.g. visual, learning</li> <li>• An ability to understand cause and effect e.g. purposeful use of a switch</li> <li>• Has some intentional communication. (The ability to initiate communication is some recognisable form)</li> <li>• Some reliable intentional movement</li> <li>• Turn taking skills at some basic level</li> <li>• Has in place a communication system using low tech equipment e.g. communication book/board</li> <li>• Able to locate in category and associate symbols</li> <li>• The client is motivated</li> <li>• The client and his/her team have reasonable expectation/s, are aware of the need for, and prepared for, a period of learning new technologies</li> <li>• Comprehension level above expressive ability</li> </ul>
Other	<ul style="list-style-type: none"> <li>• Different criteria for different parts of pathway</li> </ul>

**Key Point 26**

a broad range of eligibility criteria are used by different services resulting in variable access to services.

Criteria are used related to any combination of: age; condition; geography; funding; equipment use; procedure; and individuals' abilities. Criteria relating to funding of equipment were equally diverse and complex.

**Resources: Funding**

The range of funding was captured by the questions in the practitioners' survey focussing on funding sources for long term and short term provision of equipment.

Questions were asked to determine:

- Whether the service funds provision of powered communication aids for long term use
- Any eligibility criteria to receive funding for provision of powered communication aids
- Equipment budgets for the service
- Sources of funding for equipment

Of the 90 services that replied, 34 fund provision of powered communication aids (37.8%). Of those services, 33 have some eligibility criteria for receiving funding. These criteria have been collated under the following headings and summarised in Table 2.11.

**Table 2.11: eligibility criteria for receiving funding as collected in the practitioner survey.**

Client group	<ul style="list-style-type: none"> <li>Those of 19 years or over who are not in full time education.</li> <li>Has to be in education</li> <li>Pre-school or up to 19 years of age in school</li> </ul>
Geography	<ul style="list-style-type: none"> <li>Have a GP within the area</li> <li>Resident in the area</li> </ul>
Environment	<ul style="list-style-type: none"> <li>Supported network (e.g. school, family)</li> </ul>
Funding	<ul style="list-style-type: none"> <li>Equipment has to be over £200 in special school and £50 in mainstream</li> <li>Insurance has to be in place</li> <li>Not for individuals who have had a medical legal settlement</li> <li>If client fits the funding criteria</li> <li>If funding is available</li> </ul>
Equipment	<ul style="list-style-type: none"> <li>Initial equipment has been bought by the service (cannot fund add-on items or software where the device has been initially self/family funded)</li> <li>Fund dedicated communication aids only</li> </ul>
Procedure	<ul style="list-style-type: none"> <li>Assessment by another service as having a need for the equipment</li> <li>Identified need and justified to the relevant commissioning body (health or education)</li> <li>Request for support from the Specialist Speech and Language therapist</li> <li>Client's school has to demonstrate that it has used all its own resources to help the child before approaching service</li> <li>Statement of SEN</li> </ul>
Individual abilities/experience	<ul style="list-style-type: none"> <li>Have previously tried low/light tech</li> <li>Previously used device successfully through loan</li> <li>Successful trial of equipment for minimum of 3 months</li> <li>Following the assessment 3 targets are set for the child to achieve in 6 months from receiving the equipment.</li> <li>Providing evidence of a need for the equipment (sufficient or potential for improvement in communicative competence)</li> <li>Client has had an assessment and equipment meets the client's needs</li> <li>Motivation to use the device</li> </ul>

Budget information was provided by 30 of the 34 services that provide funding for aids. Reasons given for not providing a response to this question were not knowing and also not being given permission to disclose funding or budget information.

- 4 out of the 30 services (13.3%) do not have a specific budget, but have needs led applications.
- 9 out of the 30 services (30%) have a shared budget, with environmental control and computer access (1), accessed via PCT or other commissioning body (4),

total specialist ICT (including all visual impairment equipment)(1), Information, Communication and Technology (ICT) provision for children with physical disabilities (2), other (1).

- For those services with a dedicated budget who provided an amount (N=19), the budget size ranges from £1,200-£90,000. Of the 19 services providing a total budget, the total sum was £713,700, with an average of £37,563. Table 2.12 shows a summary of the budget information and Figure 2.10 shows the distribution of the budget information for those services.

**Table 2.12: Budget information from 19 services which have a dedicated budget and provided the total amount**

	£ (N=19 services)
Total budget	713,700
Minimum	1,200
Maximum	90,000
Range	88,800
Average budget	37,563

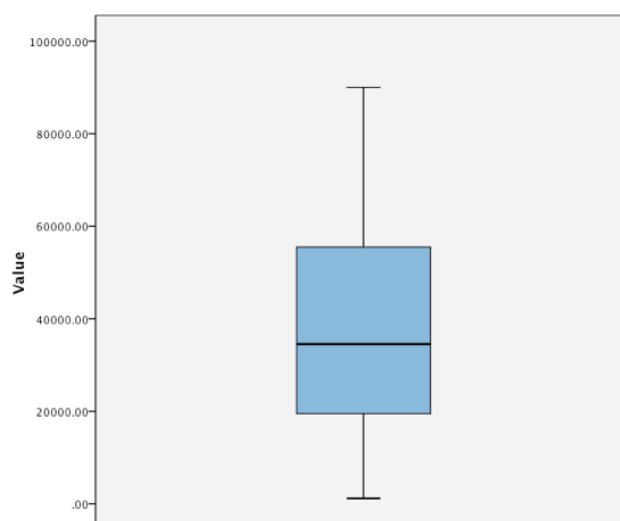
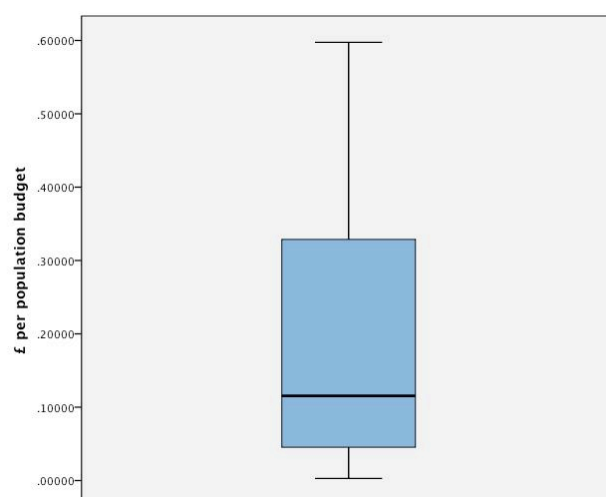
**Figure 2.10: distribution of budget information provided by 19 services.**

Table 2.13 and Figure 2.11 detail the amount of budget information per population head for the services which have provided sufficient data.

**Table 2.13: Budget information from 17 services per population head**

	£ per population head (N=17 services)
Minimum	0.003
Maximum	0.598
Range	0.595
Average	0.194

**Figure 2.11: distribution of budget information per population head calculable for 17 services**



Other sources of funding for aided communication provision were gathered from the services, with the results presented in Table 2.14. Services were asked which sources of funding they used for equipment purchase and could indicate as many sources as necessary. The % represents the proportion of services which indicated that they used that funding source.

**Table 2.14: Sources of funding for the services surveyed.**

Funding source	Service uses (%)	No data (%)
Private purchase	45.7	2.2
Charities	51.1	2.2
Local authority	37.0	2.2
NHS	50.0	2.2
Education	35.9	2.2
Pooled budgets	23.0	2.2
Other	10.9	89.1

Other categories of funding included “social services” (N=3), “grants”, “donations” and specific funds, such as ICES (Integrated Community Equipment Services).

5 out of the 92 services (5.4%) do not use any other sources of funding, external to their own budget, for their provision of aids. 45.7% of services indicated that aids were purchased using private funding and 51.1% of services look to charity for funding of aid provision. These figures may be in addition to other sources of funding.

#### Key Point 28

46% of services relied on private purchase and 51% use charities to fund communication aids for some of their provision.

#### Resources: Teams

The practitioner survey collected information on who was involved in the teams providing AAC services and the whole time equivalent of staff members who worked within the team and the whole time equivalent for those who worked with powered aided communication. The total amount of whole time equivalent for the service and for the proportion of staff who worked with powered aided communication is shown in Table 2.15.

**Table 2.15: Total, average, minimum and maximum amount of whole time equivalent for the service and for the proportion of staff who worked with powered aided communication for the services that responded to the practitioners' survey.**

	Staff in service (WTE) (N=74 services)	Staff in service (WTE) per population head (to 8 d.p.) (N=50 services)	Staff working with powered aided communication (WTE) (N=73 services)	Staff working with powered aided communication (WTE) per population head (to 8 d.p.) (N=49 services)
Total	708.2	–	307.5	–
Average	9.6	0.00004149	4.2	0.00000948
Minimum	0.2	0.00000013	0	0
Maximum	41.3	0.00057930	26.9	0.00001149

Teams involved in AAC service provision are both interdisciplinary and single disciplinary. Job types reported in AAC services from the practitioners' survey are:

- Speech and language therapists (SLT)
- Specialist speech and language therapists
- Clinical Scientists (CS)
- Clinical Technologists (CT)
- Rehabilitation Engineers (RE)
- Teachers
- Occupational Therapists (OT)
- Physiotherapists (PT)
- Assistive Technologists (AT)
- Therapy or other assistants
- Consultant Paediatrician
- Clinical Psychologists
- IT technicians
- Managers
- Administration Staff

Table 2.16 shows the types of teams that deliver AAC services. 52.6% were single disciplinary teams, 47.4% were interdisciplinary. The majority of single disciplinary teams were Speech and Language Therapy teams. Of those teams which were interdisciplinary, the majority included a Speech and Language Therapist with fewer teams containing members of staff associated with skills in assistive technologies (e.g. Clinical Scientists, Clinical Technologists, Rehabilitation Engineers and Assistive Technologists). Table 2.17 shows the types of interdisciplinary teams delivering AAC services, which have a broad range of combinations of staff.

47 of the total number of teams had a Speech and Language Therapist with a specialism in AAC (61.8% of 76 teams returning information), 20 of which were in the single disciplinary SLT teams.

**Table 2.16: Types of teams for the services that were surveyed. 76 returns provided data for this question.**

Type of team (not including management/administration)	Number of teams	% of returns with data (N=76)
Single discipline	40	52.6
SLT	36	47.4
AT	2	2.6
Teacher	2	2.6
Interdisciplinary	36	47.4
Interdisciplinary teams including:		
SLT	33	43.4
OT	20	26.3
Teacher	16	21.1
PT	12	15.8
AT	7	9.2
CT	6	7.9
CS	4	5.3
RE	3	3.9
Total	76	100

**Table 2.17: breakdown of interdisciplinary teams**

Type of team	N of teams	% of total number of interdisciplinary teams (N=36)
SLT,OT,PT	6	16.7
SLT,Teacher	3	8.3
Teacher,AT	3	8.3
SLT,CT	2	5.6
SLT,OT	2	5.6
SLT,OT,PT,Teacher	2	5.6
SLT,AT	2	5.6
SLT,Teacher,OT	2	5.6
SLT,CS	1	2.8
SLT,CS,CT	1	2.8
SLT,CS,CT,OT	1	2.8
SLT,CS,CT,RE,OT	1	2.8
SLT,CT,AT,Teacher	1	2.8
SLT,OT,AT	1	2.8
SLT,OT,PT,Teacher,AT	1	2.8
SLT,OT,Teacher,AT	1	2.8
SLT,PT	1	2.8
SLT,PT,Teacher	1	2.8
SLT,RE	1	2.8
SLT,RE,OT	1	2.8
SLT,Teacher,OT,AT	1	2.8
SLT,Teacher,OT,PT	1	2.8
<b>Total</b>	<b>36</b>	<b>100</b>

**Resources: Loan bank of equipment**

The practitioners' survey asked questions to determine whether services had equipment to loan to individuals for a trial. It also asked for details of equipment to establish the range of equipment available. The loan bank data was collated into categories which reflect the complexity of the device:

- Unlimited message devices (those that use synthesised speech and can produce any message output depending on input)
  - Medium to large sized devices (e.g. Smartbox PowerBox, Techcess Tellus, Liberator Accent, Dynavox Maestro, Tobii C12)
  - Small or hand-held devices (e.g. TCL Lightwriter, Dynavox DynaWrite, Tobii C8, Tellus Mobi SmartPhone)
- Limited message devices (those that produce pre-recorded or digitised speech and a limited message output)
  - 9 or more message devices (GoTalk 9/20, TechSpeak 32, Tobii S32)
  - 1-8 message device (e.g. BigMac, Partner2/4, TechTalk 8)
  - Other devices (which do not fit under the above categories, e.g. voice amplifiers)

From analysis of the loan bank data, the following observations have been made:

- Out of the 92 services, 64 (69.6%) responded that they had a loan bank of equipment for trial.
- Out of the 92 services, 72 (78.3%) responded that they used trial of communication aids and evaluation as part of the assessment process.
- 43 services provided total sizes of loan bank equipment which ranged from 1-237 units with an average size of 41.6 units.
- 35 services provided numerical details of the contents of their loan bank allowing breakdown into the categories defined above.
- The total number of services that provided some detail of their loan bank (numerical or in words i.e. "some", "a few") was 55.
- 42/55 (76.4%) services that provided some detail of their loan bank contents said that they contained both unlimited message systems and limited message systems.

- 13/55 (23.6%) services had either unlimited message devices or limited message devices in their loan bank.
- 9/55 (16.4%) services had unlimited message devices only.
- 4/55 (7.3%) services had limited message devices only.
- The mean number of unlimited message devices per services was 18.8 units.
- The mean number of limited message devices per service was 18.4 units.

Figure 2.12 shows the number of services which have a total number of devices available for loan within the intervals shown. The services included were those where the total number was provided in the response data. Where wording was used in place of a numerical value (e.g. “a few”, “some”), no estimates in place of the words were added onto the total. The totals therefore show a minimum number of devices per service loan bank.

**Figure 2.12: Number of services with sizes of loan banks. Total N of services providing data = 43.**

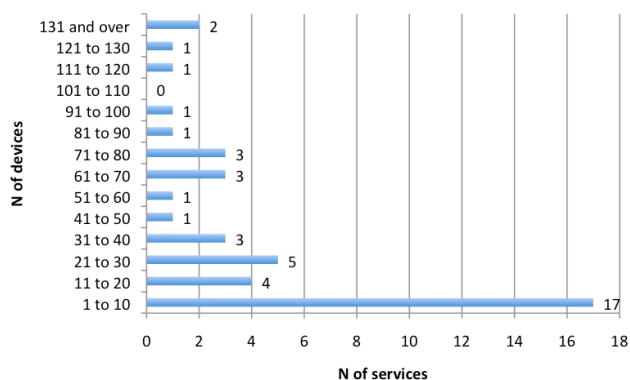
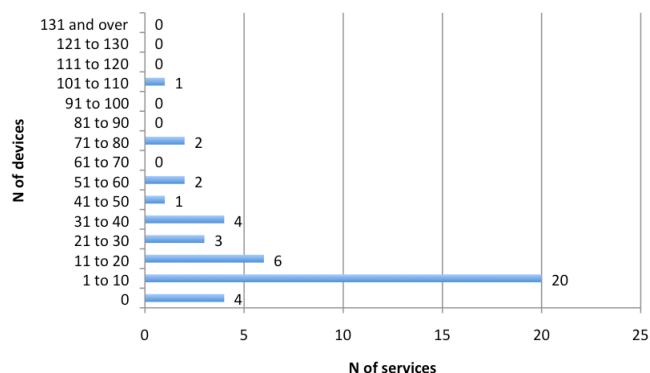
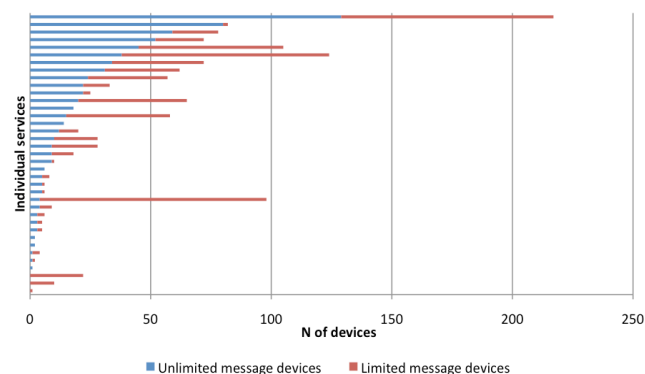


Figure 2.13 shows the number of services and amounts of more complex devices which can output an unlimited number of messages. Figure 2.14 shows the breakdown of numbers of devices with unlimited message output and with limited message output. Where wording was used in place of a numerical value for either number of devices, no estimates in place of the words were provided, and therefore neither a breakdown nor total for those services is displayed.

**Figure 2.13: Number of services and numbers of devices with unlimited messages within their loan bank. Total N of services providing data = 43.**



**Figure 2.14: Loan bank contents for each service broken down into devices that can produce any message and use synthesised speech and those that can produce limited messages using digitised or recorded speech. Total N of services providing a full set of data = 37.**



### Services offered

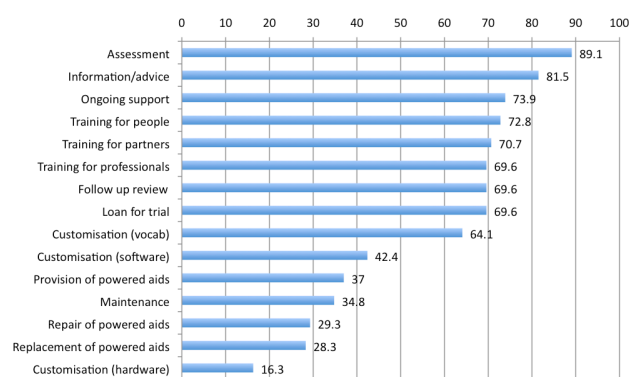
The Practitioners survey aimed to collect information about the service components offered by the team providing data. The components making up a service were initially derived from discussions with practitioners and information taken from literature searching.

The initial components were presented assuming that no definitions were required. They consisted of: information provision, assessment, loan equipment for trial, provision of aids, repair of aids, replacement of powered communication aids during repair, maintenance, customisation or manufacture of hardware, customisation or manufacture of software, customisation or creation of vocabularies, training for people who use communication aids, training for conversation partners, training for

professionals working with powered communication aids, follow up reviews and continuing support.

Figure 2.15 shows the distribution of the components that are available in the services that were surveyed and Table 2.18 and Figure 2.16 show the number of services with different numbers of components.

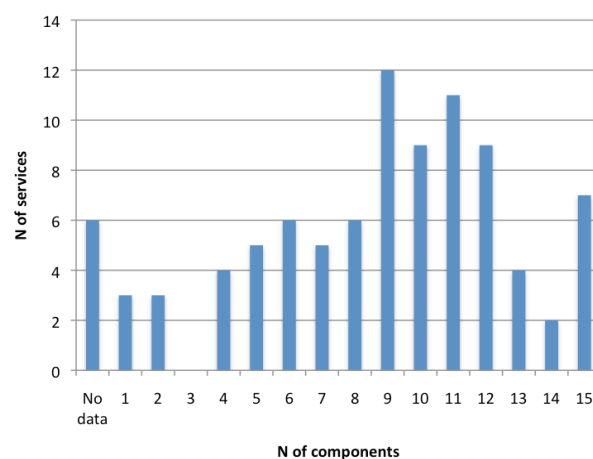
**Figure 2.15: the distribution of the components that are available in the services that were surveyed (N = 92).**



**Table 2.18: the number of services with different numbers of components.**

N of components in service	N of services	% of services
No data	6	6.5
1	3	3.3
2	3	3.3
3	0	0
4	4	4.3
5	5	5.4
6	6	6.5
7	5	5.4
8	6	6.5
9	12	13.0
10	9	9.8
11	11	12.0
12	9	9.8
13	4	4.3
14	2	2.2
15	7	7.6

**Figure 2.16: the number of services with different numbers of components (N=92).**



- The majority of services provide assessment, information and advice, continuing support, training, loan for trial and customisation of vocabulary.
- Very few services (16.3%) provide customisation of hardware.
- Services related to powered equipment and management of powered communication aids are less prevalent than those components which are more focussed on the people who use the equipment.
- When a service offers a smaller number of components, they do not include those components that relate to powered equipment use and management (e.g. customisation of hardware, repair, maintenance). These components are offered by those services which offer a larger number of service components.
- All components in the survey were identified as being part of AAC service provision.
- 7/92 (7.6%) services provide all components.
- 4/92 (4.3%) services provide all components except those relating to equipment customisation (hardware and software) and replacement of devices.

7 Available at: <http://www.communicationmatters.org.uk/news-item/2012-cm-welcomes-service-specification-for-aac> (Last accessed 25/02/2013) with details of the consultation <http://www.commissioningboard.nhs.uk/2012/12/12/ssc-consult/> (Last accessed 25/02/2013)

- 3/92 (3.3%) provide assessment only.
- 60/92 (65.2%) provide both assessment and loan for trial equipment.
- 19 (23.8%) of the services that provide assessment do not provide loan for trial equipment within the service.
- The most prevalent number of components for services is 9, with 44.6% of services surveyed providing 9-12 components out of a total of 15.

### Care pathway

Services also make use of other services to provide some of the components - either wholly or partly, dependent on the requirements of the individuals' need.

The survey collected information about the relationship between those services surveyed and other services external to them.

Table 2.19 shows where referrals are made for each component of the services, whether they are made to other AAC services, suppliers/manufacturers, charities or other organisations. The table shows services that refer on for the following components but they may also deal with that component within their own service.

**Table 2.19: referrals made by the services surveyed for each component of the services, whether they are made to other AAC services, suppliers/manufacturers, charities or other organisations.**

Component	Offered in house (%)	Other AAC services (%)	Suppliers (%)	Charities (%)	Other (%) and details
Information	81.5	21.7	10.9	2.2	4.3
				<ul style="list-style-type: none"> <li>• User group</li> <li>• Websites</li> </ul>	
Assessment	89.1	40.2	5.4	1.1	0
Loan for trial	69.6	32.6	26.1	5.4	0
Provision	37.0	26.1	10.9	7.6	10.9
				<ul style="list-style-type: none"> <li>• Medical engineering/physics / equipment departments</li> <li>• External equipment loan service</li> <li>• Community equipment services company</li> </ul>	
Repair	29.3	20.7	38.0	1.1	10.9
				<ul style="list-style-type: none"> <li>• Medical engineering/physics/ equipment department</li> <li>• Technician service</li> <li>• Equipment loan services</li> <li>• Community equipment services company</li> </ul>	
Replacement	28.3	15.2	29.3	2.2	4.3
				<ul style="list-style-type: none"> <li>• Medical engineering/physics/ equipment department</li> <li>• Community equipment services company</li> </ul>	
Maintenance	34.8	16.3	23.9	0.0	10.9
				<ul style="list-style-type: none"> <li>• Medical engineering/physics/ equipment department</li> <li>• Technician service</li> <li>• External equipment loan service</li> <li>• Community equipment services company</li> </ul>	
Customisation (hardware)	16.3	19.6	22.8	0	6.5
				<ul style="list-style-type: none"> <li>• Medical engineering/physics/ equipment department</li> <li>• Technician service</li> <li>• Assistive Technology service</li> <li>• Occupational therapist</li> </ul>	
Customisation (software)	42.4	20.7	18.5	0	4.3
				<ul style="list-style-type: none"> <li>• Medical engineering/physics/ equipment department</li> <li>• Assistive Technology service</li> <li>• Occupational therapist</li> </ul>	
Customisation (vocabulary)	64.1	13.0	4.3	0	4.3
				<ul style="list-style-type: none"> <li>• Users</li> </ul>	
Training for people	72.8	19.6	18.5	0	2.2
				<ul style="list-style-type: none"> <li>• User group</li> </ul>	
Training for conversation partners	70.7	9.8	2.2	0	1.1
				<ul style="list-style-type: none"> <li>• User group</li> </ul>	
Training for professionals	69.6	18.5	15.2	0	2.2
				<ul style="list-style-type: none"> <li>• External training</li> </ul>	
Follow up review	69.6	19.6	0	0	0
Ongoing support	73.9	15.2	3.3	0	9.8
				<ul style="list-style-type: none"> <li>• Local team</li> <li>• Person's support staff</li> <li>• User group</li> </ul>	

Table 2.19 shows that services have links which refer to other services, suppliers, charities and a range of other agencies, particularly in areas of technical support. There is a lot of interaction between services for all components. Suppliers can be involved for every component of AAC provision except for ‘follow up review’ and charities are involved in components requiring funding and loan equipment.

From Table 2.19 it can be seen other services, suppliers and charities are involved in assessment. The distribution of components showed that 89.1% of services provide assessment. Of those services 42.7% also refer on for assessment and 57.3% do not. 16 (19.5%) provide assessment with a clear statement of no referral and 31 (37.8%) made no response, which indicates either no referral is made or the data has not been completed.

Key Point 24

42% of services who assess for AAC refer clients onwards to other services (presumably to more specialised services).

Key Point 21

charities are minimally involved in providing AAC, but contribute to providing information and funding or loans of equipment. Companies are involved in some areas of service provision, particularly around assessment, loan/replacement/maintenance and repair.

Discussion

The provision of services for aided AAC rests with different providers including: the health service, local authority, educational authority, charitable organisations, and personal provision. The study found a number of different models and types of provision of AAC differing in the way they are funded for both staff, facilities and equipment.

From the results gathered from the Practitioners’ survey, all aspects of AAC services show a high level of variability which makes classification into a set of service models difficult but also highlights the need to be able to categorise the services to describe the ‘eco-system’ of services. The level of detail captured by the survey contributes to some ambiguity in the responses. For example, 89.1% of services provide assessment, however the level of detail is not sufficient to determine the level of assessment provided. The high number of services providing this component in combination with the number of services that refer to other services for assessment (42%) suggests that there are various levels dependent on the complexity of the needs of the individual. The hierarchy of need therefore suggests that

in order to extract accurate information from the services to determine the level of provision, further detail of the type of assessment provided is required in addition to providing definitions of all of the service components. This is echoed by the range of eligibility criteria for access to services which may depend on the individual’s condition or whether they have already received assistance in areas such as physical access, which suggests requirements to access an AAC service can be for those people with complex or multiple needs only.

Only 30% of services were accessible to both adults and children, despite the fact that it may be considered that there would be benefits in pooling of skills and resources to deliver services across ages.

The majority of services responding were health funded. Although there are very few services that seem to be jointly organised, there is a higher proportion of funding for equipment across agencies. The figures showing the range of settings where there is provision demonstrates that educational settings are frequently accessed by the services despite the majority of organisations being based in health services.

The figures showing equipment funding per population head could be extrapolated to show the expected current range of funding totals across the UK. If the equipment funding per population head was extrapolated for the UK population (using 2011 ONS mid-year figure of 63,232,800), the average amount of equipment funding would equate to £12,267,163. Using the minimum amount of budgeted equipment funding across the UK would result in a total of £189,698 and the maximum amount would total £37,813,214. The huge range of totals applied across the UK highlights the very wide range of services available to individuals.

Services appear to place high value on accessing clients in their main communication environment – with most services delivering services at home or school. There is general recognition that service delivery should involve a range of professionals with many teams including, or accessing through linked services, a range of professionals in order to deliver their service.

The figures showing staffing per population head could also be extrapolated to show the current range of staff totals if different current models were applied across the UK. The calculations again use the 2011 population estimate of 63,232,800 where the average amount of staff totals for a whole service would be 2,624.16 WTE and

staff that work with powered aided communication would equal 600.71 WTE. The minimum staffing currently available in services would be a total for the whole service of 6.32 WTE and 0 for the powered aided communication part of the service. The maximum amount would equal 36,630.76 WTE for the total service and 727.18 WTE for those working with powered aided communication.

The large range of variation in almost every aspect of provision, even for this self-selecting group of specialised and AAC-aware services, is highlighted in the wide variation in eligibility criteria applied to services with criteria related to any combination of: age; condition; geography; funding; equipment use; procedure; and individuals' abilities. Criteria relating to funding of equipment were equally diverse and complex. Evidence of the use of private purchase and charity purchase by a large percentage of services is also provided.

These data all contribute to highlighting the perception and reality of provision of communication aids and AAC services as being a 'postcode' lottery – although it indicates that the lottery is much more complex than simply postcode.

The degree of variation within the different aspects of services is very high and the varied data provided makes analysis more difficult. To maximise data collected from services, submission was accepted for incomplete surveys and those with estimates of data. This means that the data presented may include a range of quality and accuracy.

Significant challenges were faced in obtaining even this level of data. These challenges were around:

- Perception of competitive pressures causing organisations to refuse to supply some information (particularly relevant to budget information)
- Services not holding the relevant data
- Services not being able to access the relevant data (difficulties in accessing historical data or the process being too time-consuming to access through individual report or casefile interrogation)
- Services not responding (despite significant effort in requesting) potentially due to other service pressures or possible disinterest.

Service data was reported to be collected on a range of databases, some of which are set up internally by the service, others more widely across employing authorities. Some records are only paper-based providing difficulties in data retrieval. Some services report that they could not provide the data as they do not collect all the information that had been requested of them including data recorded over longer periods of time. This means that there is great difficulty for services to provide evidence for service planning and evaluation of service provision in general.

To be able to make informed decisions about AAC and aided AAC provision, better data needs to be held by services and there should be an obligation to provide this data.

To provide more accurate data collection a tool based on the practitioners' survey has been developed to be used as an audit tool for AAC services (see Appendices 10 and 11). It is designed using principles aiming to increase consistency in data collection and reduce ambiguity while still capturing the variability across services. It has also been designed to allow services to initially complete the tool without having to rely on that data being accessible for that service, although the presence of the question itself aims to encourage storage of the data for future periodic collection.

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## Service categorisation

### Introduction

The wide-ranging levels of variability of content, skills, resources and pathways of care in AAC services makes classification difficult, but highlights the need to try and find ways of categorising them. Recommendations have been made by the Office of the Communication Champion for the commissioning of hub and spoke models for AAC services, where the hubs do not necessarily coincide with one individual centralised service but a set of specialised activities which are potentially available across multiple services.

The activities required for a specialised service for AAC as defined by the NHS Commissioning Board Draft Service Specification for Specialised AAC Services (NHSCB/D1b)<sup>7</sup> comprise a set of resources and skills that cover the most complex needs of an individual requiring AAC and related services. Activities required for a specialised service have been extracted from the definition and

matched against the data collected in the practitioners' survey to define which of the services surveyed can be classified as a specialised service.

The set of requirements from the specialised service definition corresponds to criteria derived from the practitioners' survey in terms of: the components of service delivered, the teams and skills involved, the resources available and the geographical region that it covers.

The definition states that a specialised service will provide a set of service components including:

- Assessment
- Loan for trial
- Provision of powered aid
- Maintenance
- Customisation of equipment (particularly hardware)
- Training for professionals

It will comprise a team with the following competencies (p5):

- Electronic assistive technology (clinical scientists and clinical technologists, or equivalent)
- Speech and language therapy with AAC specialism
- Learning and educational development competence to support the AAC assessment and intervention service to younger clients (often a teacher)
- Seating and positioning (physiotherapist or occupational therapist)
- Access and control methods and mounting of equipment (physiotherapist or occupational therapist)
- Equipment procurement and stock management

It will be able to provide (p6):

- Assessment and a loan bank of technologies which offers a diverse range of solutions

Its coverage should be (p7):

- It should be able to deliver services across a wide geographical region

It should also be able to deal with all levels of complexity.

### Developing the service categorisation algorithm

The proposal for a hub and spoke model is not a purely binary division of services but a collection of services which may provide certain activities reflecting access to different configurations of more specialised provision as required by certain service users. This suggests a requirement to classify services as to how many of these specialised activities are provided or whether the service has more or less potential to be a fully specialised service.

To provide information on how close a service is to being a full specialised service, an algorithm has been developed based on proximity to the specialised service definition through the information collected in the practitioners' survey.

#### Algorithm

- 1 Assign a score for the service for each component listed in Table 2.20 that the service provides.
- 2 Assign a score for the service for each of the types of staff member (with any WTE), 1 point for each job type, with a maximum of 1 point per type, meaning a possible total of up to 4 per service.

If the service is based in education for clients of education age, assign a point for a teacher (or not if there is no teacher in the service).

If the service does not involve clients within education then scale the points up so that they are a proportion of 4 (i.e. if there is a SLT specialist, an OT and a Rehabilitation Engineer, then the service scores 4 points. If there is a Specialist SLT and an OT, the service scores  $2/3 * 4 = 2.67$  points).

- 3 Assign a score for the service if they have a loan bank of equipment and another point if that loan bank has greater than 10 devices in it that are unlimited message devices (devices that can generate any output).
- 4 Assign a score if that service does not refer onwards to another service for assessment.
- 5 Assign a score if the service covers more than 1 geographical unit area (where a unit is defined as a health trust or board, a local authority area, an organisation such as a school or hospital).

**Table 2.20: The points to be allocated for the service categorisation algorithm**

Measure	Detail	Points
Component score	Assessment	1
	Loan for trial	1
	Provision	1
	One of maintenance/repair/replacement	1
	Customisation of hardware	1
	Training for professionals	1
Team score	One of: Clinical scientist, Clinical Technologist, Rehabilitation Engineer, Assistive Technologist	1
	Specialist Speech and Language therapist	1
	One of: Occupational therapist, Physiotherapist	1
	Teacher (if a service involving those in education – if not, the scores for the other job titles are scaled to be a total of 4)	1
Loan bank score	Service has a loan bank	1
	Service has a loan bank with >10 devices able to generate unlimited messages	1
Assessment referral score	Tertiary assessment (no onward referral for assessment)	1
Geography score	Service covers over 1 unit of geographical area	1

Those services which total 14 points we propose should be defined as specialised services.

For all other services, the score should reflect the degree of specialism that the service represents. To categorise the services, the total points assigned the services to 5 categories:

- A Specialised service
  - B1 Tertiary specialist with custom manufacture
  - B2 Tertiary specialist without custom manufacture
  - C Local specialist
  - D Local service
- A Specialised service requires
- 14 point total
- B1 Tertiary Specialist with custom manufacture requires:
- 50% of total points (7 or over), and
  - Team score  $\geq 1$  (there has to be some specialist skill in the team), and
  - Tertiary assessment score=1, and
  - Wide geographic area=1
  - Component “customisation of hardware” is present

- B2 Tertiary Specialist without custom manufacture requires:
- 50% of total points (7 or over), and
  - Team score  $\geq 1$  (there has to be some specialist skill in the team), and
  - Tertiary assessment score=1, and
  - Wide geographic area=1
  - Component “customisation of hardware” is not present

- C Local Specialist requires:
- 50% of total points (7 or over), and
  - Team score  $\geq 1$  (there has to be some specialist skill in the team), and

- D Local service
- If total points is less than 50% (less than 7),

Or

- 50% of total points (7 or over), and
- Team score = 0

The criteria define the view that services requiring specialist knowledge should have at least one team member that has a specialist knowledge of an aspect of AAC (as defined in the service specification). The competency levels have not been detailed in the Practitioners survey except for Speech and Language Therapist team members who have indicated their specialism. Therefore there is some approximation and assumptions made for this requirement.

The algorithm defines that services requiring specialist knowledge should have at least 50% of the scores. These scores are weighted towards the components of service provision (6 points) and specialist team skills (4 points).

The selection of components reflects the statements made in the specialised service definition but covers aspects of service provision which approximate use of powered equipment and represents aspects of service defined as necessary for more regional or specialised services. The aim is not to assign these components more importance than the other components of service provision, but to indicate provision required by those with more complex needs and services that can be delivered over a wider geographical range.

### Application to service data

This algorithm was applied to the full set of service data plus an additional 6 services which submitted information late and therefore are not included in any other part of this report.

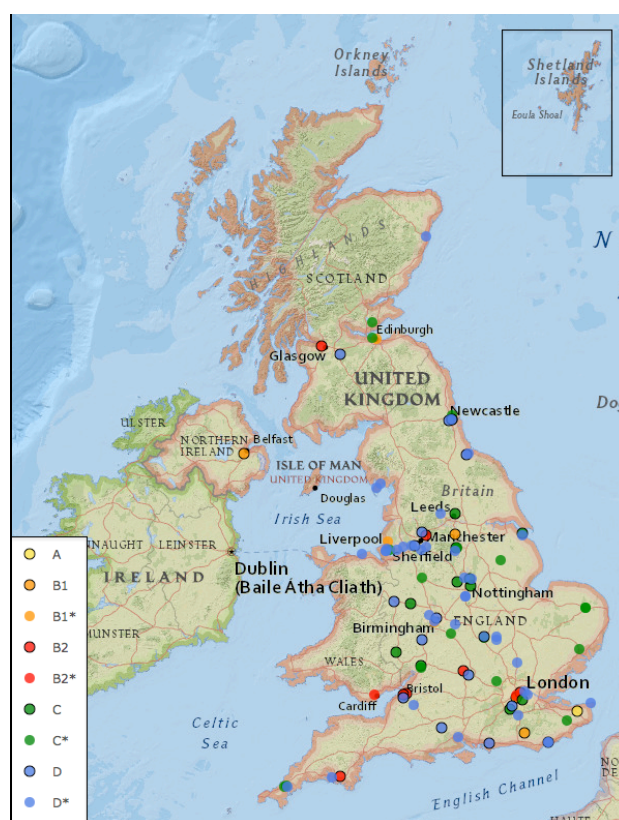
40 services provided a full set of data from which these services could be defined. For those services for which there is not sufficient data entered in the survey, assumptions have been made to classify them and they are associated with categories with an asterisk (\*). Those indicated with an asterisk therefore represent a minimum category which could have the potential to enter a more specialised category.

Table 2.21 shows the number of services that have been classified into the service categories and Figure 2.17 shows the distribution of the categories across the UK.

**Table 2.21: Number of different categories of service based on responses to the practitioners' survey**

Category	N	%
A	1	1.0
B1	5	5.1
B1*	3	3.1
B2	7	7.1
B2*	2	2.0
C	11	11.2
C*	17	17.3
D	16	16.3
D*	36	36.7
<b>Total</b>	<b>98</b>	<b>100</b>

**Figure 2.17: distribution of different categories of services across the UK. The map has been generated using ArcGIS online (Map attribute: National Geographic, Esri, DeLorme, NAVTEQ, UNEP-WCMC, USGS, NASA, ESA, METI, NRCAN, GEBCO, NOAA, iPC).**



Only 1 of the services fitted the definition of a specialised service and within the limits of the data provided, a total of 18 services (18.3%) represented a tertiary specialism (categories A-B) (see Figure 2.18 displaying only service categories A-B). From the data provided only 23 services covered more than one geographical area providing a maximum number of potential services categorised at level B and above. Services categorised at this level do not refer onwards for any further assessment so they represent the services at which there is no further specialism. The centres are distributed across the UK but the small total number of tertiary services indicates that individuals would have to travel a reasonable distance to reach the specialised service which could be problematic for those with mobility problems and influence decisions on pursuing that level of care.

The small number of tertiary services highlights that the majority of the data set is reported from what could be categorised as specialised-local and AAC-focused-local services. It suggests that in the current model of services, significant resource and service delivery is currently delivered through services at this level. This may be a reflection of the lack of co-ordinated policy around this area to date.

**Figure 2.18: distribution of categories A-B of services across the UK. The map has been generated using ArcGIS online (Map attribute: National Geographic, Esri, DeLorme, NAVTEQ, UNEP-WCMC, USGS, NASA, ESA, METI, NRCAN, GEBCO, NOAA, iPC).**



#### Key Point 35

Only 1 service responding to the survey could be classified as a specialised service using the full definition within the specialised services definition set.

## Establishing Current Use of Powered Communication Aids

### Method

Identifying the numbers of individuals using powered communication aids is important as it assists in determining unmet need, when comparing this figure with that determined in the epidemiological study, and required skills, resource and market.

To establish the number of people who use AAC in the UK, the practitioners' survey asked the services to provide information about their current caseload and to detail how many people were known to the service who used powered aided communication. The questions aimed to extract different information about use of communication aids to encompass the variety of service models for services for AAC.

Given the variety of models, using this data to understand the use of powered aided communication is challenging for a number of reasons.

#### 1 Service Remit

The data set is aimed at 'specialised services', these services may or may not have a universal remit over a geographical area – i.e. an obligation to provide aided communication to all who need it in an area. They also may or may not have an obligation to maintain a register of these users.

#### 2 Caseload data vs population data

Some services only interact with a person while assessing them, whilst others provide long term services to the clients. Looking only at caseload therefore would not capture the total number of people who use powered aided communication at a point in time for these services, it may only capture a combination of people who are new users and those who are being reviewed. Unless the service keeps a 'register of users', this will not capture people who have used aided communication for a longer period of time and are still currently using that equipment.

#### 3 Data recording

Services record a variety of different information about their activity. This may not transfer appropriately into caseload or population data.

Where previous years’ data was supplied and could be identified, the past 5 years was taken as a maximum to increase the likelihood of people still using their powered communication aids being represented in the data.

To compare the profile of conditions of individuals who use powered aided communication with that found in the epidemiological study, the practitioners’ survey requested total numbers of people who use powered aided communication by aetiology. The survey requested that if historical data was not available that the services provided the breakdown in terms of current caseload.

Results

The number of people who use powered aided communication on caseloads and in total are shown in Table 2.22.

**Table 2.22: descriptive statistics of the data provided on how many people are currently using powered aided communication on current caseloads and in total.**

	People who use powered aided communication on caseload	People who use powered aided communication known to the service
<b>Total</b>	<b>2955</b>	<b>9537</b>
N services	67	72
Average	44.1	132.5
Median	20	23
Minimum	1	1
Maximum	350	3,627

A measure of the % of people who use powered aided communication is detailed in Table 2.23, Table 2.24 and Figure 2.19 which show the number of people who use powered aided communication on the services’ current caseload and in total in terms of the % of the population covered by the service. This measure relies on data being accurate and the geographical region being described accurately. Population figures have been extracted using CASWEB<sup>8</sup> from 2001 census data as using this procedure allows association of boundary data with population data, including dividing the figures into adults and children. The population figures were scaled up by 7.1% to represent the increase in population in England and Wales since 2001 (Office for National Statistics, 2012).

Where a specific calculable geographical region has not been defined or where the population is within an organisation (such as inpatient hospital services or school) the population has not been included.

Of the 63 services providing data for caseload, 55 of the services either recorded the same number or did not record another number for total people known to the service using powered aided communication. This highlights the difficulty services have in accessing historical information.

Where the available information was only on those currently using powered aided communication the number was used for both responses.

**Table 2.23: the % of the geographical population on a service current caseload who use powered aided communication.**

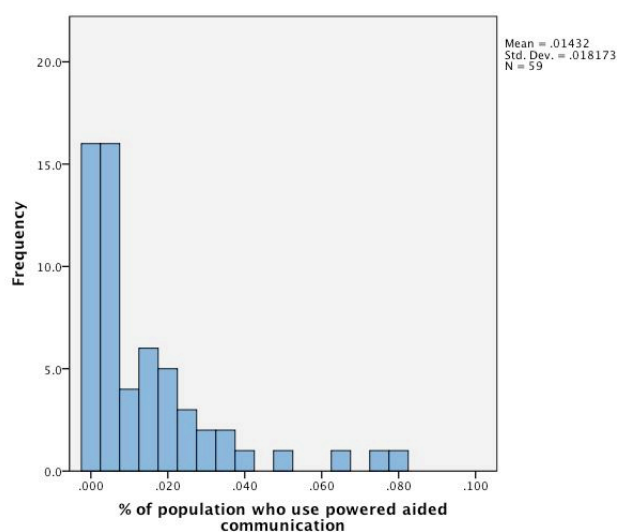
	% population on services’ current caseload who use powered aided communication (to 3 decimal places)
N services	59
Maximum	0.081
Minimum	0.000 (negligible)
Range	0.081
Average	0.012

**Table 2.24: the % of the geographical population who use powered aided communication.**

	% population who use powered aided communication (to 3 decimal places)
N services	59
Maximum	0.081
Minimum	0.000 (negligible)
Range	0.081
Average	0.014

These figures, whilst recognised as only being indicative, highlight the substantial variation in provision of powered communication aids.

**Figure 2.19: % of population who use powered aided communication per service. (N=59 services)**

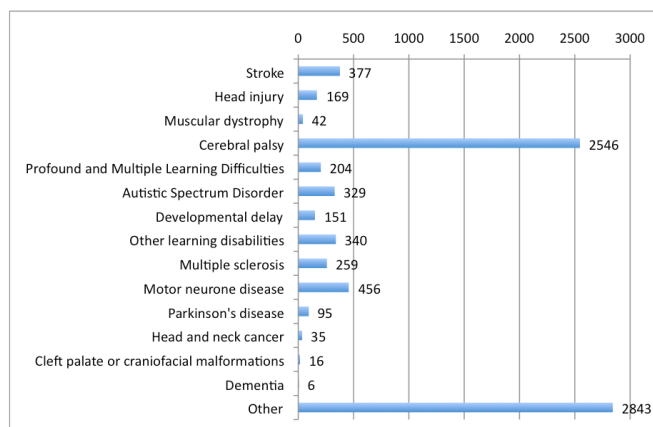


#### Key Point 36

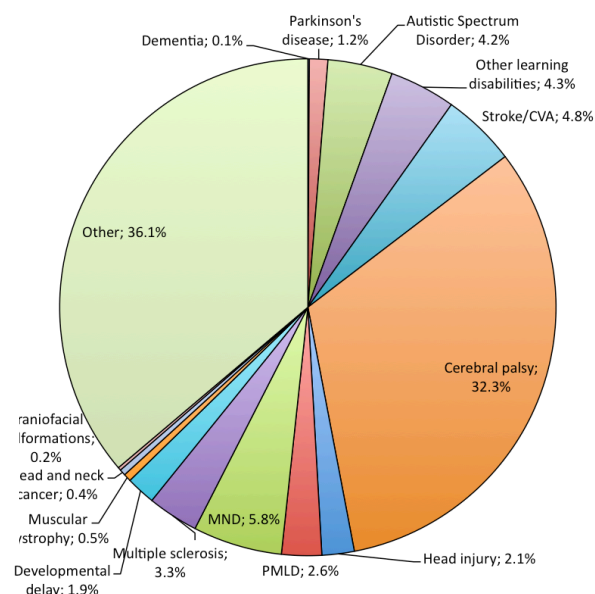
In some areas up to 0.08% of the population may currently use powered aided communication. The average within the data returned was 0.014%. These figures suggest that the estimate of 0.05% made from the prevalence data is within a reasonable order of magnitude.

Results from the breakdown of conditions across services are shown in Figure 2.20 and Figure 2.21. The largest proportion of conditions collected were those classified as other and cerebral palsy, followed by motor neurone disease, stroke, other learning disabilities and autistic spectrum. The smallest category of people who use powered aided communication is those who have dementia.

**Figure 2.20: the breakdown of conditions of people who use powered aided communication as collected from service data.**



**Figure 2.21: the profile of conditions of people who use powered aided communication as collected from service data.**



## Discussion

This study has made the assumption that 9,537 people who use powered aided communication reported here have only been seen by one service. The data mixes data from specialist, local specialist and local services and there will be links between these services which could lead to a degree of double counting of the same individuals within the data. This will cause the total use data to be higher than the real value.

Attempts were made to contact as many of the more specialised services as possible, however some services did not respond and thus the number is not a complete audit of all services and therefore reflects a subset of people who use powered aided communication in the UK. This will cause the total use data to be lower than the real value.

The data quality is problematic due to the variation in the accessibility to the data. 19 (20.7%) services did not provide any information on the numbers of people who use powered aided communication due to not having access to the data, not storing data or not completing the survey for other reasons. Some services reported use of paper-based data storage which makes extraction time-consuming and potentially inaccurate.

The high correlation between the number of people who use powered aided communication on a current caseload and in total suggests that there is a lack of historical or population data (i.e. registers of use) collected which makes accurate estimation of the total number of people who use powered aided communication more difficult. It may also show that where ongoing support is offered, then individuals remain on the caseload for longer periods of time.

The maximum number of 0.08% or an average of 0.014% of the population who use powered aided communication suggests that the estimate obtained for the need of AAC (0.5%) and powered aided communication (0.05%) is within a reasonable order of magnitude despite the clear sparsity of data.

To accurately establish data on the number of people who use AAC and powered aided communication, services must be in the position to collect and provide more data on the number of people who access services, their route to provision and the strategies and equipment used and available.

The profile of conditions of people who use powered aided communication shows that the largest category is that classified as “other”. In comparison with the estimate of need in the first section of this chapter, the number of other conditions makes up a considerably smaller proportion of the total. There are many rarer conditions not listed in the survey but the expectation is that these make up a markedly smaller proportion of those who use AAC and powered aided communication than has been collected in this study. It is therefore expected that this is most likely due to problems with data collection in situations where no condition has been recorded a category of other is assigned. This category could also be representative of different categorisation systems where the aetiology is not recorded in the same categories as presented in the survey. It may, also, be indicative of individuals accessing services without having a diagnosis of their condition at that point.

The breakdown of conditions as collected from the services is more reflective of the views of practitioners as gathered during the validation exercise reported in the first section of this chapter. The ranking of the top 5 conditions of people who use powered aided communication except for the “other” category is the same as those provided by those participating in that exercise.

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#### Key Point 31

People with cerebral palsy appear to make up the largest single user group of powered aided communication (32% of the users reported within the service data).

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The difference between the AAC prevalence of need figures and those collected by the survey for powered aided communication could be explained by a marked difference between the conditions of people who use AAC and powered aided communication. This suggestion is supported by the views of the practitioners who placed Parkinson’s disease higher for powered aided communication in the validation exercise than for AAC in general including aided communication (powered and unpowered). It also contributes to explaining the difference between expected need for AAC in general for both Parkinson’s disease and Dementia, where the profiles seem to suggest that there are differences between the types of strategies which might be more relevant for people with different aetiologies.

The differences could also demonstrate that services are underserving people with particular aetiologies due to expectations, access to the services, access to different types of technology or training in and awareness of newer technologies. The large difference between the figures for cerebral palsy and the other aetiologies could indicate that there are people with aetiologies who are well served and well accessed, potentially due to a better understanding of potential. The prevalence of these cerebral palsy figures could also be influenced by the higher number of children’s services which responded to the survey.

The epidemiological profile differences between those who could benefit from AAC and those who could benefit from powered aided communication has implications for the accuracy of the estimate that 10% of the people who could benefit from AAC could benefit from powered aided communication.

Charities were identified through means such as websites, discussions with professionals working in AAC and through the qualitative part of the study. They were contacted through email and telephone to ascertain whether they had quantitative data collected on numbers of people they had provided funds to or assisted with to get provision of equipment.

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## **Use of powered aided communication: validation using other routes to provision**

The wide range of routes to access AAC and aided communication services necessitates the collection of data from suppliers and charities to further enrich the data set and attempt to triangulate the results in order to address the research questions.

### **Method**

Data was collected from the eCAT (Electronic Communication Assistive Technology) section of the BHTA (British Healthcare Trades Association) which has collected anonymised data on AAC suppliers' sales and turnover since 2003. This provides an overall collated view of the size of the market for those companies who are members of BHTA.

The figures only represent a subset of companies: specifically those who provide or manufacture dedicated AAC equipment. The data set offers little detail which could indicate the target population and how many people use powered aided communication. Therefore, suppliers identified through directories and through those working within the field of AAC were contacted directly by email, telephone or face to face at conference exhibitions and requested if they would provide any further data on their sales, the number of units sold and who they sold their devices to (specifically health organisations, local authorities or individuals). Where required, confidentiality agreements were drawn up and signed by all parties.

## Results

**Table 2.25: figures collated by eCAT showing sales of AAC devices between 2003-2010 for a number of companies**

The eCAT data is presented in Table 2.25.

	2003	2004	2005	2006	2007	2008	2009	2010
<b>Turnover</b>								
<b>UK sales only - £k</b>	<b>4040.674</b>	<b>4377.208</b>	<b>5109.977</b>	<b>7337.419</b>	<b>7561.741</b>	<b>7805.61</b>	<b>10463.702</b>	<b>10199.057</b>
N companies	6	6	7	8	8	7	7	7
<b>Unit sales of AAC Devices £1 - £750</b>	<b>1370</b>	<b>1518</b>	<b>1693</b>	<b>1017</b>	<b>2777</b>	<b>4468</b>	<b>4363</b>	<b>2546</b>
N companies	5	5	5	5	7	6	6	5
<b>Unit sales of AAC Devices £751 and over</b>	<b>803</b>	<b>832</b>	<b>955</b>	<b>983</b>	<b>1076</b>	<b>1587</b>	<b>2549</b>	<b>1446</b>
N companies	7	7	8	7	7	7	7	6
<b>Communication software unit sales</b>	<b>n/a</b>	<b>n/a</b>	<b>n/a</b>	<b>n/a</b>	<b>n/a</b>	<b>409</b>	<b>872</b>	<b>740</b>
N companies	n/a	n/a	n/a	n/a	n/a	4	5	4

The figures show that the total sales market for the companies within eCAT is £10,199,057, with a total of 4,732 individual units (£1-750, £751 and over, software) sold in 2010.

3 out of 10 suppliers who were individually contacted for data provided some level of information from which the following statements could be made (with the number of sources providing the information included in brackets):

- Approximately 50% of their sales is for devices for children (1 company).
- Approximately 50% is to NHS (1 company).
- Approximately 10% is direct to individuals (1 company).
- Of devices sold per year, approximately 10% are eye tracking devices (2 companies).

### Key Point 32

The market size for powered communication aids may be around £10 million per annum.

2 out of a total of 8 charities responded with data.

- One charity reported the loan of 873 communication aids between February 2010-September 2012 plus other equipment which could be useful for communication, such as lap top computers and software.
- One charity reported spending £200,300 on 69 sets of equipment in one year (average £2,902.90), plus £189,927 on 93 sets of equipment in the following year (average £2,042.26).

The total figures for people who use powered aided communication could then be extracted as an estimate from the eCAT figures. The most recent 2010 figures provide the incidence of the number of people using powered aided communication by assuming that most powered communication aids will fall within the category of over £750, therefore the incidence for 2010 is a minimum of 1,446 people (0.002% of the UK population). For a total prevalence figure of those people who are currently using powered aided communication, figures can be added over a period of time to make them comparable to those calculated throughout this report. If the assumed length of time of use of a powered communication aid is 5 years, then the total number of aids over £750 between 2006-2010 are totalled to 7,641 people (0.012% of the UK population).

Assuming that these figures represent a minimum number of people using powered communication aids during this time period, the maximum number of people using aided communication can be calculated taking the total numbers of units sold across this time period. This calculation assumes that an individual is assigned 1 unit. The maximum number of people using aided communication within the limits of this data in 2010 is therefore 4,732 people (0.008% of the UK population). The prevalence of use is therefore calculated at a 5 year use period, which from the period 2006-2010 equates to 24,833 people from the data (0.040% of the UK population).

The estimates derived from the supplier data suggests that approximately 0.012 -0.040% of the UK population use powered aided communication dependent on a range of estimates and assumptions being true. This calculation is within the region of the 0.014% estimate of the population who uses powered aided communication derived from the service use data.

## Discussion

The findings provide some validation of the information derived from service use data, which gives an average of 0.014% of the population using powered aided communication, within close range of the estimations of 0.012-0.040% of the population served by the supplier data.

The figures collected from the suppliers on their own do not provide clear indication of the number of people who use powered aided communication in the UK. This is due to the range of services and equipment items that are sold by the suppliers. Company sales list contain the devices themselves, but also includes a wide range of accessories (e.g. mounting equipment, keyguards, cases, batteries, power supplies, connectors and cables), access equipment (e.g. joysticks, keyboards), software licenses, warranties, loans, repairs and training. These units all fall within the £1-750 bracket of equipment sales however, so the units sold over £750 provide a more accurate estimate of powered aided communication use.

The additional issue of powered aided communication being integrated into more mainstream devices purchased from non-specialist suppliers adds to the complications in using this data. As more mainstream technology (e.g. iPads or tablet computers) is being used and bought to address AAC needs, the ability to count the devices becomes a more complex process and it is therefore more difficult to assign numbers of people who use powered aided communication purely using the route of specialist suppliers.

When purchasing an item of equipment, the device is not necessarily allocated to a specific individual but may form part of a loan bank of equipment for assessment or short term loan to individuals. The approximations made here suggest that each item bought will be in use by an individual at all times. For these reasons, the estimate provided should be viewed only within the context of the assumptions and as a tool to help validate other findings rather than as an individual estimate.

Data gathered for the Domesday database (Reddington, 2013), collected information on aided communication equipment purchased by NHS trusts across the UK totalling an estimated £12,702,162 spend in the period 2006-2011 on equipment for aided communication. From the data stated by one company which provides approximately 50% of their sales to the NHS, this amount indicates a market share of £25,404,324 over the time period, providing a total market share of approximately £4 million per year. This information suggests that there is inconsistency between the eCAT data, the data available for the Domesday set and the statistics provided by the company generalised across the whole market. The indication is that sales and company data as they are provided for dissemination through eCAT is insufficient to make generalisations and claims in isolation to answer the principal research questions in this study.

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# Chapter 3: Provision and use of services for augmentative and alternative communication

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## Introduction

This chapter reports research aimed at identifying the routes to obtaining aided communication service provision across the UK, service user experience and barriers and facilitators to provision using qualitative research techniques.

Qualitative research aims to gather an in-depth understanding of human behaviour and the reasons that govern such behaviour. The qualitative method investigates the why and how of decision-making, not just what, where, when. It is based on investigating and analysing people's real experiences in a structured but not constrained manner.

A range of qualitative methods were used including focus groups, key informant interviews and independent responses through the use of surveys and e-mail. The content of the surveys was based on the information gathered through the focus groups and interviews.

The participants were identified from among those groups who had experience of AAC at differing levels of involvement. Data gathered from the focus groups and interviews were analysed using a qualitative analysis method based on Framework Analysis.

Part one of this chapter details the broad range of methodologies involved in the qualitative aspect of this study. Part two provides the results in three sections:

- Section 1 provides information on the development of the description and definitions of AAC service provision;
- Section 2 gives the results of the investigation into AAC provision, its components and elements;
- Section 3 provides information on user experience.

This important section (3) details reports from AAC users, communication partners, others who work with AAC users, related professionals and commissioners of services.

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## Part One: Methods and process

### Participants

This study required information from a variety of participants including:

#### Group 1: People who need or use Aided Communication

People with severe communication impairments who use, may potentially use or have used aided communication. Participants may have a range of conditions which can be developmental or acquired.

Excluded from participation were those people with communication impairment caused by deafness or blindness, children who were under the age of 12 years of age, and people who by nature of their condition did not have the mental capacity to consent to be involved in the study.

The study aimed to recruit a minimum of 3 people sampled over three age groups (12 and 17 years; 18-60 year olds; over 60 year olds) and then sufficient people to saturate (fully explore) the emerging themes.

#### Group 2: Professional group

Practitioners and educators who had responsibility for provision of AAC such as identifying need, assessment, provision and supporting use of communication aids and monitoring. Recruits came from within those employed by the NHS, Education, Social Services and independent practitioners. Professionals included Speech and Language Therapists (SLTs), Speech and Language Therapist Assistants (SLTAs), Teachers, Teacher Assistants (TA), Occupational Therapists (OTs), 'Assistive Technologists' (ATs) including Clinical Scientists, Clinical Technologists and other Assistive Technologists.

#### Group 3: Parents and communication partners of people who use AAC

This group includes parents, family members and communication partners of people who use AAC who had experience of communicating with people with communication difficulties who used or had used powered aided communication.

### Group 4: Charities and Voluntary Sector.

People from charities and voluntary sector organisations involved in aspects of AAC.

### Group 5: AAC Industry representatives.

Including AAC suppliers and manufacturers and those who developed relevant equipment.

### Group 6: Commissioners and policy makers

People who commissioned services, that allowed AAC assessment and or provision to be funded, and people involved in shaping policy and services for AAC.

## Recruitment and consent

Recruitment strategies varied according to the groups being targeted. Information sheets were prepared to inform participants about the study (Appendix 1).

In order to reach the practitioners and people who had communication needs that might use, had used or were still using communication aids and their communication partners, a number of different approaches were employed. These included snowballing, advertisements and information published in newsletters, websites and direct contact (see Table 1).

Consent forms were used to ensure informed consent in face to face contacts interviews and focus groups, verbal informed consent was taken for telephone interviews. Consent was assumed in participants who responded to emails or who provided email response.

## Methods

Different methods were employed to involve participants. The purpose and choice of each method relative to participants is described in Table 3.1.

**Table 3.1: Summary of Qualitative Methods**

Method	Details
Scoping Surveys	<ol style="list-style-type: none"> <li>1 Survey to Speech and Language Therapy Managers across the UK to ask for details of provision of AAC within their service.</li> <li>2 Survey sent out to members of two AAC SIGs to ask for details of provision of AAC within their locality.</li> </ol>
Purpose	<ul style="list-style-type: none"> <li>• To seek information about existing provision for AAC across the UK.</li> </ul>

Media Requests	<p>Request for information on use, provision and use of AAC.</p> <ol style="list-style-type: none"> <li>1 Bulletin RCSLT – read by SLT/SLTA</li> <li>2 Media request – to newspapers, specialist journals (handled by Sheffield University Media Department)</li> <li>3 Communication Matters website &amp; social media (Facebook and Twitter)</li> <li>4 Autism website</li> <li>5 Motor Neuron Disease website</li> <li>6 Parkinson's Disease website</li> <li>7 SCOPE Facebook page</li> <li>8 RCSLT Facebook page</li> <li>9 Voice webpage</li> </ol>
Purpose	<ul style="list-style-type: none"> <li>• To broaden the scope of the data gathering across the UK.</li> <li>• To seek independent responses from people with experience of AAC or who may seek information about AAC</li> </ul>
Data gathering Surveys	<p>On-line surveys</p> <ol style="list-style-type: none"> <li>1 People who use communication aids or had used a communication aid or might use one.</li> <li>2 People with experience of communicating with people who use or have used communication aids.</li> <li>3 Educators who have or had experience of working with people with communication aids.</li> </ol> <p>Paper &amp; e-mail surveys</p> <ol style="list-style-type: none"> <li>4 Suppliers' Survey</li> <li>5 Charity Survey</li> </ol>
Purpose	<ul style="list-style-type: none"> <li>• To gather information from people with an independent voice.</li> </ul>
Interviews	<ol style="list-style-type: none"> <li>1. Face to face interviewing of people who have experience of low and high-tech AAC who may use/need/have used aided communication.</li> <li>2. Also, communication partners who have experience of communicating with a person who may use/need/have used aided communication.</li> <li>3. Practitioners involved in assessment, provision, support of AAC.</li> </ol>
Purpose	<ul style="list-style-type: none"> <li>• To gain an in-depth view of the experiences of participants.</li> </ul>

Telephone/Skype Interviews	<p>Telephone and Skype interviews with stakeholders.</p> <ol style="list-style-type: none"> <li>1 People who use powered communication aids</li> <li>2 Parents of people who use powered communication aids</li> <li>3 Practitioners with experience of working with people using powered communication aids and their families and carers.</li> <li>4 Educators with experience of working with people using powered communication aids and their families and carers.</li> <li>5 Charities whose members have communication support needs requiring AAC.</li> </ol>
Purpose	<ul style="list-style-type: none"> <li>• To allow access to those participants who might be hard to reach.</li> <li>• To allow participation without the individual allowing the researcher into their home or having to travel.</li> </ul>
Focus Groups	<p>Focus Groups with relevant people</p> <ol style="list-style-type: none"> <li>1 Practitioners &amp; Educators</li> <li>2 Communication partners e.g. Parents &amp; Carers</li> </ol>
Purpose	To achieve consensus around the factors relevant to AAC need, provision and use.

## Data analysis

Data from all sources was transcribed or processed into a text format. The data was then analysed using a qualitative analysis method called Framework Analysis. Text was coded to identify main themes which enabled the qualitative data to be described. The computer programme NVIVO9 was used to code the data and this allowed validation of analysis and themes by co-researchers in the team.

## Overview of procedure

There were 3 main steps in the data gathering process, with each step iteratively building on the data gathered and information gleaned from earlier steps in the process. Data was gathered between 7 April 2011 and 30 November 2012. Full details of the research procedure is available in the study protocol (Appendix 2).

## Step 1: Scoping

The first step in the study was to identify and inform key stakeholders who were known to provide AAC resources for assessment and provision of AAC and aided communication. A scoping exercise was carried out to gather information on need, provision and use from practitioners active in the field of AAC and who had experience and expertise in the area of AAC and specifically powered aided communication.

A day on AAC was held at Royal College of Speech & Language Therapists (RCSLT) with the purpose of defining AAC, exploring the need for AAC in supporting communication needs, and to allow practitioners to describe the activity around provision and use of AAC. The attendees were split into four focus groups of 12 SLTs and 4 ATs and the information gained further informed the scoping. Findings are detailed in the appendix.

Visits were made to special interest groups for AAC and to local teams of practitioners to describe the study, the type of data gathering that would be completed and how practitioners and people with experience of using AAC could contribute to the study.

## Scoping survey

A scoping exercise was carried out to gather information from SLT managers on the provision of SLT services specifically resourced for AAC. The target group was SLT practitioners active in the field of AAC who had experience and expertise in the area of AAC and specifically the provision of powered communication aids for people needing such communication support. An e-mail was sent out via the RCSLT SLT Managers distribution list.

The scoping study helped the researchers to identify nationally SLT services who supported people with communication support needs who could use or used AAC.

Of the 280 requests made there were 59 returns.

The respondents provided some basic information regarding provision of AAC services, the geographical area covered and the age group a service was provided to. The respondents were then sent a quantitative questionnaire to complete for the mapping part of the study.

47 respondents provided a short description of their service. The data indicated a wide variation in the levels of provision of AAC across the different areas: some services indicated that they provided specialist SLTs for AAC who could assess, recommend and provide AAC and powered communication aids; others indicated they had the ability to identify need and carry out a certain level of assessment but had no funding for provision of communication aids and support. Examples of the variation in provision indicated are included in Appendix 3.

#### Development of topic sheets

The topic sheets for each group of participants were developed following a review of the literature and initial analysis of the data from the scoping stage. Consultation with practitioners who were specialists in the field of AAC and people who used AAC including powered communication aids informed the development of the topic sheets. The initial drafts of the topic sheets were reviewed by the research and steering group, selected practitioners and people using AAC who provided feedback (see Appendix 5).

#### Agreeing definitions

A one day focus group was held to explore terms and definitions related to the provision of AAC.

The focus groups were aimed at specialist AAC SLTs and Assistive Technologists (AT). Four focus groups were held with a total of 12 SLTs and 4 ATs participants. The focus groups were held at the Royal College of Speech and Language Therapists (RCSLT) on 7 April 2011.

A literature review had identified a number of specific themes to explore within the group discussion. These topics covered six areas which included: defining AAC; what a service for AAC was trying to achieve; who should be involved in provision for AAC aided communication; how a person needing aided communication accesses and progresses through a service providing AAC resources; what factors would facilitate or deter aided communication use; and wishes for aided communication provision.

A summary of the data gathered is provided in Appendix 6. The data was used as the basis of the development of an AAC definition set (described later) and to influence the development of the project topic guides.

#### Validating existence of components

The existence of the components was validated by asking

participants considered experts in the field of AAC to review the components and advise if the components, as 'top headings' represented the activity involved in providing AAC resources. The first group of experts were recruited at the National Group for Specialists in AAC held in London February 2012. The subsequent experts were specialist practitioners for AAC who took part in Focus Groups and interviews during the period February to October 2012.

#### Step 2: Main data collection.

Topic sheets were used to elicit information about the identification of need, provision and use of AAC from the six groups (AAC users, professionals, communication partners, charities, suppliers and commissioners-see above). Visits commenced in October 2011 and ended in October 2012.

#### Step 3: Broader data collection.

The information from step one and step two was used to develop the surveys to gather further information from a broader group of participants.

#### People who used AAC and communication partners

##### Interviews

Data was collected over an 18 month period from participants who lived across the UK. Among powered communication aid users there were 6 adults and 3 children interviewed face to face; one adult was interviewed over SKYPE and one by telephone; two parent focus groups were conducted. Details of participants can be found in Appendix 4.

The topic sheets for use in these interviews were validated externally by a user of communication aids and communication partner. The education topic sheet was validated by a SEN teacher and primary teacher in mainstream school (see Appendix 5).

Participants were recruited through practitioners within both Health and Education and through direct recruitment at Communication Matters Conference and the Communication Matters research volunteers list. The interviews were conducted face to face, by SKYPE, and by telephone. Some participants responded by completing the topic sheet through e-mail.

##### Surveys

The views and experiences of people who use communication aids and their communication partners were sought through an on-line survey. This allowed the

participant to express themselves in their own words and at a time that suited them. The survey asked specific questions about their experiences and also provided text boxes for responses. Survey Monkey was used to collect responses between August 2012 and December 2012.

The questions for the surveys were developed following reading the data gathered during interviews and focus groups. The survey asked specific questions about the person and their experiences and also provided free text boxes for further responses. The questions for the people using powered communication aids and communication partners were validated by people with experience of use on the Communication Matters Independent Research Panel.

The on-line surveys were marketed through general media; charity websites; via e-mail through the Department of Education for Scotland, England and Wales school e-mail distribution lists; to independent special schools and via other relevant email distribution lists.

### Surveying other groups

Paper/e-mail surveys were developed for charities and suppliers/manufacturers.

Charities were contacted by telephone and e-mail in order to gain an overview of the role of charities in supporting people with communication support needs and the information and support relevant to AAC.

The charities contacted were provided with information on the study and a request to comment on the overall aim of the charity and specifically its role in supporting people who may need or use AAC.

Suppliers/manufacturers were surveyed to establish the range and variety of approaches adopted by suppliers, including in respect of any role in assessment (trialling equipment/software), training (on the equipment/software), support (on-going) and funding provision (equipment/software/warranties).

## Part Two: Results

### Participants

The numbers of participants contributing to the study who took part in telephone interviews, face to face interviews, focus groups and initial scoping meetings and telephone interviews are detailed in Table 3.2, Table 3.3, Table 3.4, Table 3.5 and Table 3.6 below.

**Table 3.2: Pre-study scoping (Step 1) participants, meeting by role of participants**

Method	Details
Scoping Survey	a SLT Services returns 58
Meetings	<ul style="list-style-type: none"> <li>SLTs scoping meetings 10</li> <li>AAC SIG meeting (14-16)</li> </ul>
Media Requests	<ul style="list-style-type: none"> <li>Bulletin: direct by e-mail 4</li> </ul>

**Table 3.3: Focus group participants AAC Evidence Base study**

Focus group participants	Numbers
Parent	7
Education ICT Specialist	1
Education Psychologist with an AAC specialism	1
Education Teacher	5
Education Teacher with AAC specialism	1
Education Teaching Assistant with AAC specialism	1
NHS AAC Specialist Assistant	1
NHS AAC Centre manager	1
NHS Assistive Technician	8
NHS Clinical Scientist	2
NHS Engineer AAC specialist	1
NHS OT AAC Specialist	5
Social Services OT	1
NHS SLT AAC Specialist	24
NHS SLT with AAC Specialism	48
Private Practitioner SLT AAC Specialist	2
SLT Student	3
<b>Total</b>	<b>112</b>

**Table 3.4: Face to face interviews and 2 SKYPE interviews**

Participant	Number
Parent	6
Adult using AAC	6
Child using AAC	3
Carer	1
Academic	2
Education AAC Specialism	2
Education Head Teacher	1
Education ICT Specialist	2
NHS Clinical Scientist	1
NHS Commissioner	1
NHS SLT AAC Specialist	7
NHS SLT with AAC Specialism	4
Private practitioner SLT AAC Specialist & Academic	1
Voluntary Sector SLT AAC Specialist	2
Supplier	4
<b>Total</b>	<b>28</b>

**Table 3.5: Telephone interview.**

Participant	Number
Adult using AAC	1
Parent	7
Charity	5
Charity SLT with AAC Specialism	1
Education Assistive Technologist	2
Education SEN teacher AAC Specialist	2
Education SLT AAC Specialist	1
NHS Commissioner	1
NHS Nurse MND	1
NHS Occupational Therapist	3
NHS SLT AAC Specialist	2
NHS SLT AAC Assistant	1
NHS SLT with AAC specialism	1
Private Practitioner SLT AAC Specialist	2
Voluntary Sector SLT AAC Specialist	1
Welsh govt civil servant	1
Scottish govt civil servant	2
<b>Total</b>	<b>34</b>

**Table 3.6: e-mail contacts**

E-mail Contact	Number
Academic	2
Charity worker	9
Charity SLT AAC specialism	2
Commissioner NHS	1
NHS Research Dendron Worker	2
NHS SLT	2
NHS SLT AAC Specialism	6
Private Practitioner SLT AAC Specialism	1
People who use AAC	2
Welsh govt civil servant	1
Scottish govt civil servant	1
<b>Total</b>	<b>29</b>

The results from the qualitative investigation are presented below.

- Section 1 provides information on the development of the description and definitions of AAC service provision;
- Section 2 gives the results of the investigation into AAC provision, its components and elements;
- Section 3 provides information on user experience.

## Section 1: Describing AAC Provision

The approaches to the provision of AAC and the components of these services are many and various. Thus comparing services and identifying barriers and facilitators required investigation and detailing of essential elements of the services.

A framework was developed around main themes relating to provision of AAC. These initial themes centred on the activity of practitioners and those commissioning AAC resources in the provision of AAC.

### Initial development of service components: describing the AAC service 'eco system'.

An initial thematic analysis of the qualitative data identified a number of components that were present in the identification of need, provision of aided AAC and the ongoing use of aided AAC. These main components each had a number of elements that reflected the activity associated with it. Table 3.7 details the main components and their elements identified on the first pass analysis.

**Table 3.7: Components and elements identified as activities associated with the provision of AAC aided communication**

Identification of need for an evaluation for AAC aided communication	Self referral Practitioner
Assessment evaluation for AAC aided communication	Matching Access Evaluation
Customisation	Hardware Software Personalisation of vocabulary and content
Integration	PC & Telephone Wheelchair Environmental control
Loans	Short term: Trial of device Long term loan
Maintenance	Equipment Low tech AAC
Support	Person centred Communication Partner centred Surrounding Team centred
Training	Person Communication partners Support staff
Positioning & Mounting	Placement Fixings & brackets
Repair	Equipment Replacement
Review	Meeting needs Future needs
Custom Manufacture	Make to requirements
Research & Development	Research Development
Information & Advice	Inform about AAC aided communication Advise on AAC aided communication
Funding	Equipment Staff Training Support

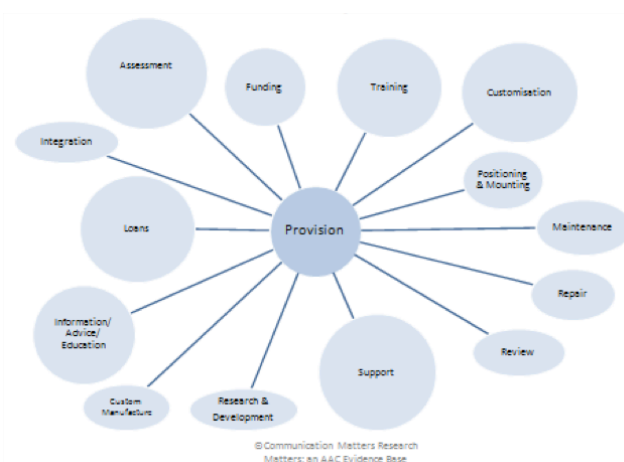
These components represent a core set of resources required for AAC service provision. The practitioners reflected that the more complex the needs of the person then more they need in terms of AAC resources.

### Validation

These components were validated by specialist practitioners in the field at a National Interest Group for AAC. The attendees at the National Interest Group for AAC practitioners were all specialists in AAC and included specialists from different disciplines and representatives from Health, Education, Charities, and Voluntary sectors. The practitioners worked in specialist AAC Centres and AAC services across sectors and across the UK.

The components were presented to the attendees who were asked to review them and validate them. The attendees were given a copy of the components and were asked to produce a diagram showing the provision of AAC within their own services. An example of one of the diagrams produced on the day is shown in Figure 3.1 below which shows the diagram produced by a specialist AAC Centre. All the diagrams were read and transcribed into tables for analysis. An example of such a table is shown in Appendix 6.

The validation exercise suggested that the components were inclusive of a wide range of activities involved in the provision of AAC and powered communication aids.

**Figure 3.1: Example service map for a regional communication aid service (see Appendix 6 for original).**

Further validation was provided via expert reviews from specialists based in centres that provided AAC resources. These included designated AAC Centres and local area specialists for AAC. There were 18 ‘expert’ reviews of the components. The researcher asked the specialist practitioners to validate the components by reflecting on their own practice and to comment on whether the components captured all the activities they undertook within their own service and to advise if there were any components missing. The elements of each components were explored within the sessions and additional elements identified.

Defining AAC service components

To ensure a common language for terms relating to AAC provision, definitions were developed for both the components of aided AAC service provision and terms to describe the makeup of teams who provide services for AAC. These definitions were based on both existing definitions within the literature and from analysis of the descriptions of activity provided by participants in the study.

The definitions were validated through a Delphi technique using those with experience of using AAC and powered communication aids as the ‘expert’ panel.

The set of definitions of terms for AAC were set out with a choice of agreeing the definition or seeking to amend the definition.

Round 1:

The first round involved giving a copy of the definitions to those attending the Communication Matters 2012 conference<sup>1</sup> with the aim of gaining an informed readership. People were asked to agree or amend the definition and if ‘amend’ to suggest the wording. There was a comments box to allow people to provide suggested wording.

Seventeen questionnaires were collected at the end of Conference and the returned questionnaires were reviewed. Table 3.8 shows the experience of respondents in AAC.

The returned forms were reviewed and those definitions that were 100% agreed were confirmed as valid definitions.

The definitions that were marked as ‘amend’ were revised by the moderator in light of feedback from validators and discussion within the research team.

Round 2:

The second round of the study included only those definitions that had been amended. The questionnaire was delivered on-line using the on-line Survey Monkey<sup>2</sup> tool, this allowed participants to respond in their own time and location. All those who had completed the first round and provided contact details were sent a request to complete the questionnaire on-line for round two of the Delphi. Eleven people responded to Round 2.

Definitions where comments had been returned were further reviewed by the researchers. On review of these comments they were found to be either style comments or observations on what respondents considered to be best practice. The moderation process thus concluded and the definitions were validated following at this stage.

Table 3.8: Respondents to Delphi study

Respondents	Round 1	Round 2
Person who uses AAC	1	0
Mother of a person who uses AAC	1	1
Practitioner AAC	11	7
AAC organisation employee	1	1
Academic	2	2
Total	16	11

The definitions developed are presented below for each of the service components described in the main qualitative data.

1 <http://www.communicationmatters.org.uk/conference-session/2012-aac-evidence-base>

2 [www.surveymonkey.com](http://www.surveymonkey.com)

## Section 2: Components of AAC service delivery

Following the initial framework development and definition of the relevant terms the qualitative data was fully analysed and the full framework of AAC service delivery components was created.

This framework is shown in Figure 3.2 below and followed by the definition and explanation of each component and its contributing features. For each component, the definition (as agreed through the Delphi process) is initially presented highlighted in grey. A summary of the qualitative analysis of the data for this component is then presented.

This data is illustrated with quotations, these are highlighted in grey.

**Figure 3.2: Components of AAC service delivery**

<p><b>Key Point i</b></p> <p>the qualitative data identified all the components discussed as being required for effective provision and ongoing use of AAC and powered communication aids: identification; assessment, information and advice, loans, positioning and mounting, customisation, funding, maintenance, repair, ongoing review, support, integration, research and development.</p>
<p><b>Key Point ii</b></p> <p>there was consensus between professionals, AAC users and communication partners that all service components were required to facilitate an effective system of identification, provision and use of AAC.</p>

### Service components and definitions:

#### Identification of need for assessment for AAC:

The identification that a person could benefit from further assistance with their spoken communication either through unaided communication techniques or aided communication equipment. This can include the identification of support and training needs of the person and their communication partners.

Prior to any formal assessment for aided communication the potential for AAC to help a person communicate needs to be identified. Therefore, before 'assessment for AAC' is 'identification'.

The need for AAC and specifically for powered communication aids was described as being identified through a number of channels, including: the person with

communication support needs themselves; a family member or carer or personal assistant; and someone working directly with the person, such as a teacher or SLT or OT. Within our data set, there were no examples of identification of need for an AAC assessment from social services or nursing and residential homes.

The specialist centres for assessing people for AAC felt the local teams were 'key' to identifying need for assessment for AAC for people. The specialists aimed to work closely with their local teams to ensure the right people were identified through advice and training and building good relationships with those teams. Specialists in AAC were open to supporting local therapists in identifying need for AAC through developing competencies in the local teams.

'You develop the competencies and the local therapists, they can identify if somebody needs something. They then ring you for advice.'

(Specialist AAC Centre)

In contrast, one parent described her difficulties in getting her sons' needs for aided communication identified by SLTs and other professions. At the time of the focus group (2012), she had only just managed to obtain an assessment for her two sons from an AAC Centre.

'Our local community raised the money for them 10 years ago so they've been using Lightwriters, they've been using laminated pieces of paper with the alphabet.'... '10 years wait has been a bit of pain. Despite the fact that various social workers, speech therapists and all those people would have seen the guys actually typing. Nobody at any point were sort of saying, "Could we not do something more?" We actually were out there trying to make ourselves available for somebody to say, "Can we help you here? Can we provide something better? Have you been assessed? And that wasn't forthcoming.'

(Parent of two adult aided communication users)

The Specialists for AAC and the AAC Centres described identification of need to their own specialist AAC services. Sometimes it was a direct approach from people and families, though the main people identifying need to them were SLTs.

'The majority of referrals come from speech and language therapists. They also come from occupational therapists because we have OTs on the

team. But they may come from parents. We have open referral so anyone can refer.'

(Specialist AAC Centre)

The Focus Group members and the practitioners interviewed from Specialist Centres discussed the competencies required to assess for need for AAC and it was felt that the experience level and competencies of local staff around the person varied. The level of competency seemed to be related to knowledge of what AAC could achieve, the previous training the local team had received and the level of experience within the local team of working with children and adults with complex needs who might need AAC and particularly powered communication aids.

Those practitioners who rarely saw anyone on their caseload with communication support needs for powered communication aids had fewer opportunities to build competencies around identifying people who may benefit from aided communication aids. Participants from local teams reflected that they valued having access to specialists and frequently sought the advice of specialists for aided communication to provide information and advice on assessment for aided AAC including powered communication aids.

Some practitioners working regularly with people with complex needs requiring aided communication were able to develop expertise that allowed them to identify need for AAC for others. For example, those who worked in special schools or specialist settings had the opportunity to gain a higher level of experience and to develop the necessary competencies around AAC than those local teams working in non-specialist settings, such as community clinics or mainstream schools.

'...the majority of the children that I'm referred had been referred from one of the complex needs schools or the preschool autism specialist or the pre-school child development unit specialist. That probably makes up 90% of the referrals to me.... Those therapists have a higher level of knowledge and skills about AAC because obviously they've got more children in their caseload and using it and more experience....because they have seen it work with other children and they've seen children where it hadn't worked.' (Specialist AAC Centre)

The practitioners described instances where the team around the child had identified the need for an assessment for a powered communication aid but the family did not want to take up the assessment as they had AAC strategies that worked for them.

'...it depends on the team around the child really because some parents are of the opinion that they don't need AAC because they communicate effectively without it and that they don't think it will add much or anything to the communication of their child.' (Specialist SLT AAC Centre)

Many of the specialist AAC centres described providing consultations for local practitioners on specific matters and this did not involve the AAC centre assessing the person themselves rather using their knowledge of current technology to make recommendations for local assessment. Some centres provided equipment loans for a local assessment to be made while others provided the option to have a consultation without equipment loan.

'...the consultation process, as well as doing formal assessments with provision, we do do these things that we call 'consultations' where there's no expectation of providing equipment...You would get a consultation but don't expect to have a piece of equipment or assessment.' (Specialist AAC Centre)

#### Key Point iii

the potential of persons with communication difficulties who could benefit from AAC needs to be recognised by people within their environment as well as health, education and social care staff who need to be kept informed of technological and behavioural developments and specialist services.

### Assessment for aided communication:

Assessment is an evaluation of the suitability of an individual to use aided communication which aims to match a person's skills, capabilities, and environment to potential aided communication methods. The assessment can take into account the cognitive, communicative, language, speech, physical and sensory abilities and needs, including those that affect the method of accessing the devices. The assessment includes consideration of the environments, attitudes, personal actions, activities and participation as well as the aims and aspirations of the person and relevant stakeholders. It may include initial training and a period of equipment loan and trial.

Those practitioners whose role was around provision of appropriate AAC were asked to describe the process used to decide which type of AAC, and specifically powered aided communication, would benefit someone.

The complexity of those needs could entail assessment by different practitioners, so while low tech systems were usually provided locally by the person's own local team, assessment for high tech devices frequently involved further specialist assessment. The specialist assessment was described very differently depending upon the complexity of the case and what AAC services were commissioned and provided locally.

In the data gathered during this study, the participants included a range of practitioners from different professions who were involved in the assessment team. The 'team' in an assessment for aided communication could include a number of disciplines according to the needs of the person being assessed and the complexity of the difficulties being assessed, the knowledge of technology and systems required. The teams were described as including SLTs, Occupational Therapists, Technicians, Clinical Scientists, Engineers, Teachers, Physiotherapists and Doctors. When discussing assessment participants described a wide range of topics, factors and elements of service delivery. These have been further broken down below.

#### **Assessment for AAC and Accessing Specialist Assessment for AAC**

The participants described different types of service organisation for their local teams with different care pathways for their area. Responsibility for providing a local assessment for aided communication varied and could rest within health, education, or jointly or with independent providers. There were a range of professions assessing at the local level. These included SLTs, teachers, educational psychologists, OTs, PTs, ICT/AT staff.

Some participants were members of local teams and they described how they had differing levels of experience and knowledge around AAC and powered communication aids with some having limited knowledge of simple tools such as communication charts, whilst others were regularly providing relatively complex powered communication aids.

Some local SLTs described their experience in providing non-powered communication aids, such as, e-tran frames, communication charts, signs and symbol based paper systems but reflected that they would not necessarily have the current knowledge of technology to assess and recommend specific powered communication aids. It was in these situations when they described wishing to have a specialist in aided communication complete the assessment.

Care pathways for referring a person to a specialist AAC centre were described with varying arrangements for the point of referral related to local policy and service level agreements. The referrals were described as originating more usually from practitioners although there were self-referrals from the person themselves, family members or from people working with them – their local 'team'.

It was felt by some that SLTs could appear to people seeking an assessment for powered communication aids as acting as gatekeepers to accessing specialist AAC centres.

'My SaLT on my initial assessment said she did not know about electronic aides, "It wasn't her thing". The next visit was over three months later when I asked for a referral to AAC. She said that she didn't think I needed a referral as it was only for complex cases. I have only problems with my speech at the moment... The only support I got was a promise to call me if there was spare iPad in the Store. I asked about microphones and she reluctantly agreed to think about it but this came from me. I felt like I was being a difficulty for her.' (Adult with MND)

'I was told that I did not need an assessment as lots of people just manage with an iPad but the SaLT was unable to give me advice. I was just told that she would look in the store for an iPad I could practice with because I refused to have one until I knew what it did as I had already downloaded two others; 'Verbally' which has too little space for people to read and when it has spoken it disappears; 'Speak it' does not have predicted speech.' (Adult with MND)

## The AAC and Aided Communication Assessment Process

Many factors were mentioned by practitioners in describing the assessment process. There were variations according to how the AAC services for a population are structured, the specifications for the services around AAC and how AAC services are commissioned. Assessment was seen to have the three stages:

### Stage 1 – Information gathering

Collecting a range of information from different sources on the person's abilities, limitations, needs, wants and environment

### Stage 2 – Matching the person to the powered communication aid

Considering the information gathered and matching this to the design features of AAC systems and devices

### Stage 3 – Trial to evaluating the communication aid

Providing a system or device along with support and training for a period of trial. Observing and monitoring progress with the system or device.

## Assessment visits for a powered communication aid

### Stage 1 Information gathering prior to appointment

Different AAC specialist services described different set criteria for accessing their own AAC services. These varied across the country and were related to how services were structured and what the AAC service was contracted to provide e.g. assessment and recommendation, assessment and equipment trial.

Local practitioners described seeking specialist opinions from an AAC specialist or team of AAC specialists according to need and for various reasons.

'It's those children where the needs are not clear and different parts of the team are arguing, well arguing might be a bit strong but they're assessing them in different ways.' (Specialist SLT AAC)

'...we maybe need to look more at a sort of holistic approach so looking at specialist mounting systems, some of the more sort of high tech complex stuff that we just feel we don't have the sort of resources or specialisms to access locally.' (Local Specialist SLT AAC)

One Specialist SLT AAC Centre described how their adult SLTs were experienced in working with AAC and so they did not need to provide the assessment. However, the AAC Centre did support the SLTs' assessment of adult patients by providing a range of communication aids in the hospitals that they could use for assessment to evaluate whether the AAC device helped functional communication.

'... adult therapists who have been around a very long time, they're very skilled, so there were some pieces of equipment that I wouldn't feel the need for an assessment for from me.' (Specialist SLT AAC Centre)

Where the assessment of a person was completed by a specialist team for AAC then the presence of a local practitioner/s and the 'team' around the person was often described as being encouraged as well as the presence of the person's main communication partners. These people may include, for example, the local speech and language therapist, the specialist teacher, the teaching assistant in addition to the key carer and the family member.

Specialist teams described using the information in the referral forms to provide them with relevant information to allow them to identify specific needs and to help them to identify which professional staff needed to be involved in the assessment process.

'The process works in that...I've got a standard form for just basic second opinion with, some of the people fill it with basic biographical information, what they want from a second opinion, what the child's achieving in terms of educational levels, ... whether they're using signs or symbols or any other low-tech system, whether they've got any physical or sensory needs. You know, are there any professionals involved? - all of that basic information. And from that, I look at whether actually, someone else needs to be involved in the assessment.' (Specialist AAC Centre)

'...it's got to be based on clinical reasoning. It's got to be based on proper clinical assessment and a proper analysis of the needs and the different options that you've got to meet those need.' (Specialist AAC Centre)

## Stage 2 – Matching the person to the powered communication aid

Participants discussed a number of considerations they considered when matching a powered communication aid to a person. These factors included: the individual's abilities, the capabilities of the device, where and how it will be used and the actual design of the communication device. The design of the aid was discussed in a number of contexts from its ability to meet requirements to its aesthetic and functional design.

Participants described how the development of communication 'apps' for tablets has affected this process through making AAC software more available to a wide number of people. Practitioners reported that the lightness, portability and 'coolness' of mainstream tablets were often reasons cited for making them a popular choice. The fact they are mainstream items was also described as having an appeal, as was their ability to integrate both spoken communication with other aspects of communication and life. For example, they could also be used as a communication passport with the device holding pictures and narrative about the person. People described using them as an integral part of their everyday life to communicate, take pictures and share pictures, to access social media and the internet.

The practitioners reported an increased demand for support for using tablets and iPads in particular with people rejecting dedicated devices that practitioners felt would suit their abilities and needs better.

'...we had a [PORTABLE VOCA] for a child more than capable of using it and loads and loads of lovely things on it and he completely rejected it, wanted his iPod ... with [AAC APP] and there's only a few sort of applications and he used that more to shout to his mum I want a drink than he ever did the [PORTABLE VOCA]. The [PORTABLE VOCA] he just totally rejected. (AAC SIG Group Member)

'He doesn't want something that's just a voice output device he wants something that does more...and he certainly doesn't want something that makes him look different from other young men his age.' (Specialist SLT AAC)

Whilst there was a greater emphasis on spoken communication in the health sector there was a view that for certain people there needed to be a more holistic approach. The examples given were related to progressive neurological conditions where the person might initially need to access the computer for work or social media and then use the same access method for speech production.

'We might be seeing somebody for communication and computer access or somebody that might need communication in the future, we might start off with computer access and bearing in mind that the device that we've identified for them we might want it to work as a communication aid and as their condition progresses.' (Specialist OT AAC Centre)

### Matching access methods

The participants highlighted the need for correct provision of means of accessing a powered communication aid. Participants described having to establish how to correctly place, adapt or manufacture the necessary switches to provide safe access with minimum effort for the user.

The level of skill required in making the correct evaluation of access was perceived as increasing with the complexity of the needs and abilities of individuals requiring specialised access.

'...if the switches are at a particular angle or on a particular chair with particular posture - people can do it. And if it's none of those then, or if one of those is missing, they can't do it. And it's the difference between, you know, independent communication and dependency really.' (NHS Commissioner)

## Stage 3 – Evaluating the communication aid

Participants also discussed using the equipment as a way of assessing a person's communication abilities and potential. For example, people with profound physical disabilities may not be able to communicate in other ways and the use of the communication aid equipment can help to identify their communication potential as well as provide information as to whether a communication aid would be suitable.

However, for some practitioners a lack of access to an equipment bank precluded their ability to assess and evaluate the potential of people to use powered communication aids.

'One of our problems is because we haven't got a budget we've no assessment devices, no loan devices even from quite basic things.' (Local SLT)

'..if you've just got something in your department which suffices but they kind of don't take to there's not a lot of opening ... let them try other things .. you can get in the different communication aid companies to show things but I can't say unless they want to buy it it's kind of showing them a present and saying yes but you can't have it unless you can raise the money.' (AAC SIG Group Member)

There was a view from those in education that the specialist assessment needed to take into consideration the wider picture of what a person needs in both spoken and written communication. Participants working in Health settings reported that their brief was very much targeted at providing AAC focussed on spoken communication.

'.. see people for spoken communication and ...don't get involved in the computer access or email-type communication.' (Specialist SLT AAC)

'..so much of everybody's communication now is not just by speech. And I think, especially for people who are house-bound or find it physically difficult to get out and about and meet people. The kind of social networking, the emailing, the being able to keep in touch by text...that is so much more important for them.' (Specialist SLT AAC)

### Assessment outcomes

The outcome of an assessment for aided communication was described in different ways. The outcomes mainly related to meeting the goals of the person assessed, their own support team and those who made the referral.

There was a view that an important part of assessment and evaluation of the equipment recommended meant looking at the outcome of the person using that device within their own environment and so the practitioners from some AAC services described giving the person and their communication support team targets to achieve during the trial period and then reviewing these targets.

'..what we generally do is we'll do an initial assessment where we're trying to gather all the information about what their goals are, how they're communicating, all of those areas. Where they want to use the aid, who they think they might use it with. Then from that we might try a communication aid at that point. We might come back to the office and go out with some other things to try. And when we found something that we think might work for them then we usually kind of set up at least a two week trial loan of the piece of equipment. And following that, we really trying to get evidence of how they used it, what they like about it, what they didn't like about it? And gather that evidence.' (Specialist AAC Centre)

'..the parents need to be involved all the way along so that they know if we're not hitting those targets that that piece of kit will come back to us and we'll go down another road.' (Specialist AAC Centre)

The specialist AAC centres and specialist practitioners described making recommendations for a particular communication aid at the end of the assessment period. The specialists in AAC emphasised the importance of the recommendations to include the different elements that needed to be in place for the person to have both the means and the opportunity to use the device and AAC strategies recommended. Therefore, the recommendations from the assessment needed to include consideration of how the device can be supported within that person's environment.

'We try to offer two reports, sort of an initial report that says, this is what I think the situation is and this is what I think we can do; and then a final report that says, which is a report summary which is, well, this is what we did and this is what we think and these are costs involved if you want to go ahead with this kind of equipment. We try to keep the reports as succinct as possible.' (Specialist AAC Centre)

'...it's just being realistic about that isn't it and I know this sounds awful but there are situations where we will have provided a perhaps less complex device to a person because we know that from discussing with the team or the client that they don't necessarily have the support in place to support a more complex system so at that point in time - providing something that okay might not be the ideal for that...' (Specialist AAC Centre)

The length of time between initial visit and final recommendation varied according to local structures and organisation and resources. The assessment time could form one session or could stretch over many months depending on the complexity of the person's condition and the need to evaluate and adjust the device so a loan period of trial equipment was reported as varying substantially.

'Our first visits are generally three hours long and those mostly involve the paediatrician and they are usually involved mostly in the first assessment, first appointment and those appointments are then, we would if there are further investigations or trials of things like that to be done, we would bring patients back for another probably two hour appointment on top of that so in terms of actual contact time two appointments maybe.' (Specialist Tertiary AAC Centre)

'...we offer a six-session package, which comes under the label "assessment" ...so we have six sessions that gives us that kind of flexibility. And within those sessions, we can assess, we can put 'kit' into trial, we can establish longer trials, we can support the professionals, the families, and then we can come up with a set of recommendations which I feel have some clout to them... these six sessions can sometimes span a 12-month period...they're not like necessarily week-on-week.' (Specialist AAC Centre)

The specialists in AAC described the need for assessing the person's needs as an on-going process and so regular reviews were a part of the long term management of the person (also discussed in the Reviews component).

'Well building blocks to be realistic, that's the other thing. We don't just provide one piece of kit and that's it, we continue with our assessment process and we might sort of provide somebody for example with a tech 32 with maybe 32 messages on it and if they do very well with that, then we would provide them with a more high tech device so it's a continuous process as their needs change whether it's improving or deteriorating then what we can provide can change.' (Specialist AAC Centre)

#### Key Point iv

assessment for AAC requires consideration of a broad range of factors including an individual's abilities (physical, sensory and cognitive); communication potential and requirements; environmental constraints; needs and aspirations of the individual and their family and resourcing.

#### Key Point v

professionals involved in assessment for AAC need a broad range of knowledge, skills and abilities and to be able to access those with extended specialist skills.

#### Key Point vi.

the term 'Assessment of AAC' is used to mean all or some of a wide range of activities including powered aided communication assessment, evaluation, matching, and physical access assessment.

### Loan trial of equipment:

Equipment loaned to people for a period of time to allow trial of the equipment within the person's everyday context. This refers only to the period of loan, trial and evaluation as part of assessment and prior to a device being recommended as that which meets the needs of the person. The device is left with the person to allow them to use the device with people in their everyday situations, not just with the AAC professionals in attendance. The loan period can include agreed aims and recording of evidence regarding its use. It can include appropriate training and support for the loan period.

Practitioners described the trial period as an important one for judging whether powered communication aids would be considered as a suitable match for the person. While someone might be able to use a VOCA in the assessment setting it does not necessarily follow that they can use it within their environment, given their personal circumstances.

'The trial period is important because it identifies whether it satisfies most of the needs or not.'

Practitioners described different approaches to loans and the length of time provided for trialing devices. For example, some services were limited in what they could offer because they had no equipment to loan. This was linked to funding issues where a lack of funding precluded their ability to purchase equipment for assessment and trial.

'One of our problems is because we haven't got a budget, we've no assessment devices, no loan devices even for quite basic things.'

One way of providing a loan to evaluate a device was to seek a loan from a supplier.

'...most companies will do a loan but it's only two weeks.'

Departments with their own equipment store had some more flexibility regarding the length of the loan depending on demands for the loan equipment. The length of time for loaning equipment varied from 6 weeks up to 3 months or 'providing the loan for as long as it took to evaluate the device' or until arrangements could be made for a long term loan or funding for a communication aid.

'Parents have said they wanted the longer term loans so we had to make a decision what's practical and long enough and three months seemed about right in order to keep the turnover of machines.'

Practitioners described the importance of supporting the person during the trial period if the suitability of the device was to be properly evaluated.

'It is important to focus everybody on those six weeks to really maximise what they can get out of it and feel like you've got a good decision at the end of it.'

The trial also allows people to assess the level of support needed to learn to use the device and support its continued use.

'I have another very trite phrase which is 'there is no bad outcome from a loan', so whatever we learn from a loan tells us something even if they take it away and they go "Blimey it takes ages to support, doesn't it?" and you think actually it does and they have learnt something about the level of support that will be required and we can work together with them to sort of work out how we're going to solve those problems.'

#### Key Point vii

loaning equipment for a trial phase is considered essential to establish whether it is appropriate and acceptable for an individual. Individuals often need ongoing training and support during this trial phase.

#### Long term provision of equipment:

Equipment can either be loaned or provided by a service for AAC on a long term basis, normally until the person has no further use for it, the equipment is no longer suitable or the equipment needs to be refreshed or replaced according to communication need. This may or may not result in the recipient owning the equipment. In cases where a service retains ownership, the equipment may have to be returned when the person transfers out of the service (due to age or the person moving out of the area).

The practitioners described different procedures regarding provision of equipment. In some services, a device provided during assessment for evaluation as a 'loan' then stayed with the person as long as it met their communication needs. These long term 'loans' of the communication aid equipment began once the person received it as part of the assessment process. Ongoing monitoring and support for the use of the communication aid formed part of the continuing assessment of need and monitoring of whether those needs continued to be met.

'We don't really have a concept of loan, we have the concept of providing for the need at the time that we see it with the knowledge ... that we will modify that and change that as it develops.'

Some specialist services for AAC are able to extend the trial loan into a long term loan and allow people to maintain using the device for communication to enable them to 'keep their voice'.

'So as long as there's money in the budget, and we've agreed that it was of sufficient benefit to them to go on with purchasing it, then we try to make it as soon as possible from a short term loan to a long term loan. So if they've got a device on a short term loan, if we can, we tend to try to make that the long term loan device.'

In other AAC services, equipment was provided once the assessment was complete and a recommendation could be made. This usually was in the form of a written report setting out the whole of the recommendations for the person. This could incorporate the hardware, software and programming of the device and the need for training and ongoing support as required to ensure the successful use of the equipment. The period between the recommendation and equipment being provided varied according to the system for provision of the loan.

'[DEDICATED VOCA] is on long term loan from MND society.'

'You know, we do the assessments and we have the aids here for loan so then we're able to get provision sorted very quickly.'

It was participants' view that the issuing of the long term loan required someone to take responsibility for the loan. This could be the person, their family or carers.

'It's the families that take the responsibility. Sometimes, it's for maybe an adult with MND, it's the person themselves that takes that responsibility but there has to be somebody who kind of signs for it even if they don't actually sign for it.'

### Positioning and mounting of equipment:

Assessment of positioning and mounting identifies the best position for the AAC device to ensure ease and safety of access. It can include identifying the correct positioning and mounting required in respect of other assistive technology equipment which may interact physically with the positioning of the communication aid. This component is solely relevant to the physical hardware provided and not any software that may need integration or installation.

The different providers had different approaches to ensuring correct positioning and mounting. The method of access through the correct positioning and if needed the mounting of a device was usually assessed as part of the assessment process for a powered communication aid. Correct positioning and mounting was described as needing careful and specialist consideration if the person was to be successful in accessing their communication device.

'The biggest thing ... is getting her positioning, the positioning in the wheelchair to activate the eye gaze is crucial.'

Participants referred to the wider team. In some cases, these skills were accessed within the team, others worked with other services to achieve this. One participant discussed the advantages of their therapists working with the wheelchair service to get the right seating. The close working of team members and the person using the powered aided communication device/AAC with the wheelchair service had provided good seating and opportunities to mount the communication aid.

As the school teams work closely with the wheelchair service, joint assessments can be carried out and access methods discussed and best options decided. For those students who have finished growing more permanent seating options can be used – moulded seats give better seating positions. Of the 96 students, 80% require the wheelchair service. The service works closely with manufacturers and has a good knowledge of the chairs and which chairs that can take mounts to support communication aids. They know the students well and can ensure the right chair and seating to meet a student's needs. All decisions are made with the student who chooses what they are getting so the chair is tailored for them.' (Specialist AT AAC special school)

Some participants reported that they would undertake mounting equipment if it was within their competence. In some areas specific teams were set up to do this (for example Medical Physics or other Engineering departments). Some specialist AAC teams described mounting communication aids and monitoring the continuing safe mounting of the device within the service.

'If there's somebody in the local team who can do it, then, that's fine. But ...usually, there's not. So, in the absence of anybody local, we would go and do it.' (Specialist AAC Team).

'Mostly you're on your own... I mean nobody for mounting.' (Local Specialist SLT)

The impact of a wheelchair not being fitted with a suitable mount for the communication aid was strongly felt to restrict the person's ability to use their aid in different environments.

'She uses it as much as possible in static locations e.g. home and school. However, due to having no mount on her wheelchair she is not able to use it easily if out and about. Being mobile would allow her to use more spontaneous communication.' (Parent of child communication aid user)

Some services and families reported that they tried to anticipate issues when new wheelchairs were provided by pre-ordering the correct clamps to ensure the communication aids are correctly mounted.

'We're purchasing this wheelchair, you might need to make sure you've got this clamp ready so when it arrives we can get that immediately set up, instead of watching the wheelchair arrive and being another five months before the Talker is attached to it.' (Paediatric OT)

One parent described how she did the mounting of the communication device each time her daughter's wheelchair changed. She did the mounting herself using their old mounts or by purchasing mounts from USA where they were less expensive to buy.

'She has been supplied wheelchairs from the xxx Wheelchair Service, and I'm just going around, you know, trying to make them all fit. I've got, you know, big boards of steel between each of the three different sets we had that went on different wheelchairs at some time. And these are ones I bought from the States because they're so expensive, that....Anyway, I have got it mounted in front of her on her wheelchair now.'

Interviewer: 'They allow you to mount on the wheelchair.'

'I don't know, and I ...to be honest, I really don't care...well, you're not taking her voice away. She needs it and she needs it right there. I've got the gear; I'm going to use it.' (parent of an AAC user)

The need to change the mounting between someone's wheelchairs was covered. One parent described the challenge of changing the mounting and positioning of the communication aid depending on which wheelchair her daughter was using at any time.

'She has both. She has the manual one, our manual one, and she has the power one that's very slow.--- ...I have to wiggle things and, you know, tighten them, loosen them up, and change them around slightly, depending on which chair she's in, because she's on a schedule of which day she can take her chair to college.' (parent of an AAC user)

#### Key Point viii

correct positioning and mounting of AAC devices requires careful consideration if the person is to be successful in accessing their communication device without restricting other activities. There is a need for close collaboration between those involved in AAC provision and wheelchair services

#### Integration:

The integration of equipment with other systems so that every component is useable by the person. This can include integrating the use of communication aid with environmental controls, computer access and powered mobility. It can include installation of software and making it work within an existing system.

The aim of integration can vary according to the needs of the individual. For example, if someone has restricted physical ability to access switches then the integration may focus on allowing them to use their one preferred method of access to use different systems. This may require consideration of accessing the communication aid and a computer or tablet, or driving a wheelchair while 'talking' or using environmental controls.

'You do a lot of integrations as well so we've got, for example, some children or adults with a communication aid that they use with the same joystick perhaps to drive their wheelchair and to access their communication aid and to drive their home computer as well.' (AAC Specialist Centre)

'This integration of function resonates strongly with the holistic rehabilitation that we practice so it's about the person as a whole...which is the way we practice in the Centre and so the way the equipment is integrated and its function is very consistent with that.' (AAC Specialist Centre)

Some of the AAC specialist practitioners interviewed felt they wanted more technical support to allow better integration of systems and support for integrated technology but that level of expertise was not available to them in their location.

'I've got several young people who are head switch users ...who have been using the communication aid since they were small but now they ... drive wheelchairs also with head switches but we haven't managed to get that integrated so they can switch between their communication aid and driving their wheelchair independently.' (Local specialist OT)

There was a perception voiced that the ability to live independently could be enhanced if the person could use integrated systems. The use of the telephone was cited as a useful technical tool if integrated with a communication aid from allowing a person to contact others to giving a person independence to be on their own both in and out of the home.

'For people who are living on their own or spend significant amounts of time in the house on their own, being able to call independently is a safety thing. So the Lightwriter...some of the Tobii things, some of the communication aids you can get as a mobile phone integrated, others ...communicating via Bluetooth to a standard Bluetooth mobile phone. ...And some of the technology works better than others.' (Specialist AAC Centre)

'It gives him peace of mind so he can if he's out and something bad happens he can call for help – it extends the range for him.' (Communication Partner)

'It allows me to be independent. I can keep in touch with everybody using e mail, phone and the internet. I can express my thoughts and ideas.' (Person using Communication Aid)

One OT described the issues in her location in getting the wheelchair service to work more closely with practitioners and the child to find solutions so those children needing the integration of powered wheelchair controls and communication aids can have a system that works for them.

'The fact is that no one else has the jurisdiction or the knowledge or even permission to mess about with the wheelchair controller which is the root to setting it up to the talkers to communication aid... It's not good enough just to say wheelchair provided tick because the wheelchair is not fully integrated...if the child is not able to talk in the wheelchair, we haven't reached the end of that... And I had it happened with several young people at that sort of complexity. It's okay when they're straightforward. If it's grabbing and go

with joysticks well that's easy. And when communication aids aren't involved. But once you involve the communication aid, we need to be working much better and much more closer together and persevere until it's done. Otherwise we're wasting tens of thousands of pounds worth of equipment.' (OT working with AAC users)

#### Key Point ix

as technology becomes more sophisticated there is a greater requirement for more technical support to allow better integration of systems and support for integrated technology. It was reported that frequently this level of expertise was not available restricting the potential of integrated systems.

#### Creation of low tech AAC resources:

Creation of personalised aided communication resources for people, such as communication boards or books. (Any ongoing changes would come under customisation eg vocabulary).

Practitioners identified that low-tech systems could be used to facilitate the development of communication skills, to communicate with others and to provide a 'back-up' when high tech communication systems were not available or did not meet communication needs. Those creating aided communication resources used their knowledge and understanding of the needs of the person to provide a personalised system to provide functional communication.

'We always advocate having the low tech back up so you know you've got communication folders, when the high tech aid breaks you've got something'. (AAC Link SLT)

'...we are developing low tech system at the moment that he wants. And he never wanted one before because he said the machine is okay but he realised that it hasn't been okay.' (Carer)

Practitioners described the creation of low tech approaches and strategies can be used as precursors to high tech approaches, as back up for high tech resources, or as the chosen means of communication.

'...when people are admitted to our hospital they will work on low tech before they work on high tech, and often high tech is informed by the work that's done in the low tech.' (Specialist AAC Centre)

### Vocabulary/content customisation

Customising and personalising vocabularies is the ongoing alteration of the content of the communication aid. This includes changing the accessible content in terms of words, phrases, pictures and icons available for use on both high and/or low tech equipment as appropriate for the person and environment.

The personalising of vocabulary and content on a communication device appeared to take place at three points:

- assessment evaluation of a device;
- initial provision of the device;
- and on-going input to meet needs.

The personalisation was described as being completed by different people from the person using the device, for example, a family member or designated carer, the company providing the device, support workers / assistants, technicians, teaching staff and practitioners such as SLTs.

At the assessment evaluation of a device, some practitioners described entering some vocabulary and content before the appointment so the vocabulary is suited to the person for the trial. The person and their family can be asked to think about the content and provide a vocabulary list prior to the assessment.

'...we'd get people to think about what vocabulary needs to go on it or .. what they'd use it for, so often the .. six or eight weeks it takes to get it into the appointment would allow them then to go away and hopefully think about vocabulary and send us vocabulary in so we can then personalise the devices for them.' (Specialist AAC Centre)

On initial provision of the device some relevant vocabulary and content (e.g. personal pictures) is usually entered. This action requires some knowledge and understanding of how to do this. Specialist centres and practitioners spoke of the need to have a key person to take responsibility for ensuring support for entering appropriate vocabulary and content (see Support component). Some practitioners reported that they did not feel that they had the skills or knowledge within their own services to personalise a device for a person and would need to access technical services or companies.

'...personalisation seems to be one of the things that helps use.' (Specialist AAC SLT).

'...we get the reps in to do it and the reps are fantastic. They provide a really good support service.' (Local SLT)

'I feel we have a big gap if we don't have anybody in our service who knows how to programme the devices, update the devices and so on.' (Specialist AAC SLT)

Some parents were disappointed in the lack of relevant vocabulary that came pre-programmed on devices while others felt the pre-programmed packages that came with their child's device were not appropriate to the age of the child. They would have wished for more personalised vocabulary to have been on the device on receiving their child's device.

'I feel that the aid could have come with more pre-programmed on it. I understand that we are adapting this aid to suit an individual child but find it very time consuming programming all the information into the machine.' (parent of communication aid user)

'it comes with words that are already on there. But it's the training of it. How we put more words on it, what it's capable of doing, you know, a lot of that was inappropriate words for a child of 6----- And 'Yes', they're taking up cells and taking up space. And you could have all those words that aren't appropriate to a six year old taken off the list for her to look at and try and find the word she does want.' (parent of communication aid user)

'I have to say that without my husband, and the amount of hours he's put into it, I'm not sure it would have been such a great success as it has been. I mean his input really has been enormous.' (parent of communication aid user)

Backing-up the personalised vocabulary on a device was one of the required tasks practitioners described. There were different procedures followed by different practitioners and schools. Some services did a regular back-up of the vocabulary; others did a back-up at the annual 'PAT' testing of the loaned device or at an annual review; others did a back-up before a device was sent away for repair. The person or communication partner, if they had the knowledge, was encouraged to back-up their personalised vocabulary so it was not 'lost' if the device broke.

**Key Point x**

customising and personalising vocabularies on high and low tech AAC was seen to be key to successful use however it requires specialist knowledge and time.

**Software customisation:**

Customisation of software is altering or developing software which is housed on the device (either a dedicated device or other technology) which changes a core component of how the software works other than the individual vocabulary content, while paying attention to safety, stability and the recording/documenting of any changes.

Technical knowledge was needed to do this so it was usually only mentioned and carried out by specialists in AAC. Specialists at AAC Centres described how they would try to customise the software so it suited the needs of the individual at that time and this could include editing the content by 'hiding' or removing categories.

'You might identify it's the right kind of software but it's too much too soon. But there's potential for the client to get there ...so you might want to hide some items and then work towards it. -- So it might be that a lot of the ones that are already in place aren't relevant and we take them out.' (Specialist AAC Centre)

The customisation can include choosing the software programmes that suit the person and this includes the language that needs to be on the device. It can include customising the 'voice' on the device to suit the gender of the person and their regional accent.'... we show them how to use the equipment certainly when talking about bilingual issues I've shown people health programmes in Polish with interpreters during the appointment because we've got access to interpreting services that we use. (Specialist AAC Centre)

The issue of putting 'Apps' on iPads, iPods and iTouches was raised by practitioners. The Apps need to be purchased through iTunes and many NHS protocols preclude accessing iTunes. Specialist Centres appeared to have established protocols with their NHS IT departments to allow them to download and install software Apps. However, SLTs at non-specialist AAC centres described problems with obtaining and downloading Apps from iTunes and in accessing iTunes in order to update software.

'We've had lots of issues with that but we've managed to get around it by spending lots of time with our own IT people... trying to set up an iTunes account to download software for Apple products through here had been very difficult because most people know iTunes as a way of downloading music, and now apps. So we basically went along to IT and said, "Look, this is what we do. This is what we're doing. How we're doing it with this piece of kit in order to get the software updates? We need an iTunes account" And that's fine. They've sort of seen what we're doing; it's fine. (NHS Specialist AAC Centre)

'...our procurements doesn't touch Health at all. And because the icon itself is never going to be linked to an NHS network in any way, then it doesn't infringe any of their protocol. But if she (SLT) wanted to look it up on her NHS provided equipment she couldn't do it. So she has to do it on equipment that isn't purchased through the NHS, that isn't attached to them in any way. That's the only way....It would have been the issue with local authority too because they have big, big problems about iTunes but I think they've had to be pragmatic ...they've had to deal with it because it is the reality and that's what happened.' (Education AAC Specialist)

**Hardware customisation**

Customisation of hardware consists of altering it to match the requirements or preferences of the person using the equipment. This may be through a combination of commercially available hardware components, or modification of the hardware. This does not include attaching access devices such as switches or keyboards to the main device.

The hardware needs to be adapted to meet the needs of the individual. Both people using powered aided communication and their communication partners commented on the need to have the right equipment to use the device in different settings. This could include equipment that had Bluetooth technology to allow access to personal computers, to accessing amplification. The participants commented on the issue of being able to communicate in noisy environments or group settings. The addition of suitable speakers increased their ability to communicate in a range of environments and social settings.

'Matching the right device to the person includes customising items of 'kit' and equipment that allows the person to access the device and for the device to access other pieces of equipment such as broadband connections and computer access. People may need to connect speakers to their device to increase the volume of their voice output particularly in noisy environments.' (Specialist AAC Centre SLT)

### Custom manufacture

Equipment made, or modified outside of its original intended purpose to meet a person's specific needs. Custom equipment may be classified as a 'custom made medical device'

A central role of some technologists is customising equipment for a person. The references to customisation tended to focus on making switches to suit specific needs. Technicians described building switches or adapting switches that were on the market to make any necessary adaptations to allow the person to use it, or to make its use easier given their functional abilities. Frustration was expressed at difficulties in accessing the specialist skills required to make or modify equipment for the particular needs of individuals.

'At the beginning our technologists used to make some switches because you'd access to labs and things. We don't really do that now. We try and use off the shelf things. And make minor adaptations but not major build.' (Specialist AAC Centre).

### Equipment management for Loan, Assessment and Review

This is the systematic management of equipment by a service including: logging loans and provision; infection control, decontamination, commissioning, re-commissioning and decommissioning of equipment; managing equipment software and hardware updates; equipment acceptance and functional testing; equipment evaluation; equipment repair; battery testing, refresh and recycling.

The different providers had different systems for logging both their demonstration and loan equipment. The contemporaneous logging of equipment was perceived as a very time consuming task and if carried out by practitioners was seen as taking them away from their

core duties.

'[EAT SERVICE] are also responsible for tracking all the equipment so they hold the database which is now System One within their system one records.. so each piece of equipment is assigned on record to each patient... It's a kind of asset registering.' (Specialist AAC SLT)

'Inordinate amounts of time all the admin when you've got people on a band 7 level being employed to do admin tasks when actually they should be with patients....and because we've merged as one big trust trying to locate equipment and keep track of it without an assistant or anyone whose got a designated role is really time consuming.' (Local Specialist SLT)

#### Key Point xi.

administrative tasks such as logging equipment associated with AAC services are often carried out by therapists which is diverting them from their core duties.

### Maintenance of equipment

Maintenance refers to carrying out tasks to keep the equipment in working order. This may include: making routine updates to the software or operating system or keeping the hardware functional; cleaning; charging; routine repairs to any fixings or mountings; and relevant training on maintenance of the equipment. Maintenance can be on request or can be 'planned preventative maintenance'.

Most departments reported that they run annual checks on equipment to ensure they are safe for people to use. This may form part of the 'PAT' testing of equipment issued to 'patients' by the NHS. Often batteries will be replaced at this point and any broken parts of the device replaced such a loose wires on switches and broken key guards.

'Medical Equipment is a contracted in service to provide all the disability and medical equipment for the NHS for all the professionals and they have a set agreed number of pieces of equipment that are held as stock items.....It's wonderful and they deal with the maintenance and the procurement and do the entire PAT testing and everything over the lifetime of the device.' (Local SLT with AAC specialism)

### Repair of equipment

Repair of equipment is required if the equipment is no longer fully functional to meet the needs of the user. This may require replacing or fixing the affected part (which is outside routine maintenance of the equipment). Warranties may be used to cover repairs.

The participants described different routes to repair of equipment depending on who provided the equipment to the person and their family. Where the equipment was a loan, then people would contact the department who had provided the loan. Some departments had technical resources and the technician would attempt to repair the equipment if they had the knowledge and resources. Some equipment was bought under warranty or extended warranties had been purchased and then the equipment was returned to the companies for repair. Other providers paid for repairs as they arose on a case by case basis.

For example, one AAC Centre would back-up a device and provide a replacement (see replacement of equipment during repair). They would endeavour not to leave the person without their 'voice'.

One of the biggest problems we face is reliability due to just wear and tear and things like that and another problem we face is from the suppliers of the equipment themselves is because they're commercial companies they're not always willing to give us technical details of how to test, repair and supply parts to us. So in those circumstances we have to return the products back to their repairers and for some of the manufacturers that can be even outside the UK for example for XXX, you return parts to the States and for XXX that has to go back to Sweden.' (Specialist AAC Centre)

The technicians interviewed described taking phone calls asking for advice on repairs and where possible they made repairs or advised about the return the equipment to the manufacturer for repair.

'an issue for them was reliability and the if the software went wrong they didn't necessarily have the skills or their PA didn't have the skill to fix it and then it's who locally would have that skill so do you find people ringing you and coming to you all the time?... which is good because that's our role isn't it.' (Specialist AAC Centre)

While some services were able to provide the support for repair of equipment other people did not have access to such technical support for repairs.

'we know how it works roughly, but we don't know how to sort it out when anything went wrong with it.' (Parent of communication aid user)

Some practitioners described using their medical physics/ medical engineering department for repairs but felt that recent changes in commissioning arrangements could end that arrangement.

'Medical physics that's it they always used to troubleshoot for us. I think sometimes now that might be getting to be a little more difficult it kind of works on when you've known people for a long time you can take something in and sort it out but obviously now we're all going into these foundation trusts I'm not so sure of the kind of contracts that might have to be there in the future.' (Specialist SLT AAC)

'we've got an agreement with medical engineering department to service that equipment and to help maintain it

While another service had a system for repair through their environmental control team.

'All the devices have a silver sticker on them with the ID number and a helpline which is twenty four hours. However, it doesn't mean that somebody's going to come out in the middle of the night for a broken AAC device but the helpline was originally set up for environmental control. (Specialist AAC Centre)

In some services, the person or their families were asked to put the communication aid on the household insurance so if there was accidental damage to the communication aid the repair was then funded through claiming on the household insurance. In other services, the school insurance covered accidental breakages on school premises.

'As part of our agreement actually ---- they need to put them on to their household insurance and that's one of the things that they sign so in a way that covers well theoretically...' (Specialist SLT AAC)

'I've had to send them back before now because kids have gone like this (indicates dropping aid) and it gets (indicates broken) well it comes out of the insurance because all schools have quite good insurance.' (Specialist SLT AAC)

The use of warranties as the only method of repairing equipment was discussed a number of times by AAC services.

'We don't do repair because we're not providing our own devices. Q. Your own devices? If they break we would send them back to the manufacturers. ... (all come with warranties).' (Specialist AAC Centre)

'We would recommend, if there's a reasonable extended warranty, a part of our recommendation is offered, that the extended warranty should be taken out.' (Specialist AAC Centre)

Another practitioner reported that they did not find it cost effective to buy warranties so they either repaired the communication aid themselves or paid to send them for repair.

'We don't get warranties for the equipment. We don't get extended warranties and we took the view that they were very expensive and over a period of a number of years, actually worked out how much we.... We just repair the, you know, we take them both to be cost out at the budget and just repair them. And over a number of years, actually, the cost of repairs was cheaper than the cost of warranties.' (Specialist AAC Centre)

Practitioners reported that the cost of the repair can have an impact on whether a communication aid is considered cost effective to repair. Where the cost of repair is high then the option of replacing the communication aid would need to be considered.

'If it's under £2500 and it's an accident- you know if it's an accident like we had a [VOCA] who had a very close friendship with a bottle of Pepsi Cola on a school trip and obviously the [VOCA] is under £2500 and the repairs were then schools pay for it because XX County Council as part of their insurance is to cover pieces of equipment like that- but if it's over £2500 that's slightly more tricky but for accidents I would have thought as long as the repair was under £2500 it should be okay. We actually haven't had any problems otherwise, if it's a minor repair and it's for something that's not an accident like part of its gone

then at the moment we're funding it. That's the XX support team funding it but we've just had something go wrong that's going to cost £600 and I can't justify it because it's nearly four years old.' (Specialist Education AAC)

### Replacement of equipment during repair

When the equipment is in need of repair, the service may provide replacement equipment to enable the person to continue to be able to communicate.

The procedures for replacing equipment when a communication aid needs to be withdrawn for repair are locally determined. Frequently the person who owned their own communication aid was described as being responsible for negotiating their own replacement if their aid had to go for a repair. If they had a warranty then the company may provide a replacement. However, often the person was without their communication aid while it was repaired and would then use either another aid they owned or other method of communication. Some warranties provided replacements during the repair period but this was not always the case.

'...sometimes we'll purchase like the platinum warranty whereby they'll get a swap out device whenever we provide anybody with equipment we provide them with what we call an issue document with details about the equipment and where to go for help and within that it quite clearly states that there should be a low tech back up and that the local team should be keeping up to date because we can't guarantee to provide a device....sometimes we'll provide a swap out device but again that's not always possible so the low tech needs to be in place.'

Where specialist AAC centres have loan banks some practitioners said that where resources allowed, they would try to ensure that the person was provided with means to communicate. The ability to back-up the person's personalised content/vocabulary was seen as important for such times when a new communication aid was needed because the existing one was broken and needing to go for repair.

'We back up everyone's device. We have all the backups here as well as the therapist might have them in their bases. But we keep a copy of most of everybody's vocabulary. So if someone's Dynavox and they phone up and say the Dynavox is broken.

We'll get another for the cupboard. We'll download their things. Someone will come and pick it up. And we'll get the broken one in and repair and things like that. ' (Specialist AAC Centre)

### Recycling of equipment

Equipment is returned to the service that is re-commissioned or prepared ready to be re-used. Equipment may also be recycled for use for parts. This includes the legal obligations to recycle items safely e.g. battery disposal, manufacturers' legal responsibilities, decontamination, data security and privacy.

The recycling of equipment required departments to follow set protocols to ensure the safety of the equipment. This included removing all personal information from the device. Where there were technicians it was usually their role to ensure the equipment was correctly cleaned in terms of software and hardware and passed fit for purpose to be reissued. In other localities often the specialist SLT assistant performed this role.

'Our technician gets it back he sorts it out and makes it fit for purpose....So it could be as simple thing like fitting a new battery or cleaning--.' (Specialist AAC Centre).

'...you do decontamination when the stuff comes back in...and after all our assessments' (Specialist AAC Centre)

'...over the years as aids have come back to us and we have kept them within the department as a sort of equipment store.' (Specialist SLT AAC).

There was a view expressed that the use of specialist SLT time to re-commission equipment and general maintenance tasks was not an effective use of their time nor was it effective in ensuring that equipment returned from loan or trial was ready for re-issue in a timely manner.

### Equipment refresh

Refreshment of equipment is the procedure of keeping issued equipment or stock in good working order and where appropriate to update items in order to maintain and improve functionality in the long term.

Some providers have a designated person to ensure the equipment is maintained for use and that obsolete

devices are identified. However, where staff resources are limited it is harder to keep equipment up to date and in readiness for use.

'There's a problem actually with that maintaining of equipment because you don't necessarily have time to go through cupboards and dust things off and check whether they're working and at the time that you need to take a piece for assessment- it's not working - and you just make do with something else don't you? So actually having resources of people to look after equipment is actually the only way to make a bank of aids really functional'. (Local Specialist SLT).

#### Key Point xii

arrangements for maintenance, repairs and replacement have been locally determined and there are many different approaches. There is no consistent approach to ensuring that a communication aid user is not left without a voice.

### Training for people who use aided communication

Training involves a period of time potentially over multiple sessions to help those involved learn about using their communication aid(s).

Practitioners identified training as important in the successful use of powered communication aids. The training described began when the aid/equipment was first provided and covered all aspects of operating and using the device. This included a number of topics ranging from the operation of the equipment, how to enter content, change the size and position of cells, integrate the equipment with other devices e.g. telephone or speakers, maintenance of the equipment. Training usually was held in the environment the person and with those supporting their communication aid.

Provision of training was mainly described as being completed by practitioners who had skills in training someone on that device and who provided training to local support workers and family who could carry on training the person in the use of the device. When the practitioner considered specific knowledge of a particular device was needed, they often described asking the company representatives to deliver the training.

Some participants described providing group practice to allow people to update their skills and to learn from each other about features and use of their communication device.

'..we're offering them an initial training session ... at the start where we will sit with them and we will tell them how to change the vocabulary and how to make the cells bigger and smaller and whatever else they need to be able to do and then we will let them get on with supporting it.' (Specialist AAC Centre SLT)

'it may be the case that we go for a piece of kit and we get one of the companies to come in and do the training because nobody knows the kit better than the companies, you know. And some companies also have excellent training like sensory software and that.' (Specialist AAC Centre).

There was variation in the amount of training people received and in their ability to access the training they wanted because of their location.

'The training is very little. The training that is provided by the manufacturers of the machine is minimum. Because we are too far away.' (Parent of Communication Aid User)

'She hasn't had any training apart from me and from her TA.' (Parent of Communication Aid User)

'I have dedicated AAC time within my schedule where I learn how to use the higher vocabulary and functions on my device.' (Communication Aid User)

### Training for conversational partners:

Training involves a period of time potentially over multiple sessions to help those involved learn about using AAC and/or how best to help the person using it maximise the effectiveness of their communication.

Communication partners described the training they received both before a device arrived and subsequent to getting the communication aid for their partner or child. There was a feeling from some participants that the training that they received was not always provided in a timely manner or in the quantity that the communication partners would have wanted.

'I feel that there should have been sort of a day's training that we went away on before it was given to her so that we know fully how to use it, how to add words, how to install things, etc. And it was sort of handed over very quickly and we were briefly shown and sort of told of well you'll work it out as you go along but it's quite a complex hard thing to

learn.' (Parent of communication aid user)

'No support given. I have previous experience using the Grid 2 in a previous school and have had to teach myself how to use the gridplayer app and read up myself how to develop communication using AAC.' (Parent of child communication aid user)

#### Key Point xiii

whilst many AAC users and partners commented that they received sufficient support and training in using a communication aid this was not the experience of all with some expressing significant dissatisfaction.

### Training for professionals working with AAC:

Training for professionals includes raising awareness and updating knowledge and theories of AAC. This may include some or all of information on: AAC strategies, research and practice; AAC systems, methods and techniques and how to access and implement them; AAC equipment and potential customisation and access options; and how to use and prepare the equipment for use. Training may also include information on any other aspects of providing a service around AAC and people who use AAC.

The descriptions of staff training included the need for specialists in AAC to stay keep up-to-date regarding technology as well as developing their own skills and expanding their knowledge of what technology can do to help someone communicate

The need to train staff who work within the local teams was also strongly referenced as being key to the successful delivery of AAC and powered aided communication. The role of this training was described as being: to raise awareness of AAC and aided communication; to learn how best to use the specialist services for AAC; to learn about details of specific AAC and powered communication aids; to learn how to use the technology; and to learn how to train people, family and carers.

'..we have delivered models of training in a plan to bring local skills up to thing...Certainly for some teams we've found that having access to the courses we've provided has a massive positive benefit hasn't it and it's made our job a lot easier because they've taken a huge amount away from it.' (Specialist AAC Centre)

Some participants referred to companies who supply the equipment providing training. The aim being to give people the knowledge about the equipment so they feel confident in supporting its use.

'The company have provided a number of training days to staff and there has been some improvement and less reluctance to get directly involved in programming and maintenance of the device.'  
(Specialist AAC Centre)

Some participants working in more local services described training people in institutions (schools, day centres etc) to implement a 'total communication' approach in order to create supportive AAC environments.

#### Key Point xiv

training is regarded as key to supporting the use and identification of AAC and powered aided communication. Training takes place at all stages from training of specialist practitioners to training to implement supportive communication environments.

### Reviews:

Review occurs in a separate period after an initial intervention that determined communication support needs. It is a process where a communication strategy employed since the previous intervention is considered and evaluated. The review will consider if this strategy is still appropriate and meets the needs of the person who uses AAC. A review may involve further assessments of the person's communication strategies, abilities and access methods and address any changes that have occurred in the person's situation and whether there is a need for further training and support around use of communication aids to develop knowledge and skills.

The need for on-going support was described and one practitioner gave the example of a person who needed regular support from her own team and then specialist support to review changing needs and introduce new devices when required.

'I've got one lady on my caseload who I've been seeing for about 20 years, who's locked in. And she just frequently needs updating because she's very bright and she needs her equipment updating. And she's very aware of what's out there and what we can do to support her.'  
(Specialist AAC Centre)

There was wide variation in the way reviews were carried out across the country.

'I'd speak with the speech therapists that we are in contact with ... and I realised that we know more about these areas that they do - and they are the ones that are making the assessments and that's where my frustration comes.'  
(Parent Communication Aid User)

### Ongoing support:

The provision of any type of support for the person, the families and those who work with them who use AAC after the provision of the equipment or strategy. This could include further customisation, information or advice on effectiveness of use or suggestions of alterations to meet minor changes in the needs. It can include strategies that ensure the on-going support of people close to and working with the person on a daily basis. Where there are more distinct changes in the needs of the person, a review may be required.

The support team surrounding the person can be formed of a number of people with responsibility for supporting their needs. In focus groups and interviews the specialists whose role was completing the assessment and making recommendations for communication aids repeatedly mentioned the importance of having good support around the person and their family when introducing a communication system as well as over the long term.

'Historically, we identified that a piece of equipment is actually only the starting point. Not really any good unless somebody will put the time in to update the vocabulary, work with the child to use it.'  
(Specialist AAC Centre)

'...it's the level of support that we think makes a difference.'  
(Specialist SLT AAC)

'...what we're trying to achieve is a very high-quality support network in that client's immediate environment, whether that's school or work, whatever, but with one lead.'  
(Specialist AAC Centre)

One of the practitioners described the on-going support that was provided to learners within their special school. This included support from staff and from specialists such as specialists in ICT, the SLT technician for communication aids and themselves as an assistive technologist. The

type of support required varied between technical issues and personalisation and support for communicating using the communication aid. Another specialist SLT reported how they worked closely with the specialist teachers to ensure on-site support for powered aided communication.

'Work 1-1 in a session in support of AAC and communication aids.... Work with students at the high end of ability while the SLT Technician will work with low & high tech communication and so there is an overlap so need to work together – working as part of a team for meeting needs.' (Specialist AT AAC)

'...vocabulary is evolving weekly, one of them especially, and the class staff are absolutely fantastic with him, they're a really good team and every week it's 'Can you just..?'..... every week we went in and worked with the TAs....using it not in a quiet room or one to one ... so we're making sure we're doing stuff - with all the communication stuff with the books and everything- everything's done within the environment the children are in as much as possible.' (AAC SIG Group SLT)

'..they (TAs) are invaluable because they're in there working with them on a daily basis in the school following the daily programmes and seeing what they do on a daily basis and sitting in the lessons, you know working in the playground, helping them to develop social skills with their communication aids so they are very much hands on.' (Education Specialist AAC)

Practitioners reported that they tried to tailor the type of support provided according to the level of need according to the person's cognitive, sensory and physical abilities.

'...we've got some people with motor neurone disease who are computer literate, there's no problem with their language or their literacy and they're absolutely flying and they don't really need very many people around them other than to set it up perhaps and then you've got the other end of the scale within adults they may be severely aphasic, dyspraxic people in a nursing home and need a lot of support.' (Specialist AAC Centre)

However, the ability of some practitioners to provide the necessary level of support was variable, frequently linked to time pressures. One SLT who worked in a hospital described how it was hard for them to give the time to supporting a person for their communication aid.

'..somebody like myself in my service I do just one day outpatients a week and the rest of the time it's Acute and we're having breach issues on referrals again over four weeks when they're supposed to be seen in two and we've lost control of our diaries. All the patients are now just booked in automatically for us so they're all just new referrals and they're all maybe Dysphagia so even once I've got that patient's equipment the problem for me is then to go out and follow that up and do all that really important follow up is where I really feel it's falling down.' (AAC SIG Group SLT)

A young communication aid user spoke of the support they had received and valued in getting dedicated help to learn how to operate and use their communication aid to develop their communication skills.

'I get a lot of support, help and maintenance from the AAC team at X College. I have dedicated AAC time within my schedule where I learn how to use the higher vocabulary and functions on my device. (Communication aid user)

Parents participating in the study spoke of the value they put on having support for themselves for communicating with a family member who used a communication aid. They mentioned the expertise of the support team, the knowledge needed to operate and run the device and the benefit of having a good support network.

'I did not fully appreciate the level of expertise and ongoing support that would be required in supporting my daughter's use of the device.' (parent of communication aid user)

'...the peripheral support, - the learning how to programme the device, getting the time to programme the device, having the network for the families and professionals around, that has been such an invaluable infrastructure that my family has needed really.' (parent of communication aid user)

Some parents expressed their concern at the lack of knowledge concerning powered communication aids among some practitioners. They had found it hard to access the type of support they felt they needed or

support was only provided for a short time relevant to specific questions.

'...we don't get support from professionals with enough knowledge in this. And I think that we are, you know, and then, I know we are alone in what we're doing. And the only links that we have is with professional staff we have respected over the years and we have clung on to them and they are the ones that are helping us to improve our service and our support.' (parent of communication aid user)

Practitioners spoke about the quality and availability of the technical support from companies and that the companies' knowledge of their own equipment was greater than theirs and they were well placed to provide support with their on-line and telephone advice lines.

'...there are the companies that supplied the equipment as well. I mean they have people who sit at computers and telephones to provide on-line support. And they can do it much, much more efficiently than I can or anyone here can.....It's what the machine does, why it hasn't turned on when this on-off button's being pressed, why has the screen gone blank, all that type of thing. I think that should go to the vendors of the equipment and they're more than happy to answer those questions.' (Specialist AAC Centre)

#### Key Point xv

whilst many services have developed innovative methods to provide ongoing support to AAC users other services were unable to provide this.

#### Key Point xvi

continuing support for developing communication skills through the use of AAC was recognised as being essential.

### Research and development:

Research and development into any aspect of AAC use, need or provision. This may or may not lead to the development of new technology, recommendations for best practice, collection and synthesis of evidence or changes in any procedures involved in any aspect of AAC.

Only a few of the practitioners interviewed mentioned that they undertook research. The examples that were given came from specialist AAC centres. Those AAC centres with clinical scientists described research into the development of technology as part of their remit.

'...so basically --one of the contributions of the clinical scientist will be to be able to see what can be done with the technology that might be a bit different to the way that it's being used and how might we adapt something in a particular way or a different way that will give us a functionality that we didn't think about so it's that creativity.' (AAC Centre)

One AAC Centre described undertaking research in collaboration with a company into the use of iPads. The Health Trust had bought the iPads and software from the company and the company were providing a full training and technical support package to people and their support team.

'...they tend to take care of, this is an iPad, don't be afraid of it. This is what it can do, etc, etc. And this is how you upload, download, and update. And then what we provide is: okay, great piece of kit. This is what we've used it for with children. This is what we think you can achieve.' (Specialist AAC Centre)

One practitioner working in education described an 'ad-hoc' study to look at the benefit of using communication aids with a specific client group. This included looking at the different ways to provide support for their use.

'...we've currently got a kind of research project running on a pretty ad hoc basis, I have to say, because that's all we can manage but I think it's got great potential whereby, rather than work on an individual child basis, we work on an individual unit basis. And we're trying to well-educate the staff running these units and open their eyes to the technology that could potentially be out there that would help the children.' (Specialist AAC education)

Another practitioner reported that they had research as part of their remit. However, they did not have the time or resources to complete research activities.

'One of the bits that again doesn't happen. And that's a very small aspect of our work.' (Specialist AAC Centre)

People using communication aids and their communication partners described seeking research information and evidence relating to current technology and things which might facilitate their communication. However, research was not always easily accessible to

them. One parent described how she struggled to find relevant research, in knowing where to look for the topics of interest to her.

'I don't think that the research is disseminated properly, you know. I got my hands in specific research only and I don't know where to go for more.'  
(parent of communication aid user)

### Information and advice

This may be as part of general awareness raising process for people who might use AAC and their families/ carers / professionals which could contribute to the identification of need. This may also be in order to provide information once a need has been identified.

Information could be provided on types of device or strategies that could benefit a person, advice / guidance that benefits communication partners or training, learning and support relevant to using a form of AAC or services available to assist with any stage of the process of care for AAC.

In the study the researchers had descriptions from four groups who sought information and advice on powered aided communication. These were the professional staff, staff who supported the person using powered aided communication, people who might use or did use powered aided communication and the communication partners.

### Professional staff

The professional staff comprised of practitioners who described a number of ways they employed to keep up to date with technology and developments. The different AAC centres' practitioners described differing approaches to providing information and advice to those using their services. Some had duty call lines, some ran courses, some encouraged practitioners to come into the AAC Centre to look at the aided communication available and to discuss options, some would find out information and provide specific advice, one AAC centre had introduced a network where information could be posted for link SLTs and other practitioners, this included a forum where queries could be posted.

'XXX AAC Centre have set up an NHS network so everybody feeds into there ... there's a forum so you can post questions on there and it all goes through on to this website which you have to be a member of but it's fantastic because you're constantly getting updates and are able to ping questions at them.'  
(Link SLT)

'XXX AAC Centre... they'll go off and find it out for you so they're very supportive to their therapists.'  
(Link SLT)

'They'll come and have a look at different equipment and software. If they're not sure about perhaps software or hardware then I try to sort of narrow down their choice of what to try for that client and maybe to access a loan through us or still come and have a look and have a chat with us on this and make a decision from there.'  
(AAC Centre)

'There are some therapists who phone in and we need to have a discussion then about what else is available for their benefit.'  
(AAC Centre)

'I find it very helpful talking to someone on the phone or emailing them so it's very helpful if you're stuck and it's not doing something you want it to do.'  
(Link SLT)

### Local team members

Practitioners described providing information and advice to the local support team that gave support to communication and the use of powered aided communication for a person and their family/carers. Two AAC Centres described their telephone support to give advice whenever the support team needed to get information and advice.

'...we're on the end of the phone. You know, they can ring and have a chat. If they're not sure about anything then ring.'  
(AAC Centre)

'...you do act as an information centre where people ring you up.'  
(AAC Centre)

### Person with communication needs

People with communications needs described different routes to gaining information and advice, for example, some described contacting practitioners and some approached AAC Centres. Practitioners described a range of queries that they received from people with communication support needs, these included people

thinking about getting one in the future or wanting to know what might be available for them.

'...someone with a progressive condition who may not need to have anything but wants to know what the options are for the future and we would do that as a consultation and just meet them and talk them through the various options that they might be able to use in the future...they're seeing what's available while they've still got speech so they can ask you all the questions and see what's available.' (Specialist AAC Centre)

Some people described difficulties in finding where to go for information and advice or where they had approached their local practitioners being disappointed in the level of their knowledge or abilities to help them gain the information they wanted. One person described their difficulty in finding any service to approach for advice in their area. The Communication Matters forum was used by some to gain answers to queries. Some people approached companies directly to gain information and advice around the suitability of different powered aided communication for them.

'...spoke to lots of people who we found had phoned up the speech therapy to ask for help and been told there wasn't a service for adults but some children had help with communication aids but that there were no adults in the area who needed communication aids. So yes going round in circles, so there wasn't a service.' (Adult aided communication user)

'...Surely there must be better equipment now available, based on mobile phone technology and setups, but I have yet to track any such down. ANY ADVICE ON THIS WOULD BE THE MOST USEFUL!' (Aided Communication Aid User)

'No advice was available. Even the speech therapist did not have up to date information and was asking him about his experiences.' (Communication partner)

### Communication partners

Communication partners described their wish to get appropriate advice on what might be available for their communication partner to facilitate communication. This included information about what an aided communication device could do and how it would work for their partner/child. One AAC Centre described parents approaching them for advice and consultation on what might suit their child.

'Parents might choose for a consultation. ... That's almost the first route actually is consultation. So our first sort of tier.' (AAC Centre)

'You just need...to get some idea. You don't have to be, you know, completely right...you've just got to know that that's what it's going to do.' (Parent)

Practitioners also described parents approaching them for advice on suitable software for the iPad or iTouch that had been purchased and how to help their child use the tablets as aided communication VOCAs. They were also asked about amplification for the iPad/iTouch as the built in speakers did not usually provide sufficient amplification in certain environments.

'I've come across quite a lot of families who've bought an iPad or an iTouch because they've heard that you can use them as communication aids and then they're coming to me and saying what do I need to get for this..' (Specialist SLT AAC)

'..We've purchased this app on this iPad and we don't know what to do with it.' (Specialist SLT AAC)

One practitioner felt that families needed to be given more information sooner to help them understand the benefits and barriers to using different powered aided communication devices.

'..the families have got their own value systems and the things that they think are important which they're trying to sort out in the midst of all these mixed information. And sometimes we're not giving them information at all; we're just telling them what we think they should do' (Specialist SLT AAC)

## Section 3: Service commissioning and funding

### Funding of services

Few examples of co-ordinated commissioning were in evidence within the data, essentially only one notable exception was evident, of a regional specialist service. Many participants referred to what are essentially ad-hoc, or idiosyncratic processes for commissioning services and for funding equipment (discussed later). Throughout discussions about commissioning and funding there was often a feeling of 'battling or fighting' to keep things that were in place.

"And there's things like budgeting that they're not sure of where the budget streams are coming from at the moment because they've been longstanding funding. The funding is still there but nobody actually knows where it's coming from but you know you're sort of conflicted as to whether to try and establish something more concrete or leave it as it is because the funding is still there."

Where service level agreements were referred to that covered AAC and/or specialised AAC these were often described more in terms of the exceptions (i.e. the people that were excluded) than by the inclusive coverage of the agreement.

Those commissioners that were able to contribute to the research reported here gave a complex picture of their challenging commissioning role (which were in flux due to the restructuring process in place at the time). One local commissioner recognised the aim of commissioning more specialist support into her area, but had not been able to do so yet. The commissioners were responsible for vast remits of service delivery and AAC was a small part of this responsibility.

"I suspect and I fear if you go around the country there's an awful lot of things that although we have commissioning responsibilities for - we absolutely do not have the capacity to do it properly. "

"The reality is there's not full responsibility on our commissioning for communication aids at this point in time because the providers are usually doing it regionally and therefore there's a lot of no-one putting their hands up saying 'well I'm the person responsible'."

The challenge of arguing the case for provision of AAC and use of communication aids in order to justify services was recognised by both commissioner and practitioner commissioners.

"we're part of an Acute Trust --- but our voice is a lone voice in the wilderness when you're working and competing against acute priorities for provision budgets etc. etc.....that is the reality."

In the same vein, for those areas that did have some resource there was a feeling of not raising their head above the parapet to protect the status quo and present agreements.

"Will we do our patients a disservice? Because, you know, funding is very tight and there's a certain amount of it and you need to go about your business below the radar sometimes..... If we flag ourselves up to be doing more than other areas in this climate there's a concern that commissioners and funders might think 'we don't need to be providing this' or 'we don't need to be doing this in this way'."

Where the argument had been successfully made and services had been actively commissioned, a range of rationales were mentioned. One budget was created following identification of the need through significant spending on an 'exceptional treatments' panel; one commissioner based this on (measurable) improvements in outcomes. The commissioners engaging with research (and the responsibility for commissioning these services) appeared to have a special interest in this area.

One specialist service highlighted the challenge between the need to monitor and measure service delivery or outcomes, and the ethos and focus of the service "the tension between what we're commissioned to do and what we think we're here for".

"It's an ongoing area of development. We, like everybody else, in the world struggle with outcome measures for AAC because it's so complex and there are so many compounding factors it is definitely one of the ways in which we are driving things forward and that is we should be able to demonstrate the quality in terms of outcome and relate it to the provision. We are in transition towards that."

Disparity in levels of service provision was discussed, but this most often occurred in discussion of equipment (i.e. communication aid) provision. There was much evidence of ad-hoc processes for funding equipment: in particular

funding requests to 'exceptional panels' and this was discussed with negativity by all, despite the fact that participants often reported success in achieving funding through this route. Eye gaze systems, because of their additional cost, were often described as being put through this route, even where communication aid budgets did exist. These low incidence, very high value systems were potentially highlighting the issues of funding.

### Funding for equipment

There appears to be no national consistency to funding of equipment for assessment, loan or provision.

"There's no hard and fast rule and it also depends on how good you are at writing applications"

Delays and lack of funding was also discussed as being caused by conflicts in funding streams, particularly between health and education and in other ways:

"It has taken me over 2 1/2 years to secure funding. Health and education have been battling it between each other but neither would say yes or no. (If they had said no I could have tried the charitable route). Eventually health agreed then battled it around departments for several months. Now I have the same issue arising concerning obtaining a mount for her wheelchair, as at the time of funding her wheelchair was too small to mount on. OT and SLT are both pointing at each other saying it's not our remit it's yours!"

A constant theme in the discussions, particularly with local services, was the limitations of the current funding. This partly manifested itself in there being much evidence of individual purchase and charity funding. This was generally referred to with negativity, disappointment and in the context of causing distress.

"she is now very dependent on a very expensive piece of equipment which will need replacing regularly, putting great financial burden on the family as we cannot secure funding despite the need."

"So we've got some young people who are interested in eye gaze and it would be a much more efficient way for them to communicate. But they're actually using a single switch talker at the moment and that seems to meet their needs. So if they wanted to go down the path of eye gaze, they would have self-funded it."

The amount of effort required to obtain funding for equipment was a very strong theme, with many participants working in local services describing the painful and effortful process required to apply for funding, often from multiple sources. This time and effort was seen as a waste and a drain on their real role and, for parents an emotional drain.

"In clinical time for a clinician to take time out of a busy caseload to go and argue the toss as to whether communication is a basic fundamental human right especially when it comes to end of life issues that really infuriates me the amount of time that it takes to go to panel and invariably be turned down."

This drain on professional participants time and resources, combined with the obvious disparity in provision, was felt particularly pertinently and linked with a sense of injustice:

"a couple of weeks ago I was asked to do a presentation to our executive board and I took along a communication aid user, very, very dyspraxic gentleman and we hadn't really had a lot of time to prepare anyway and we got in there and he started talking and he was just making a lot of noises and you could just see the entire trust board going .....(leans backwards) ...because they were just pretending they understood him"

and then he did this huge warm up thing with his finger and pressed his I Pad and it gave the whole talk and you could see the whole board kind of go... phew .... we'd had this sort of thing that as we were leaving I'd say to him right thank you very much David I'll have my I Pad back now because you've got the wrong postcode haven't you with him going no, no you can't have it it's my communication aid and me going give it back come on give it back you've got the wrong postcode and obviously worked because everybody laughed."

But it really got the message out there that this is a very intelligent, articulate gentleman who stood up in front of the trust board and gave a sort of ten minute talk on aphasia you know living with disability, living with stroke etc.

It was such a powerful talk.

And then I took the I Pad back off him because he had the wrong postcode."

#### Key Point xvii

funding arrangements for services and equipment was the issue of concern most commonly raised by AAC users, communication partners and professionals.

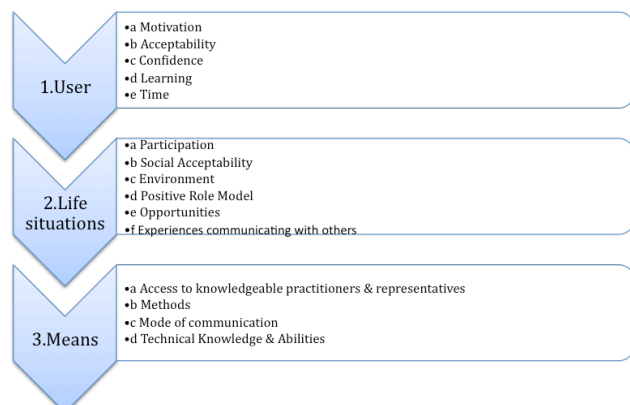
#### Key Point xviii

many participants, both professionals and users, described spending significant effort in arguing for funding of communication aids for individuals. Professionals described this as being highly disruptive to their ability to deliver a good service.

## Section 4: People's Experiences of AAC Provision

The researchers sought to involve people who might have need of communication aids but who were not using them as well as others were. This group included people with communication support needs, the people in their environment who communicated with them on a daily basis (family members, personal assistants, carers) and education staff who were teaching learners who used powered communication aids.

The topic guide for the interviews and the survey questions covered the following areas:



The analysis of the data gathered in this stage is presented below, organised by these themes.

### User

Provision of AAC resources aimed to provide people with a means of communication they could use in their life. The analysis focused on the factors that impacted on provision and use of powered aided communication alongside other AAC strategies.

Participants described various factors that made a difference to their ability to communicate effectively. These included the motivation to use a powered communication device; the acceptability of a particular device to them; the confidence to use the device to communicate with others; learning how to communicate effectively with the device; and having the time both to produce a message to communicate and other people giving them the time to do so.

#### 1a. Motivation

Participants felt that part of using a powered aided communication device rested with the motivation to use one. If a person felt it was too much effort, too tiring physically or just did not want to use one, then it would not be used successfully to facilitate communication.

'it was causing him sleepless nights... it was causing him a great deal of distress and he hated it and he got to hiding it and he'd forget it - and I said well you know you've got to acknowledge he is telling us 'I do not want that'...and he'd been given a lot of positive support and people coming in each week to help him navigate things, learn things, it was embraced in the classroom...it was embraced by his peer group but that individual personally just hated it with a vengeance and didn't want it.'

One participant described how he had lost his motivation to use his communication aid because the he felt his communication needs were not being met by AAC services, that he was being given what was available rather than what actually matched his communication needs.

'..they give me what they have, not what I need. And I think that they don't know the limitations. It's different. People should know when this is something that's beyond their capabilities. And I learned to say, "No". I take what they offer me because there's nothing else there.'

### 1b. Acceptability

The acceptability of the powered aided communication device to both the person and the communication partners was described. The issue of the actual 'voice' available on devices was mentioned. It was felt that the voice selected needed to be right voice to match the person, be suitable for the age group, gender and region of the country the person resided in so they had the same 'voice' as their peers. They expressed the wish for the right 'voice' for them and, while some people were satisfied with the synthesised voices available, others did not feel there was sufficient regional voices available.

'...the sound of the voice and as children get older they want to be credible, they don't want to stand out and be different.'

Some people did not like the sound of the digital voices and preferred to have a pre-recorded voice that was theirs or a matched individual because it sounded more natural to them.

'I showed her one that you had to programme yourself with digitised speech so it was her voice in there so she was fine.'

### 1c. Confidence

Participants described the need to develop confidence in using the high tech communication aid in different locations, settings and with unfamiliar listeners. If a person did not feel confident in their use of the device there was less chance that they would use it.

'if they've not got the confidence to use the equipment it's very difficult for everybody concerned so it's about giving them that confidence to speak in one way if they can't do that orally and also to develop their language skills.'

### 1d. Learning

Participants described the need to learn how to use who used powered aided communication as a communication tool, to communicate with others and to use it to help a person develop their own communication skills and where needed to develop their language skills.

'It's about looking at the whole dynamics of what the communication process is and it is a dynamic process that involves other people.'

'My daughter's VOCA has proved to be an essential tool in her learning. She is non-verbal so it was almost impossible to know what she could read before she had it & she couldn't write. Now her reading has moved forward & she is writing full sentences! It has also given her some level of independence for the first time ever.'

'We are currently trying to expand her use into simple sentence making. She can navigate easily around, but her physical movements often mean that she accidentally presses the wrong symbols. She doesn't get frustrated at this- just goes back and tries again.'

### 1e. Time

Time was mentioned by participants. Factors mentioned included the time taken by the person to compose and deliver a message, the time to be a competent listener for a person using a communication aid, as well as the time taken to maintain and keep the device up to date.

'...if people who would take time to listen to them, to wait for them to build their messages, it's really... important because when we all want something to say ...it's so different from being able to spurt it out of your mouth. Your brain is working so fast to get some thought out to the muscles through your mouth; it's so automatic, and yet for an AAC user .... how difficult it is if you're having to switch and scan to get access to your words.'

'...getting the time as a parent to use the aid is very difficult whilst looking after a child with disabilities.'

## Life situations

Communication is used in all aspects of life so a person with limitations in communication can experience disadvantages. The use of AAC strategies and powered communication aids can contribute by allowing people to take control of their lives and to mitigate some of the disadvantages they might experience and enable people to lead as full a life as their potential allows.

### 2a. Participation

Participants described the value of being able to fulfil normal roles whether that was being autonomous over their own affairs, socialising with friends, going to the shops or just doing something for themselves.

'it's just been brilliant but my only regret is that we didn't have it sooner. I think of the years of frustration where she really wanted to say, 'yes', 'no', 'let's go', or something, and couldn't, and you know now it's just brilliant. She can say 'no, no, no, or yes, yes, yes', or things, and it's just fantastic really that she can make up her own mind, and it's clear for everybody to hear.'

'...she fought her legal battles through her communication aid, she wrote letters, she wrote emails she was very much in control of her environment, of what happened to her, of her carer, her care packages everything in her life... she was in complete control and if she hadn't have had her communication aid she would not have been able to do that.'

Interacting with others and having a social life was important to many of the participants. This included feeling safe when going out. One participant described their communication partner getting a phone on their communication aid which then allowed them to go out on their own.

'It gives him peace of mind so he can if he's out and something bad happens he can call for help – it extends the range for him.'

However, the participant and their communication partners described the frustrations they had experienced with their bank not accepting the communication aid 'voice' as their 'voice' when using telephone banking or billing.

'...is very capable of making a conversation and holding a conversation with the bank if you say to them I am sorry he has a communication aid and he

uses this as his own voice they won't take that as confirmation for him... If he makes a telephone call – like phone the bank and makes enquires they will not use the communication aid as actually his own personal voice...When someone does that to him it makes him feel he has a disability. He can do everything normally go out round the shops but not telecommunications.'

### 2b. Social Acceptability

Participants spoke about using the communication aid in different social settings and getting different reactions to its use. Familiarity with technology appeared to influence its acceptability to others in social settings.

'.. he has even ordered curry in a restaurant using his iPad. It goes down very well with friends that we don't see very often as it puts them at ease having something they can relate to in front of them.'

Some participants explained that they sometimes had to explain what a communication aid was to others because they did not know what it was.

'We get a mixed reaction (in public). I mean some of them are just staring at you, you know, in the general public, but they're not sort of part of your social thing that you're going to. They stare there and then some people would say, "Oh, What's that computer?" "Well, this is her voice."'

Another participant felt that using an powered communication aid changed other people's attitudes to her daughter, that people appeared to associate the use of a high tech device with ability and because of that shift in attitude change their views.

'if they're using it well enough, people then think, "Oh! Well, they're not so stupid after all" you know and "They're clever," you know. "Isn't it clever?" Well, no, she's clever by making it work. But it's going to, and yes, it might bring them up in the estimation of these people that are viewing this going on.'

One participant felt that mainstream technology such as iPads and iPods were sometimes seen by young people as being socially acceptable to their peers.

'There is an element of it being socially acceptable and desirable...the younger population in particular who want to be like their peers and don't want to stand out in a crowd and pulling out an iPod or an iPad is much more socially acceptable.'

## 2c. Environment

Participants described the effect on communication of powered aided communication in different environments. One example was using the device within a building versus outside as some screens cannot be viewed in bright sunlight because of the reflection can prevent someone from reading their screen. Another example was using a high tech device in a noisy environment, environments where there was a high level of background noise affected people's ability to communicate.

The use of a powered aided communication device in different settings was described as affecting its use, for example, using the device in a small versus a large room or with one person or a large group. For example, the demands on the person and the device varied with their ability to use the device in say a meeting, with a large group of people or in a classroom or assembly versus in a one to one and face to face communication

Participants mentioned the difficulties encountered in different settings to position and mount the device and the influence this placed on use of powered aided communication.

'...she cannot use the communicator when is lying down in bed. So it is difficult to work out what she says in order to meet her needs.'

'It is more difficult to use outside of the home/school environment due to time taken to mount and start up the aid.'

Respondents described their differing approaches to communicating with others and within different environmental settings. Successful communication did not just rely on having a means of communication as a number of factors that affected their ability to communicate. These included planning how they would communicate within different settings; other people being aware of their communication needs and giving them time to communicate; level of noise in the communication setting and the ability to communicate in a large group in different settings.

'I have MND and have completely lost the power of speech. I am quite a social person and like 'talking' using an iPad with 'speak it' app for all communication. I either tap out what I want to say word for word or if I need to ask a lot of questions when seeing a doctor or nurse, for example, I write what questions I want to ask in advance and save

them so that I can bring them up instantly. The only difficulty is when several people are talking in a group, I can't keep up with them and always seem to be replying to the question that was asked before.'

'I am very chatty with people that I know. If I am with people I don't know I am quiet and prefer to let someone who is with me talk instead. I listen to them.'

'If I need help from my personal care assistant in the night I usually use my e-tran frame as it is especially hard to use my hands then.'

'I have MND and cannot speak or write and use an iPad. It is better one to one as when several people are talking I can't keep up just writing on iPad.'

## 2d. Positive Role Model

Participants described the need to have some good role models among the community of powered aided communication users to demonstrate to people how devices can be used. Also to educate people about people with communication difficulties and give ideas on how to communicate effectively.

'It must be a considerable emotional and mental challenge for someone who has never had a voice to suddenly be given a device and expected to speak. Having someone there who has personal experience of the challenges would be a huge support.'

One participant reflected on how they had no contact with any other powered communication aid users and that they would value having contact and support from people who were competent users. Their example of powered communication use was derived from the internet.

'We have not seen how the others would use AAC. Utube is our source to see how different types of AAC been used.'

There was a suggestion that AAC specialists services could have some people who were good users who could act as personal demonstrators to others.

'..you could have a service user who was your champion and that would be really good.'

'...she'd given her piece of speech, I'd do my speech. Then people would want to come up and see her actually using her device, how she was getting the words out and saying what she wants. So she'd go

over there and point, you know, "I like her earrings," "Oh, you've got a watch, J," and...you know. She would engage with them and they just seem to enjoy it. And you just hope she'd sent them away with some ideas. "Don't get those boards out. Let's go make some communication boards and...." So so-and-so at the care home can actually say what they want rather than you know, sit there and grunt and groan.'

## 2e. Opportunities

Participants spoke about the need to have opportunities to use the high tech communication device, to become familiar with using it in different social settings. One parent spoke about the opportunities they used both in and out of the home to encourage their daughter to communicate. They had found that having the communication aid readily available had increased her use of the high tech device and her communication with them as a family.

'where before when she finished eating she would just want to go and watch television or go back on her computer, or go, and do something - but now her communication aid is there on the table and she is there talking.'

Other participants mentioned that some people perhaps did not get sufficient opportunities to use their communication aid if those around them were busy with other tasks.

'...another big issue in care homes is opportunity for interaction, let alone communicating particular needs and wants and ideas. I mean just the level of interaction that is available for residents.'

## 2f. Experiences communicating with others

Respondents spoke about the value to them of being able to express themselves and the ability to communicate with others. For some it was their only means of communication.

'People like to listen to me now. It's made a big difference to my life because now people can understand what I am trying to get across.'

'Without my [VOCA] I would be totally lost as I have no other way to communicate with other people'.

Communication partners also spoke about the way it benefitted them by understanding what someone was saying and knowing what their wants and needs were.

'She is more engaging, and trying to say more rather than just you know make a nasty noise at us.'

Respondents reflected that they tended to use their powered aided communication strategies when they were with less familiar individuals and used non-powered aided communication strategies with familiar listeners or in set environments.

'Voice when face to face and in noisy environments and strangers on telephone my [VOCA].'

Participants described how their ability to communicate with others can vary with health and fatigue and how their physical condition could affect their ability to use powered aided communication. For example, one survey respondent described their difficulty in speaking when there were distractions or when they were unwell.

'I often have difficulty speaking and I have problems understanding people if there's a lot else going on or I'm very ill. I prefer information in writing so I can refer back to it and there can be not dispute about what was said so email is by far my preferred means of communication. I will not use the phone through choice - my family know I can't process info given that way and allow for it so I can cope with them but no one else'.

Participants described a variety of ways powered aided communication had made a difference in their lives in facilitating communication for both them and their partners. Respondents commented on other people's reactions and attitudes to the use of a communication aid.

'The aid has made an incredible difference to his and our life and wellbeing, giving him a voice... he can say it and be understood...the level of being able to express feelings, request thing, comment has been increased exponentially.'

'Having an electronic communication aid has radically improved my daughter's life. She now has a voice!'

'She is very sociable and her communication aid has enabled her to have a 'voice' especially with those people who are not tuned into her dodgy Makaton signs and vocalisations.'

'We could not manage without this iPad app as my husband cannot speak at all and writing is poor due to lack of arm /hand strength.'

'My daughter's VOCA has proved to be an essential tool in her learning. She's non-verbal so it was almost impossible to know what she could read before & she couldn't write. Now her reading has moved forward & she is writing full sentences! It has also given her some level of independence for the first time ever.'

'It has changed my son's life as he has realised that he can converse with us his wants and needs.'

### Means

The analysis of the data produced a wide number of themes relating to the many factors that influence the use of aided communication. The participants highlighted the need for particular types of aided communication at different times in their lives. The fact that communication demands alter over time and that technology also changes as advances in technology provides new means of communication to more people. For some people with developmental communication difficulties the use of communication aids changes over time as they develop their speech and language skills, for others with acquired communication difficulties they are compensating for loss of abilities and with progressive conditions the increasing loss of abilities.

### 3a. Access to services and knowledgeable practitioners

Participants described their experiences of accessing knowledgeable practitioners so they could get their needs identified, to be matched with a suitable VOCA, to get training and support for its use. Whilst there were participants who had gained access to practitioners, other participants described their difficulties in obtaining the help and advice that they felt they needed. There were issues regarding moving from one location to another and with transition from education to adult services.

Some participants reported having difficulty in accessing services for AAC and SLT in particular and even when they did find a local SLT then those SLTs were not always able to provide the help requested or be knowledgeable regarding powered communication aids and their use.

'Where do I find a Speech Therapist? ... "Oh gosh, she's not of school age." I thought ...well, you can clearly see she's in a wheelchair and she uses a communication device. So coming in was horrendous.'

'They came out and assessed her for various things...."Oh, we can give you a six-week course," ... So we took her in. She said, "You know, to be honest, she's far advanced from what I can give you." And I thought, Can you give me some names of speech therapists that I can hire?' And that's what I ended up doing. You hire privately.'

'I feel sad and angry at the lack of SLT input he and the other pupils in my school receive.'

One participant described how her daughter's needs for communication support were not met early in her life and that it took the arrival of a knowledgeable SLT for her daughter to get the help she felt she needed.

'I think there hadn't been a speech and language therapist at school. There was just sort of part-time lady who was lovely and had some input her on the GoTalker and would put family photos on it and things like that but it's actually wasn't until the ... school had a full-time speech and language teacher ...and showed us what was available.'

This contrasted with the experience of another participant who had been provided with a powered communication aid at the age of 3 and at 18 was now a competent communication aid user.

'I can't remember what it was like before I got my first AAC device as I was lucky enough to get my first device at the age of three...it was a [VOCA]. It was really hard work learning where all the words were that I wanted to say but it was well worth it. Although I had full use of the [VOCA] it belonged to the school. Later I upgraded to a [VOCA2] which was bought for me. Now I have an [VOCA3], I can do so much more with the [VOCA3] than I could with my [VOCA2]. I can get on the internet and mobile telephone.'

An adult participant with a progressive condition described her difficulty in accessing an SLT with sufficient knowledge to provide her with a device that might suit her needs and to provide adequate and timely support. Despite the marked speech difficulties she was experiencing, the SLT did not perceive a need for specialist assessment for a device that could meet her

communication needs and the need for information, advice and on-going support as communication needs change over time.

'My SLT on my initial assessment said she did not know about electronic aids. "It wasn't her thing". The next visit was over three months later when I asked for a referral to AAC she said that she didn't think I needed a referral as it was only for complex cases. I have only problems with my speech at the moment... (work)... I tried to explain was very important to me, and my speech problem is getting in the way of this. The only support I got was a promise to call me if there was spare iPad in the store. I asked about microphones and she reluctantly agreed to think about it but this came from me. I felt like I was being a difficulty for her.... I would have appreciated some support for my son also who is trying to support me in speaking as he is the only member of my family around... he is finding this very difficult and needs to communicate with me and I need to be able to offer him support.'

Participants described the real difficulty they were experiencing in meeting their needs when practitioners without the knowledge to provide assessment recommendations for communication aids did not make referrals to specialist practitioners in AAC or to specialist AAC centres.

'I was told that I did not need an assessment as lots of people just manage with an iPad but the SLT was unable to give me advice.'

One parent reported her efforts to convince their local SLT that their child would benefit from using a powered aided communication device. In the end she accessed specialist AAC services herself and a suitable device was obtained and used successfully by her daughter.

'SLD school SLT opposed us getting a VOCA for my daughter as SLT said she was not able to use one. I did a couple of courses at the ACE Centre... We showed the SLT with videos that my daughter was very capable of using a variety of devices that we had on loan and bought the Palmtop privately. We obtained a private assessment and permission for funding a VTL from the LEA. The school SLT held it up for 6 months just to demonstrate her power. Now had the VLT for 3 years and the SLT is all in favour!'

One participant described the journey that he took to gain his means of communication using a powered communication aid. The school staff did not identify his need for a powered communication aid and when he obtained one and they did not have the knowledge to develop his communication through use of the aid.

'When I at home with my family I used to communicate using facial expressions, eye pointing, body language hand signals and the picture book but in school only to use the picture book... This went on for years I was 15 by then and I had not learned to read – OK that is not completely true. I did not learn to read letters or words but I learned to read people to listen to their voice and to read their face. It was around this time my mum approached the charity to ask if they would consider funding a machine so I could start communicating in an effective way. I used to take the stellar talker to the school and in school it was put in a cupboard. I am not kidding! I did not always have a communication aid I did not get a high tech aid till I was 17 I changed many schools and I changed many systems Was I frustrated !!! I was 17 years old when I arrived at XXX special school and I still used to same technique to communicate with body language and pictures. And the communication aid that I used was before Rep-programme with the different language. The new language this time was Mystic. I started with 24 pictures, with single messages, and it was such a relief. The SLT from there let me express myself and what I had been accumulating for years so I used the talker to swear! Yes I swore a lot and for a long time! I was so frustrated and angry and I was able to put that across in words. Far all the more pictures were needed in the communication aid. As I changed communication aid to allow for this. Today I use the same language – but with 144 squares with the 3 layers sequence. It is the same programme that over the years I have expanded. It took me a long time to go from expressing myself with behaviour as way to communicate to be able to say, 'Actually, I don't like this or this makes me uncomfortable' but I got there and now I can talk about these feelings. I am not proud of it and it feels good to be able to explain to people why I behaved that way but it is me and I love myself!'

One respondent complained that despite having a knowledge and understanding of a specific software programme the practitioners did not take account of this and he had no choice in the device that was provided to him.

'There was no trial and I was given no choice at all about what device was provided. The fact that I already knew Minspeak was completely ignored, even when I attended a communication aids day and was given a minspeak device to use for the day with huge success.'

The timing of getting powered aided communication was seen as important to participants with progressive neurological conditions because of the speed of change in their abilities that can occur.

'Eyegaze for MND patients is the way to go. These systems need to be in place well before needed so that the user has plenty of time to get used to it. My poor husband had to wait so long due to inadequate service from xxx that by the time he got the eyegaze it was very hard for him to get used to it. Without Eyegaze we would be in serious trouble, as even facial expression is difficult for my husband. Motor Neurone Disease and communication requirements has to be dealt with in a completely different way to many other conditions as there simply is not the time due to terminal nature of disease to hang around waiting for assessments and slow provision of equipment and delays in funding.'

#### Key Point xix

people who use AAC reported varying levels of satisfaction with different aspects of AAC provision and were conscious of the variation across the country.

### 3b. Methods-design characteristics

A broad range of communication methods were described by the respondents. For example, one person used both non-powered and powered aided communication methods of communication depending on need and speed. She had a Tablet PC which had communication card apps and communication cards to use when it was important to get her meaning across quickly to strangers.

'I also use some communication-card type apps on my tablet PC. I have communication cards to use when I have the need to tell strangers how to deal with me - if there's a problem - falls, meltdowns, faints etc because I usually need to make myself understood quickly.'

Also, people reported the need to use amplification so people could hear them. While amplification systems were adequate for quiet environments they were not always successful in meeting communication needs in noisy environments and comments were made on the design and weight of such devices as well as price.

'I am amazed at the lack of decent equipment! I currently have a [AMPLIFIER] and [AMPLIFIER2] system on loan. It is the best they have but is very expensive, heavy, and "clunky". While this works better than most in quiet environments in things like meetings, or in a pub, it is next to useless!'

An holistic approach to communication was observed in the many different strategies used to communicate. These incorporated face, eyes, signs, gestures, speech, an E-tran eyegaze frame, alphabet cards and communication cards as well as communication aids. People reported using whichever communication system was most effective for them with a particular communication partner or setting.

The range of communication aids reported by respondents to the survey included dedicated aids such as Lightwriters, Dynavox 5, Grid on PC, Dasher, Powerbox, Tellus Four with EZ Keys, a desktop computer with EZ Keys, slate PC, running JayBee communication software for speech email and text, F2F, Alea eye gaze and iPads.

The design of different powered communication aids was mentioned by a number of participants. Participants described the function of the device and its size, weight and colour. The size and weight influenced whether the device was portable for the person using it. Also, where it could be used and whether it could be positioned and mounted appropriately for them. Parents felt that the designs should consider the age of the child and in the same way that glasses are made to look stylish for children so communication aids should be personalised to the age of the child.

'..So, you got this big old bulky case that is very ugly and it's black and she's six years old. You know, I said to them, you know, for children you want pink, blue, red, orange colours, not a big black suit case that looks like a businessman going to work because they're just not attracted to it.'

The portability of the high tech device influenced its use. Those who were mobile needed to be able to carry it safely. Those who needed to use it in different locations needed it to be portable or have someone with them to take it and position it for them in the new location. The size and weight of the high tech device was a consideration for some people.

'there is always somebody with her so, but it does need to be portable, yes. It goes off to school every day, and it's quite heavy.'

The ability to access the communication aid through switching and scanning was an issue for some. One participant expressed frustration at the limitation of single switches and the slow speed of scanning which affected his ability to respond to others in a timely manner.

'I still find the scanning slow. I am a single switch user. I recently changed the scanning method and I have to press the switch 4 times for a word when previously I had to press the switch 6 times. I am interested in listening to other switch users for strategies and ideas to speed communication and reduce tiredness. My communication depends a lot on my communication aid and I have not managed to develop a low tech communication system for when the high tech is not available.'

The participant mentioned their wish for software that would help them to produce 'speech' faster. People had tried using predictive text programmes which helped speed up their expression, though this was not always a solution. One participant reported that she was still finding it hard to communicate in a conversation even using this approach.

'I would also like a recommendation of a programme I can use to type quicker as I am too slow to keep the thread of a conversation when two people are talking.'

The software on the device raised issues for some users and those who were programming the device. One example was provided by a mother who spent time putting in words that were misspelt so the device would

produce the correct spoken word. This raised issues for her daughter who was learning to read and write and who needed to enter different misspellings to produce words the listener would recognise and understand.

'..and also some of the words - say for example minute comes out mynute. So, we have to go in and change the spelling of minute, M-I-N-N-I-T to get the pronunciation right. And to me that shouldn't be right. I thought you shouldn't have to do that. If it's minute, it's minute. Because she is saying that word and spell it wrong.'

The prosodic features of speech were mentioned. That the way speakers of natural speech could use stress and emphasis to alter meanings and to make a point was difficult to emulate on powered communication aids.

'I also find intonation is very bad - surely a full stop or a question mark can be emphasised more?'

Access to a 'high-tech' device can be the only way a person has to communicate and when that device is not there it impacts greatly on the person's ability to communicate. Participants described their frustration when their device did not work as well as they wished or if it broke and was taken away for repair. It took away their 'voice'.

'The idea of becoming even more patient when my communication aid is not available makes me angry and as long as people misunderstand why I lose my temper -but when the echo 2 breaks and goes for repair I have to communicate like I used to do 20 years ago. And after 20 yrs of being able to be active with my speech and mind going back to getting someone to guess what I want to say is not OK. It is not good enough!'

This issue of volume on the devices was raised by participants. The ability to increase the volume to suit the needs of the environment affected the effectiveness of the communication. Adding speakers or having a case that incorporated speakers helped though this did not always resolve the issue of being heard.

'..they really like the communication aid but they have a problem when they're out that people can't hear it and that's why they then have to have these plug in speakers to make it louder but that's not just straightforward amplification - it's volume that is an issue.'

### 3c. Mode of communicating

The means of communicating with others through other than natural speech can include many different modes of communication from facial expression, gesture, signs to coded sign systems, picture/symbol based communication aids to aided communication that involves powered communication aids.

The participants described how the different means of communication they had were used and how at times the technology available did not always meet their needs. There was a need expressed by some participants to be able to change the method of communicating depending on the circumstances and the demands of the situation. People used a range of strategies in communication.

'Mostly communicate face to face, very limited use of telephone.'

With wife - verbal (one word hints and short sentences), writing, body language!

With other family and close friends - verbal, letters drawn in air, iPad

With less close friends - starts conversations with iPad, some verbal

With strangers - verbal with back up from wife if needed. iPad if appropriate.'

One participant observed that their partner had tried different communication aids over time and how what he was looking for in terms of technology for communication changed with his current circumstances and what he was wanting to do in his life.

'He held different devices. He held different ways of accessing them. He tried different stuff... His drive change. Difference in exposure through his communication at different stages for different things. On some stages, he just gives up with communication because he wasn't now going where he wanted to go.'

The need to communicate through different communication modes was influenced by the way technology was used in modern life and this influenced the person's chosen means of communication.

'Communicate with [VOCA]. If not handy, by writing or with gestures. With family by sign language (only by alphabet spelling).'

One participant described a range of communication activity carried out by a number of their learners. The use of the powered communication aids to produce speech output was only one aspect of communication the young learners wanted to use. They wanted to be able to use social media and to use the internet to e-mail and to blog just as their contemporaries would do. They were happy to use a designated communication device and a PC or to have a communication device which could integrate a number of functions such as, telephone, text or email.

### 3d. Environment

The demands of different environments influenced respondents' ability to communicate. Most frequently mentioned was background noise levels or needing to speak to a large group or work requirements to use the telephone or send e-mails. Respondents reported that communicating with people in groups often did not give time to respond or join the conversation or even ignored the speech or written communication provided by a device.

'I use lots of ways of communicating for three reasons: because of the way my impairment fluctuates; because of who I am communicating with (for example my deaf-blind friend can't see the screen of my communication aid but she can see my signs if she is close enough); and because of the environment I am communicating in.'

'...The only difficulty is when several people are talking in a group, I can't keep up with them and always seem to be replying to the question that was asked before.'

'I find the iPad is not loud enough in crowded places so I would like an option of a larger screen rather a "speak it" option for when I am in public. My biggest hurdle is my confidence in using this in public .... I would also like a recommendation of a programme I can use to type quicker as I am too slow to keep the thread of a conversation when two people are talking.'

'Using a [VOCA] and have done since 1997 very hard to make myself heard in a group. When meeting and talking to strangers I feel they don't listen to the machine and I get very frustrated and tend not to join in with the conversation.'

### 3e. Technical knowledge and abilities

Participants felt that the ability to use a powered communication device involved having a degree of technical knowledge and ability to keep the device up to date. Some participants felt that they had this knowledge; some felt they wanted access to specialist help when needed; and some felt that there needed to be timely training.

The timing of training was described and it was felt that having training prior to getting a high tech communication aid was beneficial as well as access to supplementary training. This training can facilitate the person and their communication partners' use of the different features within the high tech device at a point when they are 'ready' to learn.

'I feel that there should have been sort of a day's training that we went away on before it was given to her so that we know fully how to use it, how to add words, how to install things, etc. And it was sort of handed over very quickly and we were briefly shown and sort of told of well you'll work it out as you go along but it's quite a complex hard thing to learn... one thing you would like is some better manuals, better instructions.'

Some participants in describing their own experiences of gaining a VOCA and described their frustrations with the process in meeting their needs. Those respondents who described negative experiences reported a lack of knowledge of how powered aided communication can support communication needs and a lack of support from practitioners.

'My SaLT on my initial assessment said she did not know about electronic aides.' (Person using AAC)

'My poor husband had to wait so long due to inadequate service from xxx that by the time he got the eyegaze it was very hard for him to get used to it.' (Communication partner)

Frustrations extended to a lack of knowledge about powered aided communication equipment, insufficient time to assess their needs, to trial their powered aided communication device and for training to use it.

'...was so unimpressed with SaLT department, sorted all myself, much faster and better, I'm Systems Engineer.' (Person using AAC)

'SLT gave some information about companies that

sell communication aids but we as parents were left to do the assessments/trials of the devices with our daughter ourselves.' (Parent)

'My sister did all the research and made recommendation for me - this worked well. Trying devices was hard because I could only get them on loan for 2 weeks so I could not always get my language pack written for the device so it was all a bit alien to me at first.' (Person using AAC)

'I trained as a SLT before I had my daughter so it was me pushing all the way. The official SLT assessment was rubbish, out of date and long winded, I therefore took things into my own hands and contacted the AAC companies directly to organise trials and this was much more successful.' (Parent)

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#### Key Point xx

whilst many users and carers expressed satisfaction more expressed frustration with all or some part of the service. Of particular note was the lack of technical skills and knowledge of speech and language therapists.

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### Suppliers

A survey was conducted of suppliers specializing in the provision and support of all forms of AAC. The survey sought to establish the range and variety of approaches adopted by suppliers, including in respect of assessment, training and funding provision. The following paragraphs summarize the key findings of this survey. The topic sheet can be found in Appendix 8.

Those suppliers who responded to the survey questionnaire represented companies that specialize in the supply of software and equipment, those who provide software only, and equipment providers only. Responses were obtained from eight companies. An important caveat is that a number of suppliers did not respond. While conjectural, it is probably the case that concern over competitors' having access to findings and the commercial implications of this on their own business, will have discouraged them from responding.

The survey questionnaire was designed to be easily and quickly completed, with questions grouped into the following categories: Needs; Provision; Support and Training; and Funding.

**Needs.** Questions and responses under the heading of Needs can be summarized as follows:

**a. How are you usually contacted regarding products or devices?**

Responders reported that there were many routes to people contacting them: phone, e-mail, website, roadshows, exhibitions, product demonstrations, Trade shows and field-based sales calls.

The responders described an open access for people contacting them. People contacted them directly if interested in the product. This included people wanting to find out more about the product for themselves, home users, families, schools, local authorities, specialists such as SLTs and engineers, technicians.

**b. Do you have a role in identifying the needs of the person?**

Responders varied in their responses according to the type of product that they supplied.

For example, software specialists said they tended not to get involved in the identification of needs, focusing instead on fitting their product to the consumer. One responder described their approach as a personal one where they had a 'conversation' discussing the requirements of the person or organisation' including 'how they would like to use the software'.

Companies supplying VOCAs said that they worked in partnership with the involved specialist practitioner such as the SLT. Some long established companies felt their representatives had a lot of personal experience in working with AAC and working with those in the Health and Education sector who provided powered and non-powered aided communication.

Responders from the different companies did not feel they had a specific role in identifying an individuals' needs, rather supporting decision making by giving the information people needed to make an informed decision about which equipment might be suitable. Some of the companies described that they provided support as needed beyond this with assistance during trials and advice about funding. Some companies stated that they do not seek to identify the needs of the person but would 'recommend

them contacting a professional'. One company advised that they would ask if an assessment has been completed and would ask for information from the assessment.

One company representative described how their eye gaze technology could be used to identify if a person had the ability to use an eye gaze system. While another company described how in seeking to identify the needs of the person, they would provide support to assessment teams to carry out evaluations from an equipment perspective and would always recommend customers get an independent evaluation before purchase. The representatives from another company described their ability to assess postural management and so were able to undertake their own assessment to assess any needs regarding positioning and seating.

'..we understand the features in our products and how they might benefit the user..so we work with the SaLT or other professionals to find the best solution to the user's needs'.

**d. What are the usual steps in providing the most appropriate aided communication system for the individual?**

There were a range of opportunities provided by different companies to find out if their product would suit the person.

Software companies varied in their provision of software, some sold the software outright while others provided those using the software with a short trial period to test the suitability of the software for them. One company described their on-line information which included demonstration videos on their website.

Companies providing VOCAs described different activities to ensure the product was right of the person. They could demonstrate the product, if appropriate arrange a free loan, the period of loan varied with the average being a 2 week trial and some provided training for that trial to maximise the trial from the point of view of the individual. The practitioners usually knew what they wanted for a person when requesting a trial or making an order.

'..the person enquiring often knows what they are interested in especially professional enquirers'.

**Provision.** Under Provision, suppliers offered possible methods of providing communication aids to people, providing straightforward supply, setting up or demonstration as possible options.

#### How is the communication aid usually provided?

The software providers described sending software direct to purchasers along with any necessary key to install it. The responders described the installation process as being simple one software provider provided technical support during the working week to help with any queries. Some software was purchased directly from the internet e.g. Proloquo2Go or other apps.

The equipment companies described a range of activities that they would undertake. These activities varied by company and by the type of equipment/software provided. The range of activities undertaken included setting up the device for the user, eg, setting up scanning rate or screen delays. The equipment delivery and set up for the customer could include training if ordered or provided as part of the package.

**Support and Training.** Under Support and Training suppliers were asked the following questions, eliciting the responses set out below:

#### e. What is the role of the company in supporting aided communication?

Software companies described a range of training resources which included on-line training resources and technical support on their software, the responding companies provided these resources for free.

Equipment companies also provided a range of training and technical support. This was provided to people using the equipment, families, carers, practitioners. The amount of training and technical support described appeared to vary with the type of equipment and abilities of the people seeking company training and support and companies tried to provide the best customer service they could given their resources. All support provided by responders, which included a helpline, remote access, product advisor support and internet website was provided for free.

#### f. What is the role in the company in the provision of training?

Again there was a range of responses in the sort of training provided by companies on their products.

One company described the range of their training from basic on-line training for certain products with help sheets and video tutorials and technical support during the working day on weekdays. They also had 100 product centres and had trainers who were able to offer advice, guidance and training. While another company limited their training to support staff only and did not get involved in supporting the person using equipment beyond this. Others focused on providing 24/7 email support. Direct teaching was provided by another company to people on their powered aided communication systems to develop the necessary skills to use their system through use of programme designed to train the person on the system. One company reported that they provided 900 free downloadable resources together with product training from a product specialist and implementation training from a company specialist SLT/teacher.

The range of training from some companies encompassed many forms that included: workshops/presentations; tutorials on-line; 'Webinars' on-line, Resource Centers; and the provision of trainers who are professionals and have 'completed the webinars and a no-fail quiz'. Companies responding to the survey described providing free training as often as was needed by the person for the life of the device. Training could be provided at different levels to different people such as support staff, practitioners, people using equipment and to family members. One company stated that they were able to provide the training that was requested, usually a half-day training which included giving an overview, trial or case studies all depending on context.

#### g. What is the role in repair of devices?

Companies that provided software did not respond on this section as they supported their software and this was reported above.

Companies that provided equipment described a range of options when it came to repairs. New equipment was covered by a one year warranty which covered repairs and responding companies provided

the opportunity to purchase a further 3 years' warranties. Companies reported that they aimed to repair equipment as quickly as possible. For example, one company reported that they provided a full repair service, picking up and returning the device, usually in one week.

One company advised that most of the products supplied by them were sealed units or relatively inexpensive 'low-tech' aids and usually there was no repair option. If a device was reported as faulty within the warranty period it would most likely be replaced under warranty. Where a device developed a fault outside the warranty period, repair or replacement was quoted for on a case-by-case basis.

Apple products were covered by the Apple warranties as were other makes of tablet.

**Funding.** In the Funding category, questions and responses were as follows:

**h. What is the main system for funding the purchase of your products?**

Companies advised that the funding system usually varied depending on location and the age of the person, the family, the assessment team recommendation/advice and other relevant factors. The sources of funding for products came from private purchases, the NHS, Education Sector, some charities and insurance companies.

One company advised that they were able to provide a support package to help people acquire the relevant equipment.

**Are there any systems in place for facilitating the purchase of your product?**

Companies providing software reported that they did not direct purchasers to sources of funding for software.

Companies providing equipment described how they tried to provide information to people regarding local funding systems if it was relevant. For example, one company had links to various organisations on their website which could provide a purchaser with information regarding funding. One company described participating in presentations of their equipment to inform funders about the features of the equipment and how it supported communication needs.

Another company offered advice about who to contact first, though 'this is really only necessary for private purchasers though, and is rare'. While another company felt their representatives had a good understanding of how equipment was resourced and provided within their region and were able to advise people who to approach either regionally or locally for information regarding provision of powered aided communication.

Some charities supported part funding of equipment and company representatives could direct people who were self-funding towards relevant charities where local provision was not available, though where possible local routes to provision were encouraged.

One company described a range of what purchasers asked in terms of information concerning funding, usually the kit that was selected was purchased and that people purchased what was required.

**Caveat.** While the number of AAC supplier companies who responded to the survey was limited, respondents did include hardware and software specialists, as well as those who provide both. The responses are representative of these supplier companies and reflect the range of their differing approaches to providing appropriate software and equipment to meet a need, support and training, maintenance and repair, and funding.

**Survey of Charities Involved with AAC**

In order to gain an overview of the role of charities in supporting people with communication support needs and the information and support relevant to AAC, charities were contacted and provided with information on the study and a request to comment on specific types of support for AAC. Accordingly, a list of charities was obtained from Communication Matters. Charities were sent an email to seek information about the potential areas where charities may be involved with AAC which may include: provision of a helpline or other sources of information; advocacy; signposting; AAC brokerage; specialist AAC services; education and training; day services and respite services; residential services; provision of grants; campaigning; fundraising; and research.

Information on these topics was sought via questionnaires (see appendix 8) sent to the charities identified by Communication Matters, together with a review of charities' on-line presence. The questionnaire suggested the potential areas of involvement outlined above and in addition sought information on three specific issues:

- a The overall aim of the charity and specifically its role in supporting those people supported by the charity who may need or use AAC.
- b Enabling those people who may need or use AAC to contribute to the AAC evidence project by describing their own experience of AAC and whether that experience was a successful or unsuccessful.
- c Identifying unmet need.

Generally, the responding charities were set up to support a particular group of people. The breadth of the activities varied by the aims and objectives of each charity and whether it was a national or local charity. The charities approached were charities that provided specific information, advice and support for people could develop or did have communication difficulties as part of their condition and those whose communication difficulties could benefit from communication support that could include the use of powered aided communication.

Of those charities that actively worked with people with communication support needs, the activities reported included equipment loans; financial support; training on AAC; direct advice and support for both people, families and professionals; research and literature resources; visitors offering friendship and support. One charity supported members by organising 'Fun' days when people who had communication difficulties could get together and enjoy a day together and where families and carers could share in the fun and exchange information with each other.

### Summary of Aims and Objectives Related to AAC of Surveyed Charities

The following paragraphs set out a summary of the charities surveyed, summarising their stated aims and objectives, providing their responses to the survey questionnaire and other approaches made during the survey, and highlighting AAC-specific concerns and issues.

### TreeHouse

TreeHouse School is registered with the Department for Education as a non-maintained special school. The School intake is for children on the autistic spectrum and aims to provide children with specialist, intensive and integrated support to enable them to learn, thrive and achieve. There are 140 staff members and over 80 pupils, the latter ranging in age between 4 years and 18 years, all of which have a diagnosis of autism and have TreeHouse School named in their statement. Members of staff include qualified teachers, ABA (Applied Behaviour Analysis) professionals, SLTs and occupational therapists. The School provides family support through transition services, training and help in accessing support, information and advice, with pupils having access to extended day services, holiday clubs and overnight stays. The School also undertakes vocational training leading to employment experiences.

### Scope

Scope works with disabled people, of all ages, and their families, across England and Wales. The majority of disabled people supported by Scope have Cerebral Palsy, who are offered 'practical, everyday support', the Charity seeks to deliver campaigns 'that can change lives'. The Scope website provided details of AAC in the following terms (May 2012):

'Supporting communication through AAC, a package containing 12 modules that aims to help parents, teachers and professionals to support individuals who may benefit from using AAC. The modules are available to download from SCOPE webpage and each module stands alone and addresses a specific topic or a particular group of use. They produce guides for people working with people with communication difficulties and for social work services.'

Scope responded to the survey questionnaire with details of the suggested areas of involvement relevant to their charitable aims as follows:

- a **Helpline/Information**  
'Our helpline deals with a wide range of disability related queries. Those enquiring about ACC would be directed to the resources on our website (<http://www.scope.org.uk/help-and-information/> communication) or other sources of information (such as DLF, ARCOS etc). The helpline also deals with

Signposting via telephone, email, on-line and postal queries.

- b **Specialist AAC Services, Education and Training, Day Services and Respite Services, Residential Services**  
 'Scope has a number of day and residential services; adults attending these would receive general support with their communication needs from care staff but any specialist communication provision would be supplied via statutory sources. We also have a small number of specialist schools (see: <http://www.scope.org.uk/services/education-and-learning/schools>) where many of the students have communication difficulties. Provision varies in each school but staff may have specialist skills/ knowledge/ training. Some students are resident, whilst others attend on a daily basis. Our schools are sometimes able to offer respite care. For details of what AAC provision individual schools offer, please contact them direct.'
- c **Campaigning/ Research**  
 'We have previously researched and campaigned on issues to do with communication and these reports are still available on our website (follow links from web address shown above).'
- d **Fundraising'**  
 Our fundraising is not specific to AAC'.

### Capability Scotland

Capability Scotland stated on its website (May 2012) that it was 'Working across Scotland to provide services which can meet needs at every stage in life from birth to older age. The society provides four main services: Residential Care; Support for Independent Living; Education, Early Years and Childcare and Allied Health Services'. Its website does not refer specifically to AAC. The survey questionnaire did not elicit a response. However, a telephone call did elicit information about the organisation of Capability Scotland that it supports people with physical disabilities e.g. cerebral palsy. It supports age groups and maintains two special schools which employ Allied Health professionals and special needs teachers to support learners who have communication support needs and includes learners who use AAC.

### AFASIC

The AFASIC England website stated (June 2012) that it 'seeks to raise awareness, and to create better services and provision for children and young people with speech and language impairments.' The Charity works in partnership with local and national government, professional and statutory bodies and other voluntary organisations. The AFASIC England website did not refer specifically to AAC and the survey questionnaire elicited no response.

AFASIC Scotland has its main office in Dundee, and works with parents, professionals, local authorities and agencies across Scotland, promoting the rights, needs and aspirations of children, young people (up to the age of 25) and those of their parents and carers, all whom have lived experience of the daily challenges that speech and language difficulties present. The AFASIC Scotland website did not refer specifically to AAC and the survey questionnaire elicited no response.

AFASIC Northern Ireland and AFASIC Wales did not have a web presence. AFASIC Northern Ireland responded to the survey questionnaire, advising that currently they had no clients or members using AAC, and suggesting that contact is made with RCSLT N Ireland for an overall view, with CBIT and the Stroke Association of Northern Ireland, and with the AFASIC central office.

### MS Society Scotland

The MS Society Scotland website provides detailed information on AAC, as follows: 'For people with severe speech and/or language disabilities, AAC strategies can provide the opportunity for individuals to express themselves. AAC is used to communicate when expression through verbal speech is not sufficient for successful communication. There are many types of AAC: gestures, sign language, picture symbols, and devices that generate voice. It has been reported that use of a voice output communication device may help nonverbal individuals with autism overcome their unique communication barriers. The reason for the increased communication is not yet understood. It may be that hearing the 'voice' from the auditory output provides feedback that lacks the intonation variations in natural speech to facilitate development of receptive and expressive language skills. A speech output device may improve verbal speech as it allows the non-verbal child to become an active participant in the learning process. Or, because synthesized speech lacks the prosodic and

intonation variations of natural speech, the consistent auditory signal might be easier for the autistic child to recognize. Another factor may be that having the ability to combine sounds and words together in different ways helps improve phonological awareness.'

In responding to the survey questionnaire, MS Scotland advised that they act as an information centre for people with MS and communication support needs. These people have links to organisations that help with advice on communication, who would point them in the direction of individuals and organisations that could help them given their location.

Grants for AAC equipment are potentially available to eligible people with less than £16000 in savings. Those with between £8000 and £16000 are asked to contribute to the cost of the item, and those with less than £8000 in savings are not asked to make a contribution.

### **MS Trust, England and Wales**

The MS Trust England and Wales advised that they 'have more than 20 dedicated full-time staff and many more volunteers working across the UK, to help service providers improve the support they give to people with MS. Plus advice on speech problems that can be encountered – dysarthria'.

In responding to the survey questionnaire they stated that they do not focus on AAC and were therefore unable to provide any specific input.

### **Autism Research**

- 15 Autism Research do not have a website, but responded to the survey questionnaire by advising that as a 'tiny charity' with limited resources they are not always able to respond [to such requests] as quickly as they would like. They suggested an individual SLT professional as an initial point of contact.

### **National Autistic Society**

- 16 The National Autistic Society (NAS) states that 'We are the UK's largest provider of specialist autism services. Our trained staff and volunteers provide a lifeline for 100,000 people affected by autism every year.' The website describes how speech output devices give non-verbal children a 'voice', and how a team of relevant professionals determine the most appropriate technology option. NAS then explain that once this has been established the team then

decide on an appropriate vocabulary selection, the layout of the device, the size of the symbols and the principal situations to encourage the child to use the device.' The website states that a wide range of devices are available, including simpler ones for people who do not understand visual symbols. Such devices include the BIGmack™ (with further information available from Ability Net or the Ace Centre). The website states that the combined use of AAC, social supports, organisational supports and visually cued instruction can enhance the social communicative interactions in children with autism.

Details of AAC Evidence Base surveys were placed on line on the charity webpage.

### **Parkinson's Disease Society**

The Parkinson's Disease Society website states that 'We bring people with Parkinson's, their carers and families together via our network of local groups, our website and our free, confidential helpline (0808 800 0303). Because we're here, no one has to face Parkinson's alone. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's. As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services. Our work is totally dependent on donations.

In response to the request for information in support of the survey, the charity advised that 'We give information and will point people in the right direction for information on AAC.'

Details of AAC Evidence Base surveys were placed on line on the charity webpage.

### **Motor Neuron Disease Association**

The Motor Neuron Disease (MND) Association has two branches, one in Scotland and one in England. The MND Association offers a range of services to help support and advise people affected by MND. There is an AAC care pathway and the website describes the following specific activities:

- a **Equipment Loan**  
Where it is not available from local statutory services, the MND Association advises that it has a limited number of items of equipment available for loan, to provide independence and help make life more

comfortable. It states that 'these should be requested by an appropriate Health & Social Care Professional'.

**b Financial Support**

The MND Association can also supply limited financial support services for items not normally covered by statutory services.

**c MND Connect**

MND Connect provides direct advice and support for professionals, with a comprehensive range of literature available.

**d Association Visitors**

Association Visitors play a vital role in the Association's work by offering friendship and support to people affected by MND. The Association invites requests for Visitors to be provided to Regional Care Development Advisers.

**e Training**

MND can provide training courses on AAC which covers assessment, support and use of AAC.

**Connect – Communication Disability Network**

Connect, the 'Communication Disability Network', is a charity for people living with aphasia. Connect aims to improve the lives of people living with aphasia and communication disability, equipping them to re-connect with life. There is no specific reference on the Charity's website to AAC, though it does set out its specific objectives as follows:

- a Support to people with aphasia to develop and deliver services that they need and want.
- b Provision of training and consultancy to a wide range of service providers.
- c Provision of information and support to help everyone understand aphasia and its impact.
- d Championing the rights of people with aphasia and communication disability.

In response to the survey questionnaire, Connect advised that not being a specialist AAC centre, their role is therefore a much more a support and signposting one. They stated that 'many of the people with aphasia who use our services and have an extremely strong interest in finding out about new technologies, both in terms of hardware and software'. They run an informal helpline and signpost people to various websites, particularly the Tavistock Trust-funded impartial review of software for

aphasia. However, the Charity stresses that decisions about AAC should ideally be made with the support of SLTs, to help target most appropriate approaches, and to avoid unnecessary cost. They do not themselves provide advice, which they see as outwith their area of expertise and outside their remit. They have identified increased interest in iPad, iPhone, iPod and software for laptops, 'all of which of course are socially acceptable'. They confirm that funding remains 'a huge issue': they believe that all AAC used by the people they support is privately funded, or occasionally obtained with grant assistance from SLTs, which 'clearly stops many people who use our service benefiting from AAC'. In some areas, they do obtain funding from local authorities to provide a communication support service which may involve discussing communication aids.

**Stroke UK**

Stroke UK advised that the Stroke Information Service, which includes their helpline, can provide information and advice about communication aids. They produced an information resource sheet 'Electronic Communication Aids and Software'. This listed organisations that sell or provide help with accessing communication aids, and is available via the following link (June 2012): [http://www.stroke.org.uk/information/our\\_publications/factsheets/computers.html](http://www.stroke.org.uk/information/our_publications/factsheets/computers.html)

Stroke UK further advised that in some cases they may also provide grants towards communication aids through their Life After Stroke Grant Scheme. They also host an on-line discussion forum, which is used by people who have had a stroke and their families and carers ([research@stroke.org.uk](mailto:research@stroke.org.uk)). They try to access services and funding from local authorities for communication support. This may involve discussing communication aids, see following link: ([http://www.stroke.org.uk/professionals/life\\_after\\_stroke\\_services/communication\\_support/communication.html](http://www.stroke.org.uk/professionals/life_after_stroke_services/communication_support/communication.html))

**The UK Stroke Association**

The UK Stroke Association provides information and support to stroke survivors and families. An annual UK Stroke Assembly brings together stroke survivors and their families to deal with the issues that affect them. Their website acknowledges that many people have communication problems after a stroke, with about a third of stroke survivors having some difficulty with speaking or understanding what others say, and that this can be frightening and frustrating. The Charity offers a factsheet

to download and is aimed at family members and carers who support people with these difficulties. It explains the types of problems that can arise, the help and support available, and offers some tips to aid communication. In response to the survey's request for information they provided the following link: [http://www.stroke.org.uk/information/our\\_publications/factsheets/computers.html](http://www.stroke.org.uk/information/our_publications/factsheets/computers.html)

### **1Voice**

1Voice provides 'Network and Support for Children and Families Using Communication Aids' seeking to establish 'a world where the voice of every child and adult, however they communicate, is listened to and heard'. 1Voice aims to take a family and social perspective on communication and 'recognises the great need for adult role models to inspire children and families alike'. 1Voice promotes families supporting each other to overcome the isolation that being unable to speak can bring.

The Charity offered included details of the AAC survey on their website.

### **The Child Brain Injury Trust**

The Child Brain Injury Trust states that child and family support gives children and families the support that they need in order to live their lives to the full within their local community. The Child Brain Injury Trust also offers training for all parties involved in Acquired Brain Injury (ABI). They have dedicated Child and Family Support projects in Scotland, Northern Ireland, the North East of England and the Thames Valley. There is no time limit on the support offered. The Trust works with the Children's Trust, Tadworth, a national charity working with children with ABI, multiple disabilities and complex health needs.

There is no specific reference to AAC on the Trust's website and the survey's request for information elicited no response.

### **U Communicate, Leonard Cheshire Disability**

Within the Leonard Cheshire Disability charity, U Communicate acts as a conduit to other charities, providing practical support including training, the provision and funding of AAC, and a range of contributions. More broadly, Leonard Cheshire Disability supports thousands of disabled people both in the UK and in more than 50 other countries and provides assistance to people with physical impairments, learning difficulties and long-term health conditions, as well as their carers, friends and families. The Charity provides

services and aims to engender an understanding of disability and to combat discrimination. The Charity aims to remove the barriers that can stop people with disabilities from pursuing their goals and living their lives to the full, with its ABI services responding to the unmet need for specialist rehabilitation for people with brain injuries. The services are dedicated to providing the required support for people to regain their maximum potential for independence, choice and opportunity. The Charity currently supports over 500 people with an ABI in its network of specialist rehabilitation and long-stay services, and is one of the UK's leading providers in this sector. Staff are carefully recruited and trained to meet the very specific needs of this client group.

The Leonard Cheshire Disability charity specifically references AAC on its website, stating that it has so far trained 133 staff and volunteers to use AAC techniques ranging from simple symbol boards to sophisticated voice output aids and Talking Mats. It further states that 'All staff who work with people with speech communication impairments at Leonard Cheshire will be trained over the next three years'.

### **The Sequal Trust**

The Sequal Trust is a registered charity covering the whole of the UK. Its stated primary objective is to provide relief to children and adults who are severely disabled and depend on electronic communication aids and adaptations to alleviate their problems. The Sequal Trust is membership-based and open to people of all ages with speech, movement and learning difficulties. The Trust receives no public funding, and relies on donations, legacies, investment income and membership subscriptions for income. Under its 'Early Years Services' it delivers direct support to families of very young children, providing two residential special schools which are nationally renowned for their work. The Trust offers assessment, short-term placement, shared placements with a local mainstream schools and, if required, 52-week residential placements. The Sequal Trust advises that resources developed by Capability Scotland and Talking Mats that will improve services for people with communication support needs have been launched by the NHS.

In response to the AAC survey questionnaire, the Trust advised that first referrals usually come from health care professionals – typically SLTs and OTs, Special Needs Tutors, or simply the family of the individual. Their remit

is speech, movement or severe learning difficulties; local authority support has to be investigated before an application is made to them, and they can accept partial funding from local authorities. They request that people who can afford to purchase the systems themselves do not turn to the Trust for help, as do so many other organisations at present. The Trust will liaise with SLTs and other professionals to arrange trials on equipment, in order to ensure that the correct AAC is decided upon. They then fundraise in order to gain sufficient funds to purchase the particular device. Following issue of the device, the Trust also remains responsible for all necessary repairs and maintenance. If and when, over time, it is no longer viable to do so, they initiate the process to replace the device, underlining that their 'support is there for life'.

### Find a Voice

Find a Voice is a charity based in Ashford, Kent, and has been providing advice and support to people with speech and communication difficulties since 1996. Their website is intended to be a useful source of information whether 'you are someone who uses a communication aid; a parent, family member or carer of someone who has communication difficulties; a professional working in the field of augmentative and alternative communication (AAC); or someone with an interest in the field'. Find A Voice supports children and adults who have a severe speech, language or communication difficulty, and who may require some form of AAC support. This can include signing, symbols or a communication aid. Support is provided in person, by telephone and via this website.

The Find A Voice website provided details of its aims and objectives. These include 'Supporting people of all ages who have severe speech, language and communication needs by providing access to life enhancing advice, equipment and training' in order to provide 'a well-informed and sympathetic advice service via telephone, email and personal contact for anyone with severe speech and communication difficulties; their families and carers, GPs and other practitioners'. Specific services include:

- a The provision of specialist equipment on a no-cost trial basis to build basic communication skills, establish suitability of use and evidence of need.
- b Advice and awareness training to public and private organisations to enable them to understand and communicate with those without a voice.

- c Advice to legal, professional and public bodies on how best to communicate with and assist clients who have difficulty in voicing their needs.
- d Contributing to and liaising with research and development channels to keep abreast of advances in communication technology.
- e Developing relationships with organisations involved in relevant medical research, providing case histories when appropriate.
- f Establishing robust, diversified and sustainable funding.
- g Continuing to actively seek value and build positive networking, exchange of information and collaboration with partners.

### Conclusion

This rich study has exposed the exciting developments in technology which have the potential of facilitating severely disabled individuals to communicate more effectively, participate in life more fully and achieve and enjoy a more fulfilling life. However, whilst we have met many who have benefited from integrated and appropriate services we have also met many who have not.

There are many challenges to having effective services for people who have complex conditions. Amongst the most important is acknowledging the need for such specialist services with links to more generic and local services and clarifying the commissioning and funding arrangements for service delivery, funding of equipment and its maintenance along with ongoing support for those who require equipment and whose needs frequently change. Ensuring that a broad range of professionals have the opportunity of developing their skills and knowledge in order that they can identify, support and extend the use of technology is another requirement if people's needs are to be met.

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# Chapter 4: Examining the Need for and Provision of AAC in the United Kingdom

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## Executive summary

This is a summary of the research carried out by the University of Sheffield in collaboration with Barnsley Hospital for Communication Matters and funded by the National Lottery through Big Lottery Fund. Readers should refer to the main report for full details of the methods, data collection and detailed results.

### Objectives of this research:

- To investigate evidence of need for Augmentative and Alternative Communication (AAC) i.e. how many people could benefit?
- To map the provision and use of services for AAC and powered aided communication. Identify the numbers and types of services in the UK, their funding arrangements and types of service provision.

### Why this research is important:

There appears to be an increase in the number of individuals with communication problems who could have improved lives with appropriate AAC and there are many anecdotes suggesting fragmented provision. In order to improve services it is important to gather basic information to assist those commissioning and providing services to determine what is needed and how provision could be improved.

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. It can include the use of eyes, facial expression, gesture, signing, symbols, communication boards or books and technology based systems such as voice output communication aids. AAC may incorporate the integration of different systems.

Studies identified in the course of this project suggested that AAC can:

- improve the quality of communication
- improve the effectiveness of communication
- reduce challenging behaviour
- increase assertiveness

Which can lead to:

- increased educational opportunities
- increased social opportunities
- improvements in quality of life and independence.

### Research overview

The data collected during this project is summarised here and in full in the main report. The results are structured by the over-arching themes and research questions related to the need, service provision and use of AAC. The research looked at provision of AAC with a focus on the provision of powered aided communication – this area having been previously identified by government and other reports as having the most significant service delivery problems.

The overall potential need for AAC and powered aided communication has been estimated through epidemiological investigation – making estimates of the need for AAC based on figures from the literature and experts.

Existing service provision has been investigated through an analysis of the qualitative data gathered from over 150 people who use AAC, professionals and related others. This work generated a framework of AAC service components representing the range of possible activities associated with the provision of AAC and aided communication services. Each component has been defined using a Delphi methodology to reach consensus and qualitative analysis of the data have generated a comprehensive picture of the perceptions of all those involved in this field.

The picture of current UK AAC service provision is reported through analysis of data returned from a wide-ranging survey of UK services. This analysis allows identification of variances in service provision and models in the UK.

Data on the current level of use of AAC and, in particular aided communication, is provided through analysis of quantitative data returned from AAC services in the UK.

## Literature review

All aspects of the study were informed by a broad ranging literature review. This review, published in 2012 (Baxter, Enderby, Evans, & Judge, 2012a, 2012b) was undertaken to review powered aided communication provision. The aim of the review was to establish the current best evidence for researchers, people who use AAC, service commissioners and providers. The review investigated: the technologies in use; the populations described as benefitting; the outcomes reported following provision; and the barriers and facilitators to use.

Eight databases were reviewed and initially 2883 papers were identified. The abstracts of these papers were then screened for relevance and quality of the methodology; this resulted in 299 papers which were fully accessed and scrutinised. 133 papers were identified for scrutiny and a further eight for general context leading to 141 papers being relevant to this study and included in the review.

### Key Point 1

only three studies identified included more than ten individuals.

### Key Point 2

there are many references in the literature related to funding difficulties for the provision of powered communication aids.

### Key Point 3

the range of powered communication aids available and used for persons with language rather than motor speech disorders appears to be increasing.

### Key Point 4

there are few research studies examining the benefits that AAC may bring to users however those undertaken demonstrate measurable benefit.

### Key Point 5

outcomes are not consistently reported making the pooling of data difficult.

### Key Point 6

the evidence of the impact of AAC is mostly limited to low-tech devices and provides little information which would facilitate generalisation or knowledge or maintenance of use.

### Key Point 7

more evidence is required to underpin recommendations by practitioners regarding choices between devices or features of AAC devices.

### Key Point 8

case and group studies indicate that AAC interventions have been found to be useful in expanding the communication of many individuals with a broad range of underlying conditions affecting their communication potential. The complexity of the multifactorial impairments and frequently associated cognitive, sensory and environmental situations has an impact on study design and limits the wider application of the findings.

### Key Point 9

the majority of studies have indicated the importance of identifying the right AAC approach within the context of a service offering a programme of support and teaching for users and carers to maximise usage.

### Key Point 10:

there is little existing evidence around the efficacy of different service models.

## Objective 1: Investigate evidence of need

The systematic literature review established the current evidence of the level of need for AAC and confirmed the requirement to establish the level of need within the UK population.

### Key Point 11:

the few papers reporting demographic information relating to AAC provide different figures suggesting variation in access to services.

### Key Point 12:

none of the papers reporting an indication of the level of need were relevant to estimating the need within the UK population.

## Epidemiology

Having an estimate of the numbers of individuals requiring services is necessary for the development of services and the commissioning of such. These numbers will also assist in identifying unmet need and benchmarking of provision.

The context to attempting to quantify the need for AAC is complex:

- the population of individuals requiring and benefitting from AAC is heterogeneous and changing;
- medical successes have led to a larger proportion of children with severe disabilities and those with acquired injuries such as head injury surviving for longer;

- the population is becoming older with an associated increase in complex conditions and acquired neurological disease, e.g. Parkinson's disease.

In this study, the need for AAC was estimated using three methods: deducing prevalence from the literature; inspecting existing data sets for information; and consulting experts through survey and other methods.

### Aetiological Conditions

The first part of the process of estimating need was a comprehensive process of identifying the aetiological conditions that may lead to a need for AAC (summarised in table 1). These conditions were identified from the literature, initial data from services and consultation with AAC professionals.

**Table 1: Examples of aetiological conditions associated with AAC use for both adults and children as mentioned in the literature**

Child Group	Adult Group
<b>Acquired neurological e.g.:</b> Stroke Head Injury	<b>Acquired neurological e.g.:</b> Stroke Head injury
<b>Progressive neuromuscular e.g.:</b> Friedreich's Ataxia Muscular dystrophy Myasthenia gravis	<b>Progressive neurological eg:</b> Multiple Sclerosis Motor Neurone Disease Parkinson's disease Dementia  <b>Changes to laryngeal and oral pathology e.g.:</b> Head and Neck Cancer
<b>Congenital conditions e.g.:</b> Cerebral Palsy Cleft Palate & craniofacial malformations Syndromic conditions Profound and Multiple Learning Difficulties Learning Disabilities Autistic Spectrum Developmental delay	<b>Congenital conditions e.g.:</b> Cerebral Palsy Cleft Palate & craniofacial malformations Syndromic conditions Profound and Multiple Learning Difficulties Learning Disabilities Autistic Spectrum Developmental delay

### Existing data

The second step of the process was to identify any existing potential data sources. The General Practice Research Database (GPRD) and English Health Survey were identified. These sources were searched to provide information about statistics relevant to the need for AAC.

The GPRD is taken from UK primary care data, covering approximately 8.32% of the population and containing data from over 600 practices. The database provides research standard information on 11.39 million patients, of which 5.14 million are currently active (July 2011).

The Health Survey for England is a series of annual surveys commissioned by the Department for Health. The survey is addressed to approximately 16,000 adults and 4,000 children (1995) although this is variable dependent on the year.

#### Key Point 13

existing data stored in the UK regarding the need for AAC is limited. The English Health Survey data suggests that 0.4% of the population both have difficulty speaking and have a severe communication disability.

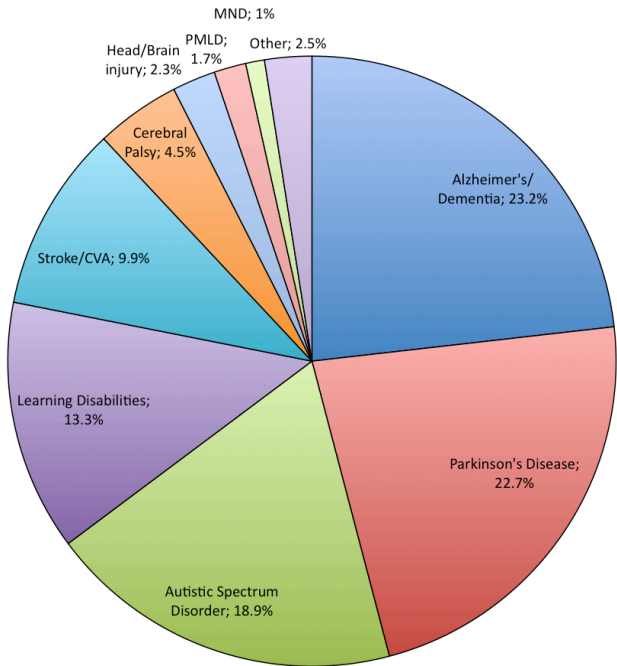
### Construction of Estimate of Need

For each of the identified conditions the literature and UK data sources were searched to provide a figure for the prevalence of each condition. The literature was then searched for figures relating to the prevalence of speech, language and communication needs. Finally professionals involved in the treatment of people with the conditions on the list were consulted to assist with providing estimates of percentages of people with speech, language and communication needs and those who could benefit from AAC and powered communication aids. These figures were then compiled into a total population estimate for those who may need AAC and additionally those who may need powered communication aids.

#### Key Point 14

we estimate that 0.5% of the UK population require AAC. This equates to 529 people per hundred thousand population. The population of potential AAC users has a broad range of complex conditions with different underlying medical diagnoses.

Figure 1: The percentage of the total number of people who could benefit from AAC in terms of the individual conditions .



**Key Point 15**  
nine conditions account for 97.5% of the total number of people who could benefit from AAC (see figure 1). Just two of these conditions Alzheimer's/Dementia and Parkinson's disease account for nearly half of the total (45.9%). These are conditions associated with an older population.

**Key Point 16**  
approximately 0.05% of the UK population are estimated to require powered communication aids.

Validation exercise

This data was subject to a validation exercise with participants knowledgeable in AAC ranking the most common aetiologies that they considered required AAC services.

**Key Point 17**  
the validation exercise showed that there was some difference between the perception of AAC use and the estimated need calculated from conditions. Of particular note is the discrepancy relating to Alzheimer's disease and Parkinson's disease.

**Key Point 18**  
there may be a large unmet need for AAC within the population of people with Dementia and Parkinsons Disease. This may as the result of amenable technologies becoming available but distribution, practice and use lagging behind. This discrepancy may be caused by other factors and warrants further investigation.

Objective 2: Mapping & Identifying AAC Service Provision

Surveys and interviews with AAC users and communication partners explored their experience of provision whilst surveys, interviews, site visits and focus groups were used to capture the views of practitioners and associated professionals.

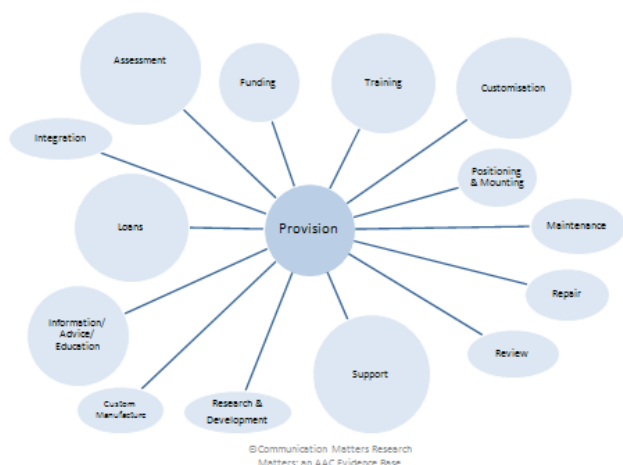
- 35 AAC users responded to surveys: the respondents were almost entirely adults with a broad range of communication strategies and experience of communication aid use.
- 27 communication partners responded to surveys: the respondents were mostly family members and all but one had English as their first language.
- 123 professionals working in the field of AAC were involved. Most professionals involved were SLTs or specialist SLTs with other professions including occupational therapists, teachers, clinical scientists, and managers.
- 92 services responded to the practitioners' survey and 4 freedom of information requests were made to obtain data on AAC service provision.

Service components

A framework of 'components' involved in AAC with a concentration on powered aided communication service delivery was developed through a qualitative analysis of the data from interviews and focus groups (Error! Reference source not found.).

Within each component participants described a range of different elements of activity. The component discussed at most length was 'Assessment' and this, for example, incorporates: formal and informal assessment of physical and cognitive abilities, access requirements, needs and wishes of individual and their carers, environmental facilitators and barriers, identification of communication partners and their needs, training and support requirements, and matching the device to the person.

Figure 2: Components required for appropriate AAC service provision.

**Key Point i**

the qualitative data identified all the components discussed as being required for effective provision and ongoing use of AAC and powered communication aids. These include identification, assessment, information and advice, loans, positioning and mounting, customisation, funding, maintenance, repair, review of needs, support, integration, research and development.

**Key Point ii**

there was consensus between professionals, AAC users and communication partners that all service components were required to facilitate an effective system of identification, provision and use of AAC.

To ensure a common language for terms relating to AAC provision, definitions were developed for each of the components. These definitions were then validated through a 'Delphi' technique using those with experience of using AAC and powered communication aids as an expert panel. The main research report contains the agreed definitions of each service component. Analysis of the qualitative data was carried out against the framework of components identified. Through this analysis a comprehensive picture of people's perceptions of the effectiveness and role of the various components of AAC service delivery was generated. These are summarised in the following key points:

**Key Point iii**

**the potential of persons with communication difficulties who could benefit from AAC needs to be recognised by people within their environment as well as health, education and social care staff.**

**Key Point iv**

assessment for AAC requires consideration of a broad range of factors including an individual's abilities (physical, sensory and cognitive); communication potential and requirements; environmental constraints; needs and aspirations of the individual and their family and resourcing.

**Key Point v**

professionals involved in assessment for AAC need a broad range of knowledge, skills and abilities. Furthermore they need to be able to access those with extended specialist skills.

**Key Point vi**

The term 'Assessment of AAC' is used to mean all or some of a wide range of activities including powered aided communication assessment, evaluation, matching, and physical access assessment.

**Key Point vii**

loaning equipment for a trial phase is considered essential to establish whether it is appropriate and acceptable. Individuals often need ongoing training and support during this trial phase.

**Key Point viii**

correct positioning and mounting of AAC devices requires careful consideration if the person is to be successful in accessing their communication device without restricting other activities. There is a need for close collaboration between those involved in AAC provision and wheelchair services.

**Key Point ix**

as technology becomes more sophisticated there is a greater requirement for more technical support to allow better integration of systems and support for integrated technology. It was reported that frequently this level of expertise was not available.

**Key Point x**

customising and personalising vocabularies on unpowered and powered AAC was seen to be key to successful use however it requires specialist knowledge and time.

**Key Point xi**

administrative tasks associated with AAC services such as logging equipment are often carried out by therapists, diverting them from their core duties.

**Key Point xii**

arrangements for maintenance, repairs and replacement have been locally determined and there are many different approaches. There is no consistent approach to ensuring that a communication aid user is not left without a voice.

**Key Point xiii**

whilst many AAC users and partners commented that they received sufficient support and training in using a communication aid this was not the experience of all with some expressing significant dissatisfaction.

**Key Point xiv**

training is regarded as key to supporting the use and identification of AAC and powered aided communication. Training takes place at all stages from training of specialist practitioners to training to implement supportive communication environments.

**Key Point xv**

whilst many services have developed innovative methods to provide ongoing support to AAC users other services were unable to provide this.

**Key Point xvi**

continuing support for developing communication skills through the use of AAC was recognised as being essential. However this provision varied greatly and concern was expressed with the lack of on-going support, particularly for adults.

## Service Models

The provision of services for aided AAC rests with different providers including: health services, local authorities, educational authorities, charitable organisations, and personal accounts. The study investigated the configuration of UK AAC services through gathering quantitative data from services. The study found a number of different models and types of provision of AAC in the way it was funded, the skill mix, facilities and equipment.

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### Key Point 19

there is little consistency in the elements or components of service provision of any of the teams delivering AAC in the UK.

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### Key Point 20

AAC services are commonly delivered in the individuals' own setting e.g. either at home or school. This may reflect practitioners' belief in the efficacy of AAC being assessed and used in context.

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### Key Point 21

charities are minimally involved in providing AAC, but contribute to providing information and funding or loans of equipment. Companies are involved in some areas of service provision, particularly around assessment, loan/replacement/maintenance and repair.

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### Key Point 22

the numbers of staff, skill mix and methods of working are unique to each AAC service. This applies to both local and specialist services.

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### Key Point xvii

funding arrangements for services and equipment was the issue of concern most commonly raised by AAC users, communication partners and professionals.

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"A couple of weeks ago I was asked to do a presentation to our executive board and I took along a communication aid user, very, very dyspraxic gentleman and we hadn't really had a lot of time to prepare anyway and we got in there and he started talking and he was just making a lot of noises and you could just see the entire trust board going .....(leans backwards) ...because they were just pretending they understood him

And then he did this huge warm up thing with his finger and pressed his I Pad and it gave the whole talk and you could see the whole board kind of go... phew ....

we'd had this sort of thing that as we were leaving I'd say to him right thank you very much David I'll have my I Pad back now because you've got the wrong postcode haven't you with him going no, no you can't have it it's my communication aid and me going give it back come on give it back you've got the wrong postcode and obviously worked because everybody laughed.

But it really got the message out there that this is a very intelligent, articulate gentleman who stood up in front of the trust board and gave a sort of ten minute talk on aphasia you know living with disability, living with stroke etc.

It was such a powerful talk.

And then I took the I Pad back off him because he had the wrong postcode."

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### Key Point xviii

many participants, both professionals and users, described spending significant effort in arguing for funding of communication aids for individuals. Professionals described this as being highly disruptive to their ability to deliver a good service.

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## Mapping of Services

Mapping of services was achieved through collecting survey data from AAC services. This data allowed comparisons of service delivery across the UK and for services to be categorised.

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### Key Point 23:

up to 70% of AAC services responding were health funded with over 66% solely health funded. Less than 5% of services responding to the survey reported joint service funding arrangements.

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### Key Point 24

42% of services who assess for AAC refer clients onwards to other services for assessment (presumably to more specialised services).

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### Key Point 25

the majority of services responding cover an area equivalent to a local authority or NHS trust/board area with less than 20% of those surveyed covering a wider area.

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### Key Point 26:

a broad range of eligibility criteria are used by different services resulting in variable access to services. Criteria are used related to any combination of: age; condition; geography; funding; equipment use; procedure; and individuals' abilities. Criteria relating to funding of equipment were equally diverse and complex.

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### Key Point 27

only 33.7% of services responding were accessible to both children and adults.

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### Key Point 28

46% of services relied on private purchase and 51% on charities to fund communication aids for some of their provision.

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The survey tool used to collect this data was developed into a proposed service audit and mapping tool as an outcome of the project. This development was completed through analysis of the data collected and further consultation with professionals and comparison to published standards. This audit tool was used during the life of this project in a project separately funded by the Department for Education to map provision of AAC delivered through local services.

### Experience of services

AAC users, their family members and carers provided information through interviews and surveys regarding their experience of services. Frustration was expressed relating to time taken to identify that they would benefit from AAC, funding difficulties in provision of communication aids and lack of support. It was particularly disappointing that there were many negative comments relating to the knowledge and skills of speech and language therapists relating to AAC technology.

‘Speech and language therapists... have allocated no budget to technology, do not use technology themselves, and are therefore fearful of it.’ (Adult communication aid user).

It was generally recognised that it is challenging for speech and language therapists to keep up-to-date with the rapidly changing technology and what it has to offer. This may add to the argument for the need for specialists, however, access to the specialists is dependent on therapists and others recognising the general potential of technology.

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#### Key Point xix:

whilst many users and carers expressed satisfaction more expressed frustration with all or some part of the service. Of particular note was the lack of technical skills and knowledge of speech and language therapists.

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#### Key Point xx:

people who use AAC reported varying levels of satisfaction with different aspects of AAC provision and were conscious that the level of service provision varied across the country.

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### Service categorisation

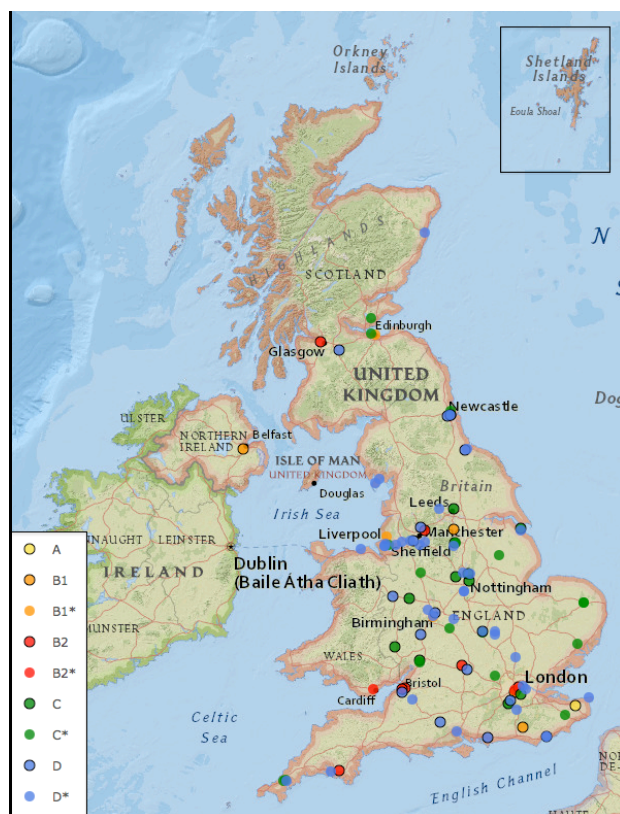
During the project, the Draft Specification for Specialised AAC Services was drawn up as part of the ‘Liberating the NHS’ reforms. This specification was used to create a definition that could be applied to the data collected in the study in order to categorise and map service provision across the UK.

The definition determined that a specialised service should deliver services across a wide geographical region, provide a wide ranging loan bank of technologies for assessment and trial and provide a set of service components including: assessment; loan for trial; provision of powered aids; maintenance; customisation of equipment (particularly hardware); and training for professionals. Additionally, the definition required an interdisciplinary team with competencies in:

- electronic assistive technology (clinical scientists, clinical technologists, rehabilitation engineers, assistive technologists or equivalent)
- speech and language therapy with specialism in AAC
- learning and educational development for those clients in education (teacher)
- seating, positioning, mounting of equipment and access and control methods (physiotherapist or occupational therapist)

An algorithm was developed in order to apply this definition to the data collected in the study. The algorithm was also expanded to allow classification of other types of services identified in the data.

**Figure 3: distribution of different categories of the services across the UK.**



A: Specialised service

B1: Tertiary Specialist with custom manufacture

B2: Tertiary Specialist without custom manufacture

C: Local Specialist

D: Local service

#### Key Point 29

only 1 service responding to the survey could be classified as a specialised service using the full definition within the specialised services definition set.

## Use of Powered Communication Aids

The survey asked services to provide information about their current caseload and to detail how many people were known to the service who used powered aided communication. The different questions aimed to extract different information about use of communication aids to deal with the variety of service models.

#### Key Point 30

in some areas up to 0.08% of the population may currently use powered aided communication. The average within the data returned was 0.014%. These figures suggest that the estimate of 0.05% made from the prevalence data is within a reasonable order of magnitude.

#### Key Point 31

people with cerebral palsy appear to make up the largest single user group of powered aided communication (32% of the users reported within the service data).

#### Key Point 32

the market size for powered communication aids in the UK may be around £10 million per annum.

## Recommendations

### For Commissioners:

For AAC services to be fully commissioned the arguments for provision must be made nationally, commissioning responsibilities must be clear and commissioners adequately resourced to carry out recommendations.

- Identify provision of services available to AAC users and potential users.
- Ensure that all the components of service delivery identified are available within the population being commissioned.
- Ensure that criteria for access are clear and equitable across all groups.
- Facilitate and require collection of consistent data reflecting service provision and patient outcomes.

**For Service Providers:**

To be able to make informed decisions about AAC and powered aided communication provision, appropriate data needs to be collected by services and made publicly available. There is a requirement for a knowledgeable and skilled workforce to exploit the potential of new technologies.

- Identify the components of service provision available for all potential AAC users within your population
- Calculate the potential population of AAC users (0.5% of your population) and estimate the level of unmet need by comparing against your caseload.
- Collect consistent data on provision of and outcomes from AAC service delivery. Ensure an infrastructure exists to allow this data to be interrogated.
- Identify what AAC service components a potential AAC and powered communication aid user is able to access within the area and make the pathways explicit to users and commissioners.
- Highlight any missing components to effective and acceptable AAC service provision to commissioners.
- Consideration should be given to the processes of ensuring an AAC user is not left without a voice when their device is removed for repair.
- Establish clear routes for reporting issues associated with unmet need and difficulties with finance to service managers and commissioners.
- Ensure service users are able to make their views on all elements of service provision and outcomes of provision known.
- Ensure continuing professional development is provided that will enable local and specialist practitioners to be kept informed of technological and service provision developments.
- Facilitate collaboration with all professionals involved in the care of AAC users across sectors.

**For Higher Education Institutions**

In order to allow appropriate identification of the need for AAC and appropriate intervention, qualifying healthcare professionals, particularly speech and language therapists, need to be equipped with knowledge related to AAC, technological developments, methods of assessment appropriate for this population, and methods of facilitating AAC usage.

**For Researchers**

To be able to demonstrate the effect of different AAC interventions researchers need to improve their measurement of outcomes and better investigate factors that are associated with successful use.

- Where possible use outcome measures reflecting the broad impact of AAC provision. Report outcomes of interventions consistently.
- Consider research reflecting long-term usage and follow-up.
- Consider using the research case study template developed by the AAC Evidence Base research project to allow consistent reporting of single case studies.
- Determine the factors and processes associated with positive outcomes of AAC use.

## Conclusion

The objectives of this research seem rather simple; they were to identify the numbers of individuals requiring or who could potentially benefit from AAC and to identify current service provision with a particular focus on powered communication aid provision. Both objectives have been challenging given that the population can be described in many different ways and data related to the epidemiology is collected indirectly, the population is heterogeneous, those using AAC frequently have complex conditions, the technologies range from unique and specialist to off-the-shelf and easily available, and no two areas provide the same range of services to the same group of clients.

In order to address these objectives a broad range of research designs were used including literature reviews, quantitative data collection through surveys, face-to-face and telephone interviews, focus groups and questionnaires. Those who have participated in the research include people who use AAC, people who have not succeeded in using AAC, communication partners and a broad range of professionals including those from health, education and the third sector.

Our conclusion that the best estimate for AAC need is 0.5% of the population is, surprisingly, the same as the estimate previously published by the Communication Champion. It is likely that we will only be able to estimate the need for AAC services rather than being assured of a set figure. The changing prevalence of disability in the community associated with survival and longevity along with the changing nature of technology and its accessibility are likely to result in the need to adjust figures of need on a regular basis. Even our estimate, which is likely to be on the low side, should give cause for concern as it appears that there are many who would benefit from AAC who are not accessing services or benefiting from the new technologies. The gap between what AAC interventions can achieve and the benefits they can bring and the use of AAC that we observed is becoming greater. We would suggest that this is due to the historical patterns of service delivery, funding arrangements and the knowledge and expectations of the professionals involved.

It is likely that those responding to our invitations to be interviewed or who have completed questionnaires and surveys are those who are familiar with AAC services or have benefited from them. It is hard to make contact with

those who may need such services but are unaware of them! Thus, it is possible that our data is biased in a positive direction. Despite this there are many direct quotations in our full report reflecting inequity, frustration and disappointment which has led to individuals having difficulty in achieving their potential. Of particular note is the marked variation in approaches to funding services and the provision of equipment. Many services reported taking considerable time to seek funding from different sources or being dependent upon the fortunes of 'end of year monies'. Service commissioning and funding arrangements are often inconsistent and dependent upon in year savings from other budgets making it difficult for services to plan strategically and to ensure maintenance and replacement are built into continuing care plans.

This research provides detailed descriptions of the service components required to deliver effective AAC provision. This is a significant contribution to the field as it is supported by agreed definitions and will allow service providers and commissioners to stipulate and monitor local and specialist provision. It also underpins another major contribution which is an explicit algorithm leading to a typology of AAC services which has facilitated the mapping of the services available in the UK. Our map demonstrates the disparity in provision. This disparity is reinforced by the wide variation in eligibility criteria applied to services with criteria being applied related to any combination of: age; condition; geography; funding; equipment use; procedure; and individuals' abilities.

Thus we have been able to define the characteristics and domains of an acceptable service which we would suggest needs to be available to all using AAC and powered communication aids and we have clarified the different levels of local provision. This explicitly details the requirements of local services and the support needed to access dedicated facilities needed by a proportion of AAC users.

The rapid increase in mobile technologies offers exciting opportunities for many people with severe disabilities. But they also introduce challenges to service providers who may not have the knowledge and skills to support and exploit their use. These new technologies will be able to assist individuals who are at present not well served but practical issues such as mounting and positioning this equipment, teaching its use and extending communication skills through the technology will need constant development by service providers. Of concern are the limited learning opportunities of undergraduate

and postgraduate healthcare professionals, particularly speech and language therapists in AAC. It is a challenge for therapists to keep up-to-date with the rapidly changing technologies, programming, mounting systems, facilitative strategies etc. in this specialist area. This can lead to frustration and disappointment for service users and their families and can be a major cause of the disparity in provision.

This data provides a 'snapshot' of service provision before what has been termed as the largest reorganisation of the National Health Service. This reorganisation is anticipated to have a major impact on provision of AAC and specialised AAC services. The research suggests that local and specialised services following this model may be able to improve the equity of access and reduce the frustration and struggle of many families who find it difficult to get the right advice, assessment, access to equipment, training and continued support. If the proposed model is successfully implemented a repeat of this research in 2023 should not highlight the same level of disparity, inequity and frustration.

Our hope is that this report will improve the identification of those who would benefit from AAC, will clarify what is required for effective AAC provision and reduce inequity and variation in practice.

Our estimate is that 0.5% of the population would benefit from AAC generally and 0.05% could benefit from powered communication aids. But we conclude that this is a low estimate considering the rapid advances in technology and changing demography. It is disappointing that in most areas less than half of those who could benefit have access and use of these technologies. The need is there. The technologies are there. But commissioning of services, funding arrangements and the underpinning knowledge and expertise of healthcare professionals have not risen to the challenge.

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# Appendix 1

## Information sheets for potential research participants

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### Communication Matters – Research Matters: An Augmentative and Alternative Communication (AAC) Evidence Base

#### Information Sheet – Focus Group

We would like to invite you to take part in a research study by agreeing to take part in a focus group for the project 'Communication Matters – Research Matters: an AAC Evidence Base'. This project is funded by the National Lottery through Big Lottery Fund and is being overseen by Communication Matters, the national charity for AAC in the UK. Communication Matters has asked researchers at the University of Sheffield to find out the need for Augmentative and Alternative Communication (AAC) and to map the provision of services for AAC in the UK.

The objective of the study is to find out about AAC use in the UK and to develop an online evidence database that will make information about AAC research and best practice available to everyone. This part of the research study will involve finding information on a number of areas: about who needs AAC, who uses AAC and if not why not, what do AAC users/and non-AAC users think about the AAC available, and to review how effective AAC provision is and identify effective practice. This information will help Communication Matters to inform the AAC community and help the organisation plan future services. The results will help provide information to those who make decisions regarding AAC at a local and national level. The involvement of people who are knowledgeable about AAC is crucial to the success of the study.

Before you decide whether you want to take part, it is important for you to understand why we are doing this research and what taking part will involve. Please read the following information carefully. You may wish to discuss the research and your participation with others before agreeing to take part. You can ask us if there is anything that is not clear or if you feel that you would like more information.

Research Project Title:

This study is part of a study called 'Communication Matters – Research Matters: an AAC Evidence Base'.

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### 1 What is the study's purpose?

The aim of the study is to find out about Augmentative and Alternative Communication (AAC) use in the UK and to develop an online evidence database that will make information about AAC research and best practice available to everyone.

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### 2 Why am I being invited to take part?

We are looking to work with people who have experience and knowledge of AAC. This may be through use or provision of AAC services that provide an assessment and have experience in use of communication aids and other AAC strategies or devices.

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### 3 What will I have to do?

Participating in this study will involve a taking part in a focus group which is likely to last up to two hours. A focus group consists of a group discussion on a particular topic, led by a facilitator, who helps to keep the discussion on the topic of interest. We will contact you one week after the receipt of this letter in order to answer any questions you have about this study. If you want to take part in the study, we will also arrange a time to hold the Focus Group. The location will be decided and a time arranged that suits you. In order to help us to analyse the Focus Group we will record the interview using an audio recorder. Participants will be anonymised in transcriptions and publications.

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### 4 Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do take part, you will have this information sheet to keep and you will be asked to sign a consent form. You are still free to withdraw from participating in the focus group at any time. If you withdraw from the focus group before the end this information will still be analysed.

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## **5 What are the possible disadvantages and risks of taking part?**

The participation in the study simply involves taking part in a focus group with the researcher so there are no anticipated risks to taking part other than the use of your time.

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## **6 What are the possible benefits of taking part?**

There are no direct benefits to you. However, your responses will help us to understand the picture of provision and use of AAC in the UK and may help influence future policy and practice.

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## **7 Will my taking part in this study be kept confidential?**

All the information that we collect during the course of the research will be treated as strictly confidential by the research team. Please be aware that this is a group discussion and therefore your views will be shared with the other members of the group. Members of the group will be asked to keep the discussion and participants' identity confidential. The information you give will be anonymised and you will not be able to be identified in any reports or publications. This information may be used in future research.

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## **8 What will happen to the results of the research study?**

Information of use to the AAC community will be used by Communication Matters to inform members and the wider public. The results will be published in journals and at conferences and in a report that will be distributed widely including to politicians and other people who are in the position to make decisions around provision of AAC. The results will be used where possible to inform further research and development projects on AAC. You can request a copy of the study results by contacting us.

---

## **9 Who is organising and funding the research?**

The study is funded by the National Lottery through Big Lottery Fund and is being led by Communication Matters, the national charity for AAC in the UK. This part of the research study is organised by the University of Sheffield.

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## **10 Who has reviewed the ethics of the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by NHS Research Ethics Committee.

---

## 11 What if there is a problem?

If there are any problems, if you have any concerns about any aspect of this study, or if you have a complaint you should in the first instance contact the researcher or the professional that referred you to the project.

### **Contact for further information:**

#### **Researchers**

Alex John and Sarah Creer  
School of Health and Related Research,  
Regent Court,  
30 Regent Street,  
Sheffield,  
S1 4DA

Email: a.k.john@sheffield.ac.uk

Email: s.creer@sheffield.ac.uk

Tel: 0114 22222978

#### **Principal Investigator**

Professor Pam Enderby

Email: p.m.enderby@sheffield.ac.uk

Tel: 0114 222 0858

**If your complaint has not been handled to your satisfaction you may contact the NHS Patient Advice and Liaison Service (PALS) representative John Armin.**

John Armin,  
Patient Advice and Liaison Service,  
Barnsley Hospital Foundation Trust  
Gawber Road,  
Barnsley,  
S75 2EP

Email: john.armin@nhs.net

Tel: 01226 432430

## Communication Matters – Research Matters: An Augmentative and Alternative Communication (AAC) Evidence Base

### Information sheet

We would like to invite you to take part in a research study by agreeing to take part in an interview for the project 'Communication Matters – Research Matters: an AAC Evidence Base'. This project is funded by the National Lottery through Big Lottery Fund and is being overseen by Communication Matters, the national charity for AAC in the UK. Communication Matters has asked researchers at the University of Sheffield to find out the need for Augmentative and Alternative Communication (AAC) and to map the provision of services for AAC in the UK.

The objective of the study is to find out about AAC use in the UK and to develop an online evidence database that will make information about AAC research and best practice available to everyone. This part of the research study will involve finding information on a number of areas: about who needs AAC, who uses AAC and if not why not, what do AAC users/and non-AAC users think about the AAC available, and to review how effective AAC provision is and identify effective practice. This information will help Communication Matters to inform the AAC community and help the organisation plan future services. The results will help provide information to those who make decisions regarding AAC at a local and national level. The involvement of people who are knowledgeable about AAC is crucial to the success of the study.

Before you decide whether you want to take part, it is important for you to understand why we are doing this research and what taking part will involve. Please read the following information carefully. You may wish to discuss the research and your participation with others before agreeing to take part. You can ask us if there is anything that is not clear or if you feel that you would like more information.

## 1 Research project title:

This study is part of a study called 'Communication Matters – Research Matters: an AAC Evidence Base'.

### What is the study's purpose?

The aim of the study is to find out about Augmentative and Alternative Communication (AAC) use in the UK and to develop an online evidence database that will make information about AAC research and best practice available to everyone.

### Why am I being invited to take part?

We are looking to work with people who have experience and knowledge of AAC. This may be through use or provision of AAC services that provide an assessment and have experience in use of communication aids and other AAC strategies or devices.

## 2 What will I have to do?

Participating in this study will involve a taking part in an interview which is likely to last up to one hour. We will contact you one week after the receipt of this letter in order to answer any questions you have about this study. If you want to take part in the study, we will also arrange a time to hold the interview. The location will be decided and a time arranged that suits you. In order to help us to analyse the interview we will record the interview using an audio recorder. Participants will be anonymised in transcriptions and publications.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do take part, you will have this information sheet to keep and you will be asked to sign a consent form. You are still free to withdraw from participating in the interview at any time. If you withdraw from the interview group before the end this information will be destroyed.

### 3 What are the possible disadvantages and risks of taking part?

The participation in the study simply involves taking part in an interview with the researcher so there are no anticipated risks to taking part other than the use of your time.

#### What are the possible benefits of taking part?

There are no direct benefits to you. However, your responses will help us to understand the picture of provision and use of AAC in the UK and may help influence future policy and practice.

Will my taking part in this study be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. The information you give will be anonymised before publication. You will not be able to be identified in any reports or publications. This information may be used in future research.

#### What will happen to the results of the research study?

Information of use to the AAC community will be used by Communication Matters to inform members and the wider public. The results will be published in journals and at conferences and in a report that will be distributed widely including to politicians and other people who are in the position to make decisions around provision of AAC. The results will be used where possible to inform further research and development projects on AAC. You can request a copy of the study results by contacting us.

#### Who is organising and funding the research?

The study is funded by the National Lottery through Big Lottery Fund and is being led by Communication Matters, the national charity for AAC in the UK. This part of the research study is organised by the University of Sheffield.

### 4 Who has reviewed the ethics of the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by both an NHS Research Ethics Committee and the University of Sheffield Research Ethics Committee.

#### What if there is a problem?

If there are any problems, if you have any concerns about any aspect of this study, or if you have a complaint you should in the first instance contact the researcher or the professional that referred you to the project.

#### Contact for further information:

##### Researchers

Alex John and Sarah Creer  
School of Health and Related Research,  
Regent Court,  
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Email: a.k.john@sheffield.ac.uk  
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##### Principal Investigator

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Email: p.m.enderby@sheffield.ac.uk  
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Barnsley Hospital Foundation Trust  
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S75 2EP

Email: john.armin@nhs.net  
Tel: 01226 432430

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## Communication Matters – Research Matters: An Augmentative and Alternative Communication (AAC) Evidence Base

### Information Sheet –People who use AAC

#### AAC Research Study Information for Participants

We would like to invite you to take part in a research study by agreeing to be interviewed by a researcher for the “AAC Evidence Base” project. Before you decide whether you want to take part it is important for you to understand why the research is being done and what it will involve.

Please read the following information carefully and discuss it with others if you wish. You can ask us if there is anything that is not clear or if you would like more information.

The objective of this study is to find out how many people in the UK use things to help with communication. We also want to find out about services that support people who have difficulty communicating.

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### 1 Research Study Title:

This study is part of a project called “Communication Matters – Research Matters: an AAC Evidence Base.

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### 2 What is the study’s purpose?

The aim of the study is to find out about how many people use things to help them communicate and who helps them in the UK. We also want to put the information that we get from the study somewhere where everyone can access it.

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### 3 Why have I been selected?

We want to work with people who have experience of using communication aids and other things that help them communicate. We also want to work with people who have tried these things but rejected them. We would also like to talk to people who have not tried any

strategies or devices but who have problems with their speech and so may find them useful. We want to work with people who are over the age of 12 are able to contribute to an interview and consent to taking part.

---

### 4 What will I have to do?

Participating in this study will involve an interview. During the interview we will ask you questions about your communication methods. We will also ask you about your experiences of services that may have been involved in this.

You can also complete a study topic sheet. The topic sheet asks you to tell us about your experiences of getting, using and maintaining use of aided communication.

The topics include:

- Accessing services according to need.
- Choosing an aided communication system
- Trialling an aided communication system
- Learning to use an aided communication system
- Support for using an aided communication system
- Maintaining an aided communication system
- Using your aided communication system

If you are at all worried or upset during the interview we will stop immediately.

In order to help us to analyse the interview we will record the interview using an audio recorder and maybe a video recorder.

---

### 5 Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive. If you withdraw from the study once the interview has started, the information you have given previously will still be analysed.

---

## **6 What are the possible disadvantages and risks of taking part?**

This stage of the project simply involves an interview with the researcher so we do not think there will be any risks to taking part other than the cost to your time.

---

## **7 What are the possible benefits of taking part?**

There are no direct benefits to you. However, your responses will help us to understand how communication aids are provided and may help things to be done better in the future.

---

## **8 Will my taking part in this study be kept confidential?**

All the information that we collect about you during the course of the research will be kept strictly confidential.

You will not be able to be identified in any reports or publications. The information we collect may be used in future research.

---

## **9 What will happen to the results of the research study?**

The results will be published in journals and at conferences and in a report that will be distributed to lots of people.

You can request a copy of the study results by contacting us.

---

## **10 Who is organising and funding the research?**

The study is funded by the National Lottery through Big Lottery Fund and is being overseen by Communication Matters, the national charity for AAC in the UK.

This part of the research study is organised by the University of Sheffield School of Health and Related Research and Barnsley Hospital (Assistive Technology Team).

---

## **11 Who has reviewed the ethics of the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and been approved by the NHS ethics committee and the Sheffield University Research Ethics Committees.

---

## **12 What if there is a problem?**

If there are any problems, if you have any concerns about any aspect of this study, or if you have a complaint, you should in the first instance contact the researcher or the professional that referred you to the project.

---

## 13 Contact for further information

### Researchers

#### Alex John and Sarah Creer

Principal investigator

Professor Pam Enderby

Phone: 0114 222 2978

Email: a.k.john@sheffield.ac.uk

or s.creer@sheffield.ac.uk

or p.m.enderby@sheffield.ac.uk

If your complaint has not been handled to your satisfaction you may contact the NHS Patient Advice and Liaison Service (PALS) representative John Armin.

John Armin

Patient Advice and Liaison Service,  
Barnsley Hospital Foundation Trust  
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Tel: 01226 432430

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## **Communication Matters – Research Matters: An Augmentative and Alternative Communication (AAC) Evidence Base**

### **Information Sheet – on-line Survey**

#### **People who use AAC and Communication Partners**

We would like to invite you to take part in a research study by agreeing to take part in the project 'Communication Matters – Research Matters: an AAC Evidence Base'. This project is funded by the National Lottery through Big Lottery Fund and is being overseen by Communication Matters, the national charity for AAC in the UK. Communication Matters has asked researchers at the University of Sheffield to find out the need for Augmentative and Alternative Communication (AAC) and to map the provision of services for AAC in the UK.

The objective of the study is to find out about AAC use in the UK and to develop an online evidence database that will make information about AAC research and best practice available to everyone. This part of the research study will involve finding information on a number of areas: about who needs AAC, who uses AAC and if not why not, what do AAC users/and non-AAC users think about the AAC available, and to review how effective AAC provision is and identify effective practice. This information will help Communication Matters to inform the AAC community and help the organisation plan future services. The results will help provide information to those who make decisions regarding AAC at a local and national level. The involvement of people who are knowledgeable about AAC is crucial to the success of the study.

Before you decide whether you want to take part, it is important for you to understand why we are doing this research and what taking part will involve. Please read the following information carefully. You may wish to discuss the research and your participation with others before agreeing to take part. You can ask us if there is anything that is not clear or if you feel that you would like more information.

Research Project Title:

This study is part of a study called 'Communication Matters – Research Matters: an AAC Evidence Base'.

---

## **1 What is the study's purpose?**

The aim of the study is to find out about Augmentative and Alternative Communication (AAC) use in the UK and to develop an online evidence database that will make information about AAC research and best practice available to everyone.

---

## **2 Why am I being invited to take part?**

We are looking to work with people who have experience and knowledge of AAC. This may be through getting needs identified, gaining access to services that provide AAC provision by providing assessments and identifying what type of AAC would support communication. You may have experience in use of electronic communication aids and other AAC strategies or devices.

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## **3 What will I have to do?**

Participating in this study will involve completing a survey. If you wish contribute further after you complete the survey you can advise the researchers and you can give them your thoughts and views about your communication experience and using AAC – electronic communication aid/s. Participants themselves are anonymised in any report or publication that stems from the study. You are free to contact us after reading the information sheet in order to answer any questions you have about this study. If you want to take part in the study, just go to the web link at the end of this information sheet to take the short survey.

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## **4 Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do take part, you will have this information sheet to keep and you will give informed consent by completing the survey. You are still free to withdraw from participating in the study at any time. If you wish your contribution withdrawn from the study before its end this information will be destroyed.

---

## 5 What are the possible disadvantages and risks of taking part?

The participation in the study simply involves taking part in a survey for the researcher so there are no anticipated risks to taking part other than the use of your time.

---

## 6 What are the possible benefits of taking part?

There are no direct benefits to you. However, your responses will help us to understand the picture of provision and use of AAC in the UK and may help influence future policy and practice.

---

## 7 Will my taking part in this study be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. The information you give will be anonymised before publication. You will not be able to be identified in any reports or publications. This information may be used in future research.

---

## 8 What will happen to the results of the research study?

Information of use to the AAC community will be used by Communication Matters to inform members and the wider public. The results will be published in journals and at conferences and in a report that will be distributed widely including to politicians and other people who are in the position to make decisions around provision of AAC. The results will be used where possible to inform further research and development projects on AAC. You can request a copy of the study results by contacting us.

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## 9 Who is organising and funding the research?

The study is funded by the National Lottery through Big Lottery Fund and is being led by Communication Matters, the national charity for AAC in the UK. This part of the research study is organised by the University of Sheffield.

---

## 10 Who has reviewed the ethics of the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by both an NHS Research Ethics Committee and the University of Sheffield Research Ethics Committee.

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## 11 What if there is a problem?

If there are any problems, if you have any concerns about any aspect of this study, or if you have a complaint you should in the first instance contact the researcher or the professional that referred you to the project.

### Contact for further information:

#### Researchers

Alex John and Sarah Creer  
School of Health and Related Research,  
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#### Principal Investigator

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Barnsley,  
S75 2EP

Email: [john.armin@nhs.net](mailto:john.armin@nhs.net)  
Tel: 01226 432430

Survey Link for a person with AAC experience who is either using an AAC electronic communication aid or is thinking of using an electronic communication aid.

<https://www.surveymonkey.com/s/AACEvidenceSurveypwuAAC>

Survey link for a communication partner to a person who is either using an AAC electronic communication aid or is thinking of using an electronic communication aid.

<https://www.surveymonkey.com/s/AACEvidenceSurveyCommunicationPartner>

# Appendix 2

## Study protocol

### Research Project Title: Communication Matters - Research Matters: an AAC Evidence Base

#### Researcher

Alexandra John: Qualitative Research:  
a.k.john@sheffield.ac.uk

#### Research objectives

- to identify Augmentative and Alternative Communication use, need and routes to obtaining aided communication in the UK.

#### Aims and objectives

##### 5.1 Main objectives

- 1 Identify AAC use, need and routes to obtaining aided communication.

##### 5.2 Principal research questions

- 1 How many people are using or need AAC?
- 2 What are the routes to provision of AAC?

#### Study design and methodology

It is a national study that will look at AAC across the whole of the UK.

The study will seek to:

- determine existing data on provision of AAC services and equipment,
- determine new data around the provision of AAC services and equipment,

#### 6.1 Design

This is a descriptive study that will use mixed methods of investigation. It will incorporate systematic quantitative analysis of existing and new data and this will be combined with qualitative investigations to provide context and depth of information to expand on data sources.

**Work stream 2:** qualitative methods to explore issues around the use, need and route to provision of AAC (led by Sheffield University) and

The range of both quantitative and qualitative methods deployed reflects the challenge and complexity of obtaining an accurate picture of the evidence of need for AAC as an intervention. The investigation aims to look at the underlying factors and conditions as well as primary data about provision of equipment and strategies. Data will be collated using a variety of media and methods as appropriate, this will include questionnaires, interviews and focus groups. A summary of methodologies to be used is shown at table 1.

**Table 1: Summary of Methodologies**

Methodology	Details
Literature Review	Review of literature
Questionnaires Surveys	Online and paper questionnaires; telephone surveys
Interviews	Face to face interviewing of people who use/ may need/have used AAC aided communication and participants
Case Study Work	Anonymised case studies and, with permission, some non-anonymous case study descriptions.
Focus Groups	Group meetings of patients and participants.

## 6.2 Participants

The aim of the study is to gather data which is fully representative of the views, knowledge and experience of a range of people involved in AAC. This will include people who use aided communication to those who work within the provision of services. The groups of participants for the whole study have been identified as follows:

- 1 Users/potential users of aided communication or people who have rejected AAC
- 2 Professionals who work within AAC services
- 3 Family members of people who use AAC
- 4 Charity and voluntary sector workers
- 5 Commissioners and policy makers
- 6 AAC suppliers, developers and manufacturers

Excluded from participation are those people who have a severe communication impairment caused by deafness or blindness and children who use AAC aided communication under the age of 12.

The Sheffield University work stream 2 seeks to engage those people involved in the use and provision of AAC and specifically in aided communication. The participants will include people who use AAC (pwuAAC). The study aims to identify the relative numbers of people who need, use or have used AAC aided communication associated with differing developmental and acquired conditions. The prospective participants may have a developmental condition, such as cerebral palsy or childhood apraxia of speech or acquired condition, such as an acquired or degenerative neurological condition (Head Injury, Stroke, Parkinson's disease, Motor Neuron Disease) or have a life-long learning difficulty, such as autism.

Initial scoping of participants who use AAC will inform the researchers on those groups who need to be targeted. It will aim to inform recruitment by identifying the number, age, sex, location and range of conditions represented in order to recruit a representative sample of participants who have knowledge of aided communication. Recruitment will aim to include participants with age ranges from between 12 and 17 years; 18-60 year olds; over 60 year olds, forming three age groups.

The other participants in the study will be drawn from parents and communicative partners of people who use

AAC and those individuals involved in, assessment, training, provision, support and funding of AAC. Table 2 shows the groups of participants and their participation across the work streams.

**Table 2: AAC evidence study participants and researchers involved Study participants Work stream**

Study participants	Work stream
<b>Group 1:- Aided Communication User group</b>	
1 NHS patients - Adults.	Shef(2)
2 People who use aided communication (not recruited through NHS)	
3 NHS patients - Children.	Shef(2)
4 Children who use aided communication (not recruited through NHS)	
5. People with Learning Difficulties.	Shef(2)
Inclusion criteria: People whose communication difficulties make them eligible for having an aided communication system. This group includes those who have a need for aided communication and may be being assessed for provision, be trialling a system, may use a system or have tried a system but rejected it.	
<b>Group 2:- Professional group</b>	
6 NHS staff: Those staff in specialist centres and the community who are responsible for aided communication assessment, training, provision, support and monitoring.	Shef (2)
7 Non-NHS staff: independent therapists and independent AAC and medico-legal professionals.	Shef(2)
Includes private therapists and AAC professionals who are responsible for aided communication assessment, training, provision, support and monitoring.	
8 Local Authority staff: includes Social Services employed professionals and carers; and education staff who are responsible for aided communication.	Shef(2)
Inclusion criteria: This group includes those professionals who are directly responsible for the assessment, training, provision, support and monitoring of aided communication.	
<b>Group 3:- Family member group</b>	
9 Main communicative partners, family members.	Shef(2)
Inclusion criteria: This group includes those people who are in daily communication with people who use AAC and need to understand how to communicate.	
<b>Group 4:- Charities and Voluntary Sector.</b>	
10 Mixed group from the Communication Matters membership.	Shef(2)
11 Members of voluntary sector organisations and users of websites specialising in communication impairments.	Shef(2)
For example, Afasic, Learning Difficulties, Royal College of Speech and Language Therapists, Motor Neurone Disease Association, and those relevant charities that offer services relevant to the assessment, provision and use of communication aids and support and training for people who use AAC.	
Inclusion criteria: This group includes those people who use AAC or potential users who are members of support organisations. Also, those in support organisations who have a perspective on aided communication.	

**Group 5: Commissioners and policy makers**

12 Commissioners, policy makers and funders of AAC services. Shef(2)

Inclusion criteria: This group includes those people who fund provision.

Group 6: AAC equipment. Shef(2)

13 AAC suppliers and manufacturers.

14 Equipment developers and suppliers.

Inclusion criteria: This group includes those people who design/make and/or supply aided communication.

**6.3 Recruitment**

For Sheffield University work stream 2, different forms of approach will be required according to the nature of the source of recruitment. Participants will be approached directly where it is possible to do so, through contact details already in the public domain, for example, charity, company or service websites. Social networking sites and blogs will also be used to contact people directly.

In addition, direct approaches will be used, using organisations or individuals to recruit potential participants to the study. AAC service providers (groups 2, 4 and 6) will be approached by the researchers to advertise and recruit potential participants from their caseload, client list, network or organisation. In these cases, introductory material and a participant information sheet will be sent to the recruiting professionals (see Proforma appendix 6 for introductory letter and Proforma appendix 2 for participant information sheet). If the individual is happy to participate in recruiting for the study, they will contact the researchers for further information. If there is no response from the individual, the researchers will follow up after a minimum period of a week.

Where recruiting participants, the third party agencies will distribute project information to potential participants as appropriate to their communicative needs (if required). They will ask for verbal consent from the potential participant to pass their contact details to the researchers. No personal details will be sent to the researchers without verbal consent from the potential participant. Details required for sampling of the participant population will include the person's name and contact details and will also include information about their age, sex, communication method and disability or condition. Once verbal consent has been given to contact the individual and sampling information gathered, introductory material (protocol appendix 7) and work stream 2 participant

information sheet (protocol appendix 2) will be sent to the potential participants. One week after the information sheet has been sent, if there is no contact from the potential participant, the researcher will contact them and answer any questions they may have, check that they understand the nature of the study, what is involved and that they are happy to participate. An initial visit is then organised for further discussion and at which time consent for participation will be discussed. At all points throughout this process the potential participant is given opportunity to decline further involvement.

A further approach is the use of advertisements for participation in the study which will be requested to be placed on relevant websites such as Communication Matters, Royal College of Speech and Language Therapists (RCSLT), Afasic, Motor Neuron Disease Association, Scope, Parkinson's Disease Society, Autism etc. Organisations will be approached to ask to circulate this information via their mailing lists to approach relevant participants across all groups. Social networking sites with relevant groups and blogs will also be approached to assist with distribution of the advertising material.

Table 3 summarises the approaches to be taken with each group of participants.

**Table 3: Approaches to recruiting participants.**

Participant Group	Direct Approach	Indirect Approach
Group 1: Aided Communication User group	Direct through recruitment via e.g. specialist membership sites, charities, blogs, social networking websites.	Indirect through professionals such as SLTs, AAC specialists, education and AAC suppliers.
Group 2: Professional group	Direct to professionals involved in AAC.	Indirect through specialist membership sites, charities, education.
Group 3: Family member group	Direct through recruitment via e.g. specialist membership sites, charities, blogs, social networking websites.	Indirect through professionals such as SLTs and AAC specialists and via specialist membership sites, charities, education.
Group 4: Charities and Voluntary Sector	Direct to the organisations. Indirect through charity or voluntary sector	Indirect through charity or voluntary sector
Group 5: Commissioners and policy makers	Direct to the organisations.	Indirect through people knowledgeable about who is responsible for provision and funding in their area.
Group 6: AAC suppliers and manufacturers/ equipment developers and suppliers	Direct to the organisations.	Indirect through people knowledgeable about AAC.

## 6.4 Informed consent

Each participant will have an explanation about the study. If it is a telephone interview then the nature of the study will be explained and permission gained to record information prior to taking down information or conducting a telephone interview.

For work stream 2, information leaflets will be used which are appropriate to the communication needs of the person. The information sheet will describe the study and can be read by or read to the person and the study explained at the right level to ensure understanding. The people participating who have severe communication difficulties will need to have information sheets that are presented in a form that aids their understanding of their participation in the study. This may require using communication systems that they are familiar with, for example, using picture based communication sheets. The research team includes Speech and Language

Therapists (SLTs) and have experience in working with and understanding the communication needs of different people. The researchers will take time to ensure understanding of the study and what the participant is agreeing to do by explaining the study in a manner suitable to the person (see protocol appendices 1, 2 and 4 for participant information sheets and protocol appendix 3 for a symbolised version). A copy of the information sheet will be retained by the participant.

Each participant will indicate their consent once it has been established that they understand the nature of the study and their role in it. Individuals using AAC or with communication difficulties may not be able to write their consent so consent may need to be audio/video recorded by the researchers or screen shots taken from computers. The consent form will then be signed by the parent or carer to confirm consent (see protocol appendix 9 for consent form for adults not requiring a countersignature and protocol appendix 10 for adults requiring a countersignature). Where the participant is a child then the parent or guardian will be present to countersign the consent form (see protocol appendix 11). The researcher will also countersign the form.

The researchers will ensure that the participants are aware that they can withdraw from the research at any time without penalty or effect on their healthcare treatment. Any data that is gathered up to that point will be destroyed except if the participant is taking part in a focus group where the data will be retained.

The researchers will record the focus groups and interviews for transcription later. In the individual interviews and focus groups involving people who use AAC, video recording will facilitate understanding of communicative intent, especially when the person using AAC uses a visual or pictorial communication system and aid accurate transcription of the content. The consent form includes a section to allow participants to consent to the recording being made.

Potential participants who are not able to give informed consent due to their mental capacity would not take part in the research. This is ensured by making inclusion and exclusion criteria clear to those organisations or individuals who are identifying potential participants for the study on behalf of the research team. Active informed consent will also be determined before data collection by actively discussing and questioning the participants understand of the consent procedure. If the participant

does not demonstrate an understanding of their consent or the study, the participant will be excluded from the study.

## 6.5 Procedure

A systematic review of the literature completed in December 2010 has informed the work for the three study work streams. Table 4 shows a summary of the individual work streams. The following sections provide more detail on the structure and procedures involved in each work stream. The Sheffield University researchers' work streams (1&2) aim to determine existing data on background conditions, on provision of AAC services and equipment, and around the provision of AAC services and equipment while the Manchester Metropolitan University work stream (3) aims to describe factors relevant in accessing an AAC database, and establish a database of AAC evidence accessible to the AAC user community.

**Table 4: Summary of the three phases of the study by work stream**

Phase	2. Sheffield Qualitative Study
Phase 1 Set up phase and scoping	Development and Piloting of materials 1 The development of information sheets to suit participants' needs to explain the purpose of the study. 2 Development of topic sheets for case study interviews and focus groups. 3 Advice on the content of the information sheets and consent forms will be sought from users of AAC. 4 Piloting of topic sheets to inform pacing of interviews, content and use. 5 Focus groups. Professionals who are members of special interest groups, Communicating Matters membership, educationalists, pwuAAC. 6 Evaluate initial focus groups and interviews.
Phase 2 Construction and going live phase	1 Information from the scoping study will enable subject identification, numbers to include from across the AAC community. 2 Recruitment. Case study interviews with users/ potential users of AAC (group 1 and 3) and Focus groups (group 2) with those working the field of AAC. 3 Interviews will aim to elicit issues concerning use of AAC, need, and the routes to provision from referral to receiving equipment and subsequent continuing support for the user. 4 Focus groups will aim to gain an insight into the steps involved in the whole care pathway involved in providing AAC services and equipment from the group's perspective.
Phase 3 Data collation and data analysis and results	1 Interview and focus group analysis. 2 Revisit topics that need clarification.

## 6.5.2 Work stream 2 – Qualitative work stream (University of Sheffield)

The qualitative Sheffield University work stream will investigate the provision of aided communication, and in particular voice output communication aids (VOCAs), in the context of the progression through the assessment and implementation of AAC.

Case study work will involve in-depth interviews with people who already have voice output communication aids and people who have speech, language and communication needs but do not currently use communication aids (but may or may not use other aided communication techniques - group 1). This will include investigating experience for the person who has a need for AAC aided communication in accessing services, assessment, choices and training given, the review process, and the support provided.

Interviews and focus group work streams involve Speech and Language Therapists (SLTs) and other health professionals and AAC team members who are responsible for assessment, selection and training on AAC (Group 2). Focus groups of parents/communicative partners of people who use AAC will be held to ask about experiences of communication and AAC use (Group 3). The interviews and focus groups will be audio and video recorded for transcription purposes. These transcriptions will be stored in a secure location within Sheffield University.

The researcher, who is an SLT, will use the method of communication appropriate to the needs of the person interviewed and their communication partners. This can involve providing the vocabulary in pictorial form to allow the individual to understand and respond. Figure 1 shows an example of a symbol sheet that can be used in an interview with person who uses AAC who have a symbolic communication system.

Figure 1: Example of symbolised interview prompt sheets (taken from WLS symbols)



6.5.2.1 Analysis

A qualitative framework thematic analysis of the data collected will be completed to identify themes. The results of this analysis will be triangulated with data from the quantitative analysis to confirm findings. This will follow the guidelines recommended by Pennington, Goldbart and Marshall (2007) and analysis recommended by Attride-Stirling (2001) and Thomas (2006).

6.5.2.2 Outcomes

The study will not use any standard outcome measures. The main outcomes for the qualitative study will be:

- 1 an increased awareness relating to prevalence of need for AAC in the UK and
- 2 an increased understanding of the current provision of AAC in the UK
- 3 an understanding of use of AAC in the UK

Table 5 shows the involvement of participants according to research method and the anticipated minimum numbers to be recruited for each method of data collection.

Table 5: Minimum participant numbers by work stream and data collection method

	Interviews/Consultations	Focus Groups
Sheffield Qualitative Study	The study will aim to recruit participants who are representative of each AAC group. The aim will be to recruit pwuAAC with contrasting characteristics and AAC needs.  I Developmental Group- Seek 6 participants from each age band: 12- 17 yrs age band; 18-60yrs age band; 61yrs plus.  II Acquired Group - Seek 6 participants from each age band: under 17 yrs; 18-60yrs age band; 61yrs plus.  Minimum of 15	I NHS Staff who are specialists in AAC assessment, provision and support from specialist centres.  II Staff including Speech and Language Therapists, who provide community support to pwuAAC.  III Non-NHS community staffs.  IV Parents of pwuAAC.

The amount of time that a participant would be involved in the study is shown in Table 6 by work stream and client group. Questionnaires, either telephone, web or paper based, may be followed up with a subsequent questionnaire for clarification or further information.

Table 6: Participant involvement by work stream and client group

Participant Group	2. Sheffield University
Group 1 Aided Communication User group	Single interview, may be split into two interviews if person is fatigued or a point needs to be checked.  Face to face time therefore approximately 2 hours.
Group 2 Professional group	Focus Group: planned for 2 hours.
Group 3:- Family member group	Interview face to face time approximately 2 hours or Focus group planned for 2 hours. Single interview or Focus Group. The interview would form a single interview or a follow up interview may occur if a point needs to be checked.
Group 4:- Charities and Voluntary Sector.	Focus Group: planned for 2 hours. Telephone interviews: up to 1 hour Face to face interview planned for 1 hour.
Group 5: AAC suppliers and Manufacturers/ Equipment developers and suppliers.	Focus Group: planned for 2 hours. Telephone interviews: up to 1 hour. Survey
Group 6: Commissioners and policy makers	Telephone interviews: up to 1 hour. Interview: up to 1 hour

6.7 AAC Evidence Outcomes Summary

This study will report on the evidence of need for AAC and map the provision of services. It will provide a resource for those who need to access information on AAC.

Investigating the evidence of need for AAC

- Part 2: Establishing existing data on provision of AAC services and equipment.
- Part 3: Establishing new data around the provision of AAC services and equipment.

Mapping the provision of services

- Part 2: Identifying other routes to provision of AAC.
- Part 3: Describing the bigger picture of AAC provision.

7 Participant confidentiality

The AAC evidence database will not include information or records that would identify participants. Recorded information would include participant age, gender, geographic location (not address), condition or disability and AAC experience. Conventional identifiers will not be used for work stream 1 information, such as name, full address, date of birth, NI or NHS number. Contact details will be taken from participants for interviews, focus groups and any visits to participants. Identifiable data will be

stored separately from data collected during the research study.

The focus groups will be either audio or video recorded for transcription purposes. These transcriptions will be stored in a secure location within the relevant institution for the work stream (Sheffield University, Barnsley Hospital or Manchester Metropolitan University). Recordings will only be accessible by the researchers to whom the principal investigator has delegated responsibility (and who accept the duties of confidentiality created). All non-anonymised original materials will be kept for 7 years to allow for any further work and then wiped of their contents. Summaries of the discussions, rather than the recordings, may be used as part of project presentations at conferences and research publications.

Focus group participants will be asked to keep the identities of other participants and their views confidential. Participants will be provided with information about how the data will be processed and explained that the data gathered will not be reported, discussed or made available in such a way that will enable them to be identified.

Anonymised data will be kept securely in order to allow further validation studies and allow access for other studies that may benefit from this data.

8 Risks to participants

There are no particular or enhanced risks to participants taking part in this research project. Although the participants who use AAC have communication difficulties and are classed as ‘vulnerable’ due to their disabilities, the researchers conducting the interviews with people with communication difficulties will be Speech and Language Therapists or those familiar with working with this group who have an understanding of communication strategies. For both focus groups and interviews, venues will be selected that are convenient for participants and which have been checked for accessibility and usability and for availability of aids and equipment.

Involvement in interviews and other consultations will vary for participants in the differing parts of the study. Participants will need to be given time to prepare for the interview so they can programme their aids with the appropriate responses. The researchers are cognisant of the needs of individuals with communication difficulties, the need for time to respond and support for

communication. If the individual is tired the interviews can be completed in parts to meet their needs. Children will be interviewed with their parent or person in loco-parentis so their needs will be considered.

Interview participants may feel obliged to participate if approached by specialists who have previously supported them, to minimise the chance of this, each of the specialists will be asked to consider this when discussing recruitment with individuals and the interviewer will check and discuss consent fully with each participant before commencing the interview. If the potential participant is considered vulnerable, the consent process will take place with a carer present. Participants will also be reminded that no record of their involvement or non-involvement will be communicated to their healthcare provider and their potential withdrawal is completely independent of any care or service that they or their family members may be receiving. The researchers are not involved in providing any clinical interventions with the participants.

The researchers will respect all participants by treating them as equals, endeavouring to be fair and use resources efficiently. They will be well informed, asked to give informed consent and assured their views will be listened to and acted upon by the researchers. Where a parent or carer is present, they will also be asked to provide informed consent. It is important that the views shared are those of the participants and not their carers so additional time will be allowed for researchers to clarify meaning, researchers will be experienced in taking account of non-verbal as well as verbal communication.

If participants have any concerns about the research procedure or study itself, contact details of the researchers and principal investigator are available on the information sheets. For escalation, the contact details of the associated patient advice and liaison service representative or University registrar are also detailed.

Safeguards will be in place to ensure findings are not misleading or lead to concern for participants and their families through consultation and feedback both during the process and following completion of the project.

Everyone involved in the research team has had a CRB check (or similar for Scotland, Wales, Northern Ireland). Communication Matters have a vulnerable persons (children and adults) policy and best practice procedure and partners have similar policies in place. The researchers will also have had Good Clinical Practice (GCP) training by the time data collection has begun.

All participants will be assured of anonymity and confidentiality of data using the procedures outlined above.

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## 9 User Involvement

The need for this research has been identified by Communication Matters members, thus it can be considered that the research has been derived through a participatory or consumer-led approach.

Throughout, it is intended that people who use AAC will be active in the overall project including consulting on findings and disseminating the outcomes. In addition, beneficiaries sit on the Independent Research Panel organised by Communication Matters.

The information sheets and consent forms have been passed by members of the Independent Research Panel which includes a person who uses AAC and a family member of a person who uses AAC. The Independent Research Panel was set up by Communication Matters to oversee the study as part of research governance.

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## 10 Review of the Project

This project has been subject to a highly competitive national funding competition (the Big Lottery Research fund), this funding process included an anonymised peer review from at least two reviewers relevant to the bid. In addition Communication Matters convened an independent review panel (IRP) covering the full range of stakeholders in AAC and including an international AAC researcher. The IRP reviewed the bidding process and will continue to review the project during its lifetime.

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## 11 Dissemination

A comprehensive dissemination plan has been set out as part of the Big Lottery Fund bid. Dissemination will be managed and resourced by Communication Matters. Dissemination routes include national and international conferences, publication within Communication Matters literature (website, journal, e-news), targeted specialist and mainstream media. In addition reports and information will be sent to key national and local decision makers. Dissemination will occur around the parts of the different work streams as shown in table 7.

**Table 7: Dissemination of AAC Evidence study findings****Dissemination**

Information about the existing evidence around speech, language and communication needs. Journal paper. Press release.

Information about the existing evidence around the use of AAC services and strategies.

Journal paper. Press release.

The need for AAC services and strategies – new evidence

Journal paper. Press release.

The big picture of provision of AAC services and strategies

Journal paper. Conference presentation (national/international)

Press release. Report.

How AAC is currently provided in the UK

Journal paper. Conference presentation (national/international).

Press release. Web based resource.

What supports access to information typically unavailable to service users?  
Accessibility for all: Journal article. Conference presentation. Report

How do you develop cohort data from a complex and heterogeneous group?  
Journal article, Conference presentation, Press release.

**References**

- 1 Attride-Stirling, J. 2001. Thematic networks: an analytic tool for qualitative research, *Qualitative Research*, 1(3): 385-405.
- 2 Pennington L., Marshall J., Goldbart J. 2007. Describing Participants in AAC Research and their Communicative Environments: Guidelines for Research and Practice. *Disability and Rehabilitation*, 29(7): 521-535.
- 3 Thomas (2006) A General Inductive Approach for Analyzing Qualitative Evaluation Data, *American Journal of Evaluation*, 27 (2): 237-246.

# Appendix 3

## Scoping study example data

Scoping study data provided information on AAC resources across the UK. Those services that were commissioned to provide AAC services indicated that they provided a range of activity that generally included assessment, training and support.

'As part of the assessment loan bank the NHS X & X resource provides all of the equipment described above for assessment loans and, as required, long term loans to adults and children across the area. Ongoing support, training and technical assistance is provided. b) Unpowered (pictures / symbols) aided communication. As required, pictures and or symbols are provided by the AAC Resource. SLT's across the health board area are also able to provide 'unpowered' – 'low tech' communication resources. Training and support in doing this is provided via the AAC Resource. The AAC Resource from NHS X & X's SLT department is area wide and funded by the Health Board of NHS X & X.'

Some areas had specialist SLTs for AAC who could assess and recommend a communication aid and then make a case for funding on a case by case basis. Where no funding was approved some SLTs described approaching Charities for funding.

'We provide a range of services from assessment to device provision and support. There is no dedicated budget for AAC devices so have to apply on a case by case basis for funding.'

'SLT service provides a limited a service for AAC Adults, those with LD or CP are under another services.

Powered (light/mid/high tech) aided communication. Lightwriters, Servox, Amplifiers, Megabee are available but more specialised high tech equipment has to be applied for individually through ICES. Not all of these are funded and we have to approach charitable organisations.

Unpowered (pictures/symbols) aided communication are provided by SLTs.'

Other Trusts/Boards had specialist SLTs for AAC who were able to provide assessment and recommendations but did not have any funding for communication aids. In some Trusts there was no staff time to source Charity funding so the onus was on the family to seek funding or to self fund.

'Our local PCT XXX will pay for specialist assessment at----- but there is no money for equipment. We source equipment via appropriate charities (MNDA, Speakeasier) and suggest other charitable organizations. We will provide supporting statements but cannot source funding due to our staffing limitations. Some clients self-fund; others just go down the low-tech route.'(SLT Manager)

The different SLT services for AAC were commissioned in different ways across the UK. While services were commissioned specifically for AAC in some NHS Trusts/ Boards in others there were local specialist SLTs for AAC, or in others there were no dedicated posts for specialist SLTs for AAC and specifically for 'high tech' powered communication aids. In areas where there was no funding for an assessment equipment bank some SLTs reported that they had built up their bank of equipment through Charity funding.

'No dedicated specialist post. No, there is no specialist team for AAC on XXX. We have a bank of aids for assessment. These have been purchased with charitable or non-recurring funding. No funding stream for AAC i.e. purchase or repairs/ maintenance. Requests for aids for individuals are made on an ad hoc basis to commissioners.' (Specialist SLT)

# Appendix 4

## Study participants

Method	Details
Scoping Surveys	SLT returns: 58
Media Requests	Direct by e-mail: 4 Other respondents via on-line survey (details below)
Data gathering Surveys	On-line surveys: <ul style="list-style-type: none"> <li>• People who use communication aid: 35</li> <li>• Communication Partners: 27</li> <li>• Educators: 14</li> </ul> Paper & e-mail surveys <ul style="list-style-type: none"> <li>• Suppliers' Survey: 8</li> <li>• Charity Survey: 18</li> </ul>
Interviews	People who have experience of AAC: 9 Communication partners: 6 Practitioners: <ul style="list-style-type: none"> <li>• SLT 14</li> <li>• Clinical Scientist 1</li> <li>• Voluntary sector 2</li> <li>• Education 4</li> <li>• Suppliers 4</li> </ul>
Charity:	0
Telephone/Skype Interviews	People who use powered communication aids: 1 Parents: 7 Practitioners: 12 Educators: 5 Charities: 6
Focus Groups	Practitioners & Educators: 105 Communication partners: 7

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# Appendix 5

## Topic sheets - interviews and focus groups

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### Interview Case Studies Example of the Topic Sheet Developed for Users of AAC - workstream 2 (University of Sheffield)

#### Communication Matters – Research Matters: an AAC Evidence Base

##### Topic Sheet to use with people who need, use or have used AAC and aided communication

###### AAC system use

Collect information on different and current systems used if any and if so then for how long.

Explore the use of different technical systems (e.g. low tech - picture books vs high tech – voice output communication system) if used and the context for that use, e.g. environments where the AAC system is used.

###### AAC system benefit

Explore the benefits of the AAC system, what communication is able to be achieved with the AAC system.

Whether there are any restrictions in using an AAC system, explore the motivation and reasoning around using aided communication.

Whether there is an impact because of the effects of slowed speed of communication when using AAC systems.

Whether there are any issues around increased control through use of an AAC system.

Whether the AAC system/s used meets present and anticipated needs

###### AAC system design

Explore whether there are any issues around the AAC system.

Consider the ease of use, equipment/device reliability, performance, physical characteristics (portability, design and layout, device configuration, visually acceptable, voice output), acceptability to others.

###### Social factors that affect the use of a communication aid

Use of the aid in social settings & in public

###### Training & Learning

Effect of training and learning on using an AAC system. Explore if the effort in learning the new AAC system is worth it or whether the effort is greater than what is gained in communication.

Explore whether there has been training for the AAC user, carer and family and its effect on communication.

###### Help and Support

Explore issues around AAC service delivery, the ability to access to assessment services, the ability to trial an AAC device, and choices of communication aid.

Explore user knowledge versus a professional's knowledge of an AAC system, whether users feel they understand how it all works.

###### Management issues

How easy it is to get funding? Who meets the cost of the AAC device? How easy it is to access and learn to use the AAC system? How easy it is to repair? How available is the technical support?

At the end of each interview or Focus Group the researcher will leave the participants a leaflet describing the work of Communication Matters and a leaflet about the research work they do with contact details of the CM research office so they can take part in future research studies if they so wish.

## Topic Sheet for Focus Group for use with those working with AAC aided communication

### Communication Matters – Research Matters: an AAC Evidence Base

#### Focus groups Sheffield University Qualitative Work Stream (2)

#### Topic Sheet - Practitioners

Thank you for coming here today. As part of our study 'Communication Matters – Research Matters: an AAC Evidence Base' we are seeking find out about current Augmentative and Alternative Communication (AAC) need, use and provision in the UK and to develop an online evidence database that will make information about AAC research and best practice available to everyone. You have been invited because of your knowledge of AAC. The purpose of this Focus Group is to explore the route that an individual takes to get AAC, and specifically the route for aided communication, by asking those who are involved in the assessment, trialling and training of people on aided communication to tell us about that journey.

#### Information on composition of Focus Group members:

Introductions – post held -where based

Before beginning the Focus group discussions participants are asked them to note down a few thoughts for each of the topics so their ideas are noted.

#### Topic 1 What is an AAC service trying to achieve?

Consider the aims and objectives of the AAC service.

#### Topic 2 Who should be involved in providing AAC aided communication?

Describe the team, consider essential skills

#### Topic 3 How does a person needing aided communication access an AAC service and how does that person then progress through the service?

Consider factors: access; assessment; choosing an aid; trialling an aid; training factors: support

#### Topic 4 What factors would facilitate aided communication use or deter aided communication use?

Consider the pros and cons: such as the needs of the individual, environment, ease of use/performance of system, build quality, speech produced (recorded/synthetic).

#### Topic 5 What would be your wishes for aided communication provision?

Consider the wants and needs for successful aided communication/AAC use.

## Commissioners' Topic Sheet

### 1 Commissioning Structure

How is commissioning of services for people with communication difficulties structured? Consideration of need.

Is the provision of communication aids a specialist purchase or part of a service to people with communication difficulties?

### 2 Criteria for AAC services

What are your criteria for funding AAC services?

What are your criteria for funding AAC devices/aided communication?

### 3 Funding

How is funding organised for AAC services?

Is there shared funding with other organisations e.g. education, local authorities, charities?

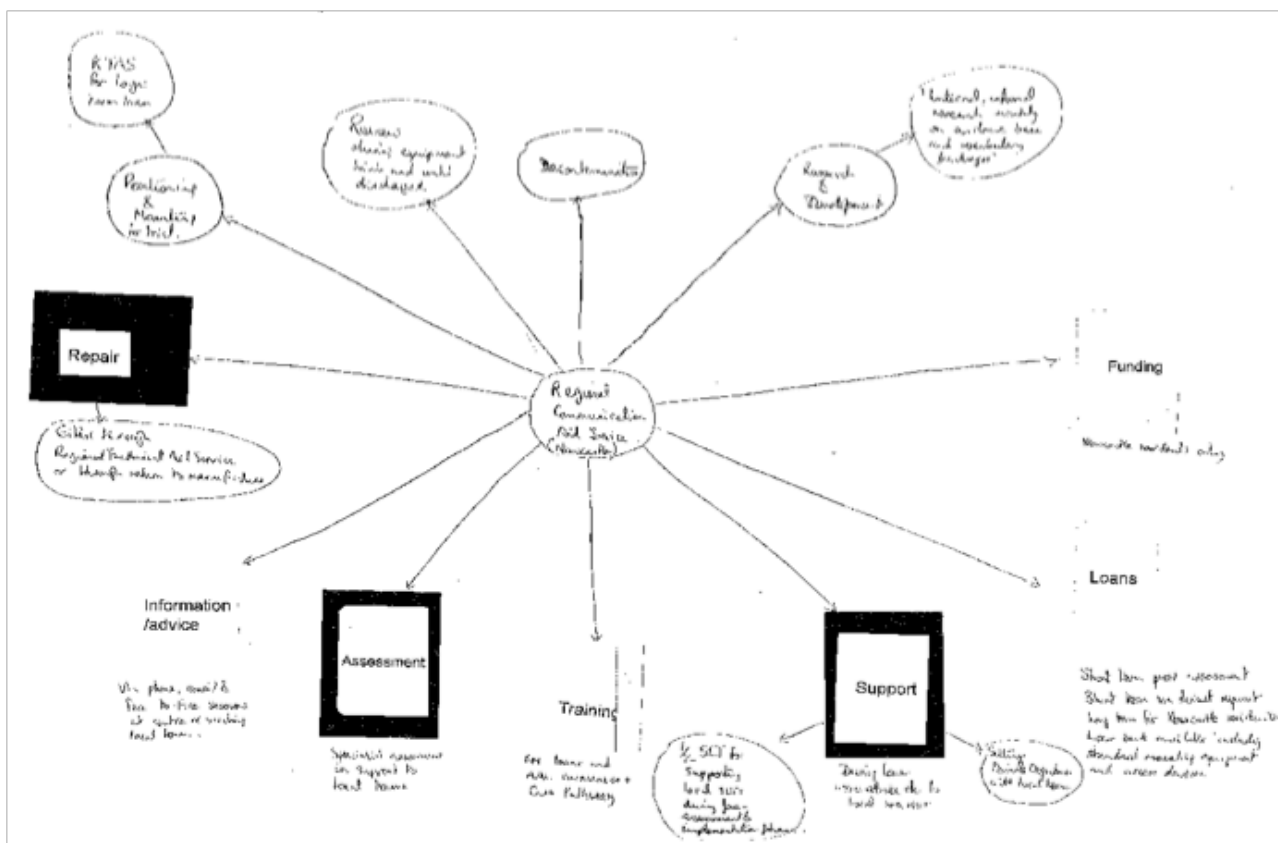
### 4 Outcomes

Which outcomes are used to judge if providing AAC services are value for money?

Which outcomes are used to evaluate effectiveness of providing AAC aided communication devices?

# Appendix 6

## Example service component map (regional communication aids service)



## Service components described by independent AAC Centre and specialist centre

### AAC provision at a Special School categorised by components

#### Component

Education Special School

**Assessment** Own clients assessed; Multidisciplinary Team joint assessments: SLT Teachers/TA on site. Trials of equipment are acquired from companies

**Loans** Limited loan bank of high tech symbol/text based systems produced by SALTs/A; loan equipment acquired via companies, ACE or RCAS.

**Training** Staff access local & national training via CM. Training to parents & staff in school/college /adult centre as regular programme; induction of new staff, specific in-service & individual training per AAC user/system/ intervention strategies

**Support** AAC user support varies according to need. Intensive in new provision, integrated with education or life skills. Part of education or life skills. Part of IEPs or goal setting. Educational support for accreditation in AAC certificate for City & Guilds in school/college & adult centre 3-60 yrs.

**Integration** Integration of equipment.

**Review** Annual review system in school - IEP. Goal setting in adults, consultation for expert advice for NHS SLTs in community. Expert witness tribunals.

**Positioning & Mounting** Wheelchairs & technical aids medical physics - local referral made

#### Maintenance

**Repair** Decontamination Renewal of low tech systems, review of high tech systems arranged via warranties, replacement equipment funding sought following review and as needed.

**Funding** No budget to fund equipment: joint Education Health, Social services, some from Charity. Funding of assessment via LEAs in children & Social Services in adults - SLT & AAC devices not always funded in adults.

**Information & Advice** Provided to AAC users; parents; carers; social services.

**Provision staffing** SEN Teachers, Teaching Assistants, Specialist Support Assistants, Physiotherapists, Occupational Therapists and Speech and Language Therapists.

AAC provision categorised by component

ComponentIndependent AAC Centre

**Assessment**Assessment from MDT and recommendation of AAC.

**Loans** Loans of AAC available for inpatients but not external referrals. Some loans of smaller equipment such as switches and switch mounts available to external referrals.

**Training** Within Hospital and in the Community (limited but developing).

**Support** Patient & staff training; training courses.

**Review** By phone; e-mail; face to face.

**Positioning & Mounting** Advice on positioning and mounting.

**Integration** Computer access, environmental control, powered wheelchair control.

**Maintenance and Repair and decontamination** Maintenance, repair and decontamination of equipment after evaluation trials. Repair own loan stock and custom made equipment.

**Funding** External referrals primarily funded by NHS, private or legal funding.

**Research & Development** Advice and reports sent to commissioners to request funding, cannot fund equipment.

Charity so raise money for assessment and equipment.

**Custom Manufacture** Custom making of equipment, particularly specialised switching and custom mounting for AAC and switches.

**Information/ Advice** E-mail and courses.

**Provision staffing** MDT: OT,PT,SLT, Technicians, Rehabilitation Engineers

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# Appendix 7

## Summary of data from RCSLT Focus Groups

Practitioners attending the Focus Group were taken through the topics. The data gathered was analysed for components of AAC provision and to identify the definitions of different components and elements within those components.

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### Topic 1: What is AAC?

The groups were asked to describe their view of what AAC means to them. The group members saw AAC as including those means and methods that augmented natural speech and provided alternative communication when speech was not intelligible or possible. The groups provided a range of descriptions that included a wide range of AAC strategies some were termed 'low tech' or 'unpowered' strategies such as, signs, gestures, picture and symbol systems and others included 'high tech' or 'powered' strategies which included all the powered communication systems from simple systems (e.g. static screens) to complex systems (e.g. dynamic screens).

'AAC is loosely any non-speech method of communicating.' (Specialist SLT AAC)

'I always base my thoughts on it around what AAC stands for: so Augmentative – so it can be working on something to augment the speech like a voice amplifier or something along those lines; and Alternative - so it can be used instead of speech if speech is difficult but also to support speech when it breaks down.' (Specialist SLT AAC)

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### Topic 2: What is an AAC service trying to achieve?

There was a consensus that the purpose of an AAC service was to meet the communication needs of the person and the 'team' that supports that person's communication. This 'team' was defined as including family members or carers or people working with the person such as therapists, teachers or teaching support staff. The groups spoke about their approach to assessing the person and identifying their communication needs. The descriptions of the assessment process included many factors and considerations. These included teasing out the desired goals and outcomes for the person and those around the person in providing a suitable communication aid

'We're looking at the specific goals of an assisted communication aids service. What are their goals? And can you have an overall goal for such a service? ...you can't have an overall goal because it sounds as if it has to be very specific to the client.' (Specialist SLT AAC)

The groups described the variation in the timing of when a person might be able to convey their wishes for a communication aid. Group members commented that some people need to learn what the communication aid can do for them before forming their goals or their impairments might be such that they were not able to formulate their goals to those assessing their communication needs. An example was provided a person with locked in syndrome who needed to be able to get a communication system before they can communicate their goals.

'I think one of the problems we would have is, if I asked some of our clients what they wanted to achieve, they may not realise what they could achieve firstly, and also they're actually in a place where they've just had a brain stem stroke, they're locked in and actually what they want to do is walk and talk and they're not at a point where they can see far enough down the road.' (Assistive Technologist)

The groups reflected on the skills of the specialists and specialist teams. The process of providing and supporting the communication aids involved many stages, part of which was providing a thorough assessment. The term 'assessment' was used to encompass a wide variety of activities. These activities focused on learning about the person, gaining relevant information around the person, in matching the communication aids be they low and/or high tech and evaluating the use of those communication aids.

'...when you've done your assessment, you understand the client, their preferences, family support, family skills, what's in school. It might be that you're going down the PC line and you suddenly find it's a Mac school. So you've really, really got to look at... absolutely everything and you make your decisions are based on that, but our skill is in – and we keep doing this, don't we? Keep standing back and looking at the whole needs, the whole picture, and not getting sucked into the technology.' (Specialist SLT AAC)

### Topic 3: Who should be involved in providing AAC aided communication?

The groups felt that there were advantages in having a team to provide AAC because of the knowledge each discipline brought to the process.

'...what we rely on our team of speech therapists for is the communication, the understanding of language, about vocabularies, all those different things. We rely on our occupational therapist for looking at posture, positioning, switch placement; all those kinds of things. We rely on our tech support to do all the kind of techy bits, to understand the software and make it do what it needs to do to meet the person's needs, so to me, you need a team. You can't – I don't think it's something you can do yourself.' (Specialist SLT AAC)

There was variation in the make-up of the different teams for AAC across the country. Some teams had a number of specialist practitioners from different disciplines while others were composed of a single discipline, usually SLTs/SLTAs, with the opinion of other disciplines being sought if required. In the local community, it was usually the SLT who supported AAC for adults while in education there were also staff to support communication as part of accessing the curriculum and specialist schools often had their own support team for children that also included an SLT/SLTA. The support of students changed on their transition out of education with their support team gone they had to rely on the services for AAC within the local community, usually the local SLT.

'...when our students move on and move out into the community, normally that team just isn't there, and so probably the speech and language therapist is the only person.' (Assistive Technologist)

The group members discussed their strong links with the local community services. They described how the AAC specialist teams relied on those in the local teams to provide support to the person and their family/carers in their everyday environment. The relationship between the specialist/s and the local team was considered important as well as recognising that the local SLT would have an understanding of the person's speech and language or vocal abilities as well as having an understanding of the communication issues associated with a particular aetiology.

'...the way I would see working best is that you have the therapists who really know the person and understand the needs and the abilities of the person coming in to people who understand the technology and saying 'actually we can meet that need with this or this' (Specialist SLT AAC)

### Topic 4: How does a person needing aided communication access an AAC service and how does that person then progress through the service?

The specialist services had care pathways and criteria for who could or could not access their service. The way services are commissioned for an area by Health, Education or Social Service/Local Authorities affects the way services are organised at a local level and at the specialist AAC centres and special schools and colleges.

At the local level someone, usually the SLT will identify if a person has the potential to communicate using a form of AAC. The local team can decide if they can meet those needs within their resources or contact their specialist AAC service for advice and information or for assessment and loan of trial equipment. Referrals to the AAC centres usually related to the need for their knowledge and expertise and access to devices to try during evaluation of an aid when matching the communication aid system to the person.

'...on the whole the technology's there but there's a big barrier about getting the person and the technology together, particularly because of resources but sometimes because the support around them, or because of the way that the health service runs in local circumstances.' (Specialist SLT AAC)

One of the group members worked in a Special College and explained that their college policy was to assess the student prior to entry to ensure they had the correct communication system to communicate and to allow them to access the curriculum.

'...there would be an intake assessment where they'd come for an overnight stay and meet all the various therapists so they can make an assessment but obviously we can speak with the school and whoever else to get as much information as we can. It's often very sketchy and incomplete and even downright wrong. So we have a team...to go through all the intake students to talk about who was likely to be of interest to the AAC department.' (Specialist SLT AAC)

### Topic 5: What factors would facilitate aided communication use or deter aided communication use?

The groups discussed the many diverse factors that promoted the success of using a communication aid. All of the groups spoke about the need for meeting the person's goals through matching the right communication aid to the person. The practicalities of matching the right 'kit' to the person with good access, correct mounting and positioning, suitable software were important but so was providing training and support for the on-going use of the communication aid. The motivation of the person to use the aid can be diminished if the communication aid does not suit their needs or they do not get the opportunity to use it.

'I think what's important is understanding the potential of what technology can offer.'

'Sometimes it's that the technology isn't absolutely ideal and the circumstances where it really doesn't work is where the technology's really not absolutely ideal and the support around the person isn't ideal'.

The presence of a good communication partner can allow the person to use a variety of communication strategies to communicate where the person can move between different strategies for speed and ease of communicating and for clarity. The communication aid can be used to express specific communications and can be used alongside other strategies. Using the communication device can be effortful for the person so having a low tech approach to use can reduce that effort and compensate for environments where it is not possible to use the communication device.

'...it is perfectly valid for somebody to have seven strategies, seven different methods that they use in all different kinds of places, and it doesn't mean that they don't need access to an expensive high tech device, just because they've got six other strategies that work, but there's situation x, y, and z where those strategies won't work'. (Specialist SLT AAC)

The groups discussed the limitations of matching the device with the person's current individual needs and they reflected on the benefit of having knowledge and skills within the assessing team to decide on the recommended means of communication.

'What do you do? Do you go with the device that's portable for a child with dyspraxia and in mainstream school to use but it hasn't got the right symbols on? Can they cope with having a low tech system with a different symbol system and a high tech with a different symbol system? So again it's balancing, and having that knowledge and skill to actually make that sort of – come to a decision as a team, to say 'well you lose there but you gain there'. So it's not just compromise within the team. It's compromise on the devices and the different strategies.' (Specialist SLT AAC)

The groups felt that putting time into supporting the use of the device within the person's environment was of value and helped its use as did training people around the person to be confident in its use as the knowledge, confidence and attitude to technology of those people around the person can influence the use of the device. The group members described experiences of working with people who were anxious about using devices because they lacked previous experience.

'We discharged someone with a Toby C12 on Tuesday morning and on Wednesday morning I had a phone call from the nursing home to say 'please, please, please, can you come down, we don't know what to do with this device. We can't mount it onto the bed, we can't plug it into the nurse call system, we've got no infrared receiver'. They were just panicking and so I'm going down next week free of charge to sort it out but I can't leave it.' (Specialist SLT AAC)

'..when we discharge people, we discharge them with a disability management book which is a book of guidelines which has photographs, very, very, clear, we colour-code the machine where all the plugs go, you know, we do as much as we can to the point where we'll teach the family members how to do it - and still it falls apart.' (Specialist SLT AAC)

There was a feeling that support for using a communication aid was as important in contributing to the successful use of the communication aid. Funding the provision of the communication aid was only part of the process and that funding needed to be in place for SLTs to support the use of the device as a communication tool.

'...my recommendations are, for the piece of kit 'watch out, this is the cheap bit', like you said, and then afterwards my recommendation is for ongoing support and training, and I say 'if the funding is not available for that, don't bother funding the device.' (Specialist SLT AAC)

## Topic 6: What would be your wishes for aided communication provision?

There was a wish to look at the wider picture concerning a person's needs and they may need to use the device to communicate but also be able to access social media, send e-mails, access a PC and to make telephone calls. Integration of the communication device might be needed with a wheelchair or with environmental controls. The demands of integration on the communication device with other technology places demands on the team assessing the person for their communication support needs and for the team to link with other provider for environmental controls and wheelchair provision.

'I think something that springs to my mind is that it shouldn't just be about AAC I think because technology can do so much more for people and often when we see people we're looking at the possibility of them using environmental controls, possibly a powered wheelchair, those kind of things and looking at how that integrates together. So I would like this trans-disciplinary team at the top to have more than just AAC skills to understand.' (Specialist SLT AAC)

'I think for adults the issue is the kind of social networking, and for children as well, the texting, and being able to make calls directly from your device as well, and I think there are a whole raft of issues that we need to deal with now that we didn't have to deal with in the past.' (Specialist SLT AAC)

There was a feeling that those with skills and knowledge around AAC should provide training and courses for the local links so their understanding skills and knowledge could be developed to ensure the local team had competencies to identify communication potential and support use of AAC.

'...we're really saying that actually having the workforce properly trained, properly integrated, proper care pathways up and down is number one.' (Group consensus summary of point)

The SLTs felt that the undergraduate training of SLTs needed to include more on AAC and contain more practical components on AAC so the SLTs qualifying would have a good level of competence on AAC strategies, technology and communication support.

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# Appendix 8

## AAC industry/supplier and charity surveys

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### Suppliers/Software Queries

Augmentative and Alternative Communication strategies are used by individuals who have communication difficulties resulting from developmental or acquired conditions. Suppliers aim to meet the needs of individuals, children and adults, who need to use aided communication by providing appropriate systems. The AAC evidence study is seeking to identify the role of suppliers in meeting the needs of pwuAAC.

Could please provide information for the following Topics? Thank you. Alex John, Researcher

#### Needs

- a How are usually contacted regarding products or devices?
- b Do you have any role in terms of identifying the needs of the person?
- c Do you assist in assessing the person for suitability of just your product? (e.g. is it technically possible for the person to use it?)
- d What are the usual steps in providing the most suitable aided communication system for the individual? (e.g. demonstration, trial, loan, length of time provided)

#### Provision

- a Can you describe people's aspirations when accessing communication devices?
- b How is the communication aid usually provided by your company? e.g. sent to AAC specialists/ education services - individual – demonstrated to individual – set up for individual.
- c Do you give technical assistance in providing a communication aid?
- d Do you advise on positioning? (placing, mounting, access issues)

### Support and Training

- a What do you perceive as the issues for the successful use of a communication aid or piece of software?
- b What is the role of the company in supporting aided communication?
- c (Individual, family, NHS, education)
- d What is the role of the company in the provision of training? (To the individual? To the family? To professional staff? )
  - Supporting use
  - Supporting staff?What is the role in repair of devices?  
(Time scales, use of device while repairs are undertaken, funding of repairs)  
What steps are taken to ensure confidentiality of content on a communication aid you are repairing or replacing an aid or software system?

### Funding

- a What is the main system for funding aided communication?
- b Are there any systems in place for facilitating the purchase of your product?
- c Are there more individuals paying for their own devices?
- d Is more funding coming from one particular source e.g. education, health charity? Has that changed over time?
- e Is acquiring funding for devices becoming easier or more difficult?
- f Are they aware of any particular delays related to funding?

### Supply Trends

- a How did supply and/or funding change during CAP and after?
- b Have there been changes in funding relative to the age of the individual? e.g. child - adult
- c How has product mix changed over the years?

## Charities Survey

### Augmentative and Alternative Communication (AAC) Evidence Base Research Project

I am a researcher working on the Augmentative and Alternative Communication (AAC) Evidence Base research project. Part of this AAC Evidence Base study aims to identify and describe the ways in which charities provide resources to people who use AAC, who could benefit from using AAC and family and communication partners.

#### AAC Evidence Base Study

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

### Project Aims

- 1 To gather fundamental evidence of the need for AAC in the UK and current provision and use of AAC. It is hoped that this information will be used to improve AAC services across the UK.
- 2 To provide access to current knowledge related to AAC in an online AAC Evidence Base that will present information in a variety of accessible formats.
- 3 To support and encourage research into AAC in the UK by building a list of people who are interested in taking part in research (the Communication Matters Research Involvement Network).

### Objectives

The University of Sheffield and Barnsley Hospital are seeking to identify the number of people across the UK currently using AAC and the various routes that they use to obtain appropriate AAC, including through health, education, commercial suppliers and the voluntary sector. Importantly, it also seeks to define the need, specifically how many people could benefit from AAC; the provision of resources for AAC and use, exploring how AAC is being used by those currently in receipt of it. In parallel, Manchester Metropolitan University is investigating the type of information required to be included in an AAC Evidence Base, and the formats preferred by those seeking information. The aim being to establish an online AAC Evidence Base in collaboration with Communication Matters.

### How You Can Help

The success of the project depends on the active engagement of all those involved in any way in work with AAC.

We are seeking information at three levels:

- 1 The role of the Charity and specifically the role in supporting those members who may need or use AAC.
- 2 Enabling those members who may need or use AAC to contribute to the AAC evidence project by describing their own experience of AAC, whether that was a successful or unsuccessful experience.

### 3 Identifying unmet need.

The types of roles undertaken by a Charity may include:-

- Helpline/Information
- Advocacy
- Signposting
- AAC brokerage
- Specialist AAC services
- Education/Training
- Day services/Respite Services
- Residential Services
- Making Grants
- Campaigning
- Fundraising
- Research

If you can give information relating to any of the three levels identified above, please contact Alex John, Research Associate at [a.k.john@sheffield.ac.uk](mailto:a.k.john@sheffield.ac.uk) or 0114 222 2978.

For more information on the progress of the project contact Katie Holmes, Research Manager, [katieholmes@communicationmatters.org.uk](mailto:katieholmes@communicationmatters.org.uk) or visit the Communication Matters website [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk).

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# Appendix 9

## Practitioners' survey

This research project is led by Communication Matters (ISAAC UK), a registered charity, no. 327500, and a company registered in England and Wales, no. 01965474. The project is funded by the National Lottery through Big Lottery Fund. The research partners are Barnsley Hospital NHS Foundation Trust, Manchester Metropolitan University and the University of Sheffield.

This survey is part of the "Communication Matters - Research Matters: an Augmentative and Alternative Communication (AAC) Evidence Base" research project. The project is funded by the Big Lottery Fund and the research is being carried out by Communication Matters in collaboration with Sheffield University, Barnsley Hospital and Manchester Metropolitan University. This survey is being conducted by Sheffield University.

The project aims to improve the quality of life of people in the UK with severe communication impairments who need AAC by producing fundamental evidence of the need for, and provision of, AAC which can be used to improve services across the UK. To do this we need to establish what the current service provision is across the UK and also provide accurate information about the population who use or need AAC.

Please fill this survey in if you are an AAC practitioner and/or provide a service related to aided communication. We need your help to collect this data so that we can provide accurate evidence to decision makers in national and local government, commissioners of services and those who work within the field.

Please fill in as much of the survey as you can and return it even if you cannot complete all the questions.

Thank you for taking time to complete the survey. If you have any questions about the survey or would like more information about how you can contribute further to the study, please email Sarah Creer at [S.Creer@Sheffield.ac.uk](mailto:S.Creer@Sheffield.ac.uk) or telephone 0114 2222 978.

If you prefer you can fill this survey out online by visiting: [www.communicationmatters.org.uk/surveys/](http://www.communicationmatters.org.uk/surveys/)

## Information about you

### 1 Name

---

### 2 Job title

e.g. Speech and language therapist, Clinical Scientist.

---

### 3 Name of department/service/team

e.g. Adult speech and language therapy, Specialist Disability Service.

---

### 4 Contact address

Please enter your full work address.

---

### 5 Email address

Please enter your preferred email address

---

### 6. Telephone number

---

## Information about your service

### 7 What is the name of your employing organisation?

---

If your organisation has recently been reconfigured or is about to be reconfigured, please answer with who your employing organisation is on the day you complete the questionnaire and state the future or recent changes.

### 8 Which of the following best describes your employing organisation?

- ☐ NHS Community Trust
- ☐ NHS Hospital/Acute Trust
- ☐ NHS Primary Care Trust
- ☐ NHS Social Enterprise
- ☐ NHS Foundation Trust
- ☐ Social care
- ☐ Local authority
- ☐ State school
- ☐ Independent school
- ☐ Higher / Further education
- ☐ Charitable organisation
- ☐ Private practice
- ☐ Other:

Please choose only one

### 9 What is the geographical area covered by you or your service?

"Service" refers to the service/department/team that you stated in question 3.

**10 Which client age groups do you provide services to?**

- ☐ All age groups
- ☐ Pre-school age
- ☐ Primary school age
- ☐ Secondary school age
- ☐ Those in further education
- ☐ Adults
- ☐ Other:

Please choose all that apply

**11 Which client groups do you provide services to? Those with...**

- |                         |                    |       |
|-------------------------|--------------------|-------|
| Developmental disorders | Acquired disorders | Other |
| Children                |                    |       |
| Adults                  |                    |       |
| Both                    |                    |       |

In this question, "children" are those up to the age of 18.

**12 What are the eligibility criteria for access to your services?**

Please enter "none" if there are no eligibility criteria for access to your overall services. Eligibility criteria for individual aspects of the service will be asked later in the survey.

**13 In what settings do you provide services?**

- |                     |       |              |            |              |
|---------------------|-------|--------------|------------|--------------|
|                     | Never | Infrequently | Frequently | All the time |
| Healthcare settings |       |              |            |              |
| Client's own home   |       |              |            |              |
| Residential care    |       |              |            |              |
| Day care settings   |       |              |            |              |
| Education settings  |       |              |            |              |
| Other               |       |              |            |              |

Please indicate all settings where you do or could provide services.

**14 For what types of aided communication do you provide services?**

- ☐ None
- ☐ Unpowered communication aids
- ☐ Powered communication aids

Powered communication aids are those which have a power system and usually display written text or speech output e.g. Voice output communication aids. Unpowered communication aids are those without a power system e.g. communication charts, Etran frames.

**15 Please indicate the total number of whole time equivalent (WTE) staff in your service by job title.**

WTE staff in service WTE staff working with powered aided communication Speech and Language Therapist SLT with specialism in AAC Clinical scientist Clinical technologist Rehabilitation engineer Teacher Occupational Therapist Physiotherapist Assistive Technologist Assistant (Therapy, teaching, rehabilitation or other) Administration staff Others Please enter a number for each item. "Service" refers to your service/department/team as stated in your answer to question 3.

**16 Which database system do you use to record your data?**

For example, SystemOne or Local Access Database. If you do not use a database system, please state how you record your data.

**17 When recording service information about your clients, what type of data do you collect?**

- ☐ Client age
- ☐ Client sex
- ☐ Client postcode
- ☐ Client linguistic/cultural background
- ☐ Client condition
- ☐ Client time of onset of condition
- ☐ Communication aids/strategies used by the client
- ☐ Other:

**18 Do you or your service assess individuals' skills and capabilities for their suitability to use powered communication aids?**

- ☐ Yes
- ☐ No

Please tick yes if you carry out any type of assessment, you can expand on this in the next question.

**19 What is involved in this assessment?**

Only answer this question if you answered yes to question 18.

- ☐ Expressive/receptive language tests
- ☐ Cognition/memory tests
- ☐ Physical assessments
- ☐ Medical assessments
- ☐ Checklists of communicative competence
- ☐ Communication aid trial and evaluation
- ☐ Other:

**20 Do you or your service provide loan of powered communication aids for trialling?**

- Yes
- No

Please choose all that apply.

**21 Please list the powered communication aids that you currently have available for loan. Please provide as much detail as possible including symbol packages if known (e.g. 1 x Powerbox with CallTalk vocabulary, 2 x iPad with Predictable).**

Only answer this question if you answered yes to question 20.

**22 Please indicate the maximum length of time equipment can be loaned to an individual.**

- ☐ 1 month
- ☐ 3 months
- ☐ 6 months
- ☐ 12 months
- ☐ No limit
- ☐ Other:

**23 Does your service fund provision of powered communication aids for long term use?**

- ☐ Yes
- ☐ No

Choose yes if the service funds devices from its budget, you can list other sources of funding in the next question.

**24. Please describe any eligibility criteria to receive funding for provision of powered communication aids.**

Only answer this question if you answered yes to question 23.

**25. What is your equipment budget for powered communication aids for this year?**

Only answer this question if you answered yes to question 23.

**26. From which sources is funding secured for aided communication provision?**

- ☐ Private purchase
- ☐ Charities
- ☐ Local authority
- ☐ NHS
- ☐ Education
- ☐ Pooled budgets
- ☐ Other:

Please choose all that apply

**27 Which of the following do you or your service provide?**

- ☐ Information on powered communication aids
- ☐ Repair of powered communication aids
- ☐ Replacement of powered communication aids during repair
- ☐ Maintenance of powered communication aids
- ☐ Customising or manufacture of hardware
- ☐ Customising or manufacture of software
- ☐ Customising or creation of vocabularies
- ☐ Training for people who use powered communication aids
- ☐ Training for conversational partners
- ☐ Training for professionals working with powered communication aids
- ☐ Follow up reviews of powered communication aid use
- ☐ Ongoing support for powered communication aid use
- ☐ Other:

Please choose all that apply

**28 Do you or your service provide follow up reviews for people who use powered aided communication?**

- ☐ Yes
- ☐ No

**29 How frequently do you or your service provide follow up reviews?**

Only answer this question if you answered yes to question 28.

- ☐ On request
- ☐ On re- referral
- ☐ Every 6 months
- ☐ Every year
- ☐ Every two years
- ☐ Other

**30 Which services do you refer your clients to for the following?**

Information on  
powered communication  
aids

---

Assessment

---

Loan equipment  
for trial

---

Provision of powered  
communication aids

---

Repair of powered  
communication aids

---

Replacement of  
powered communication  
aids during repair

---

Maintenance of powered  
communication aids

---

Customising or  
manufacture of hardware

---

Customising or  
manufacture of software

Customising or  
creation of vocabularies

Training for people  
who use powered  
communication aids

Training for  
conversational partners

Training for professionals  
working with powered  
communication aids

Follow up reviews  
of powered communication  
aid use

Ongoing support  
for powered  
communication  
aid use

Other

Please indicate any other services that you refer to, or  
work with, within the text box.

**31 How many total referrals to other services have  
you made in the past year related to powered  
aided communication use?**

**32 Which services do you receive referrals from  
for the following?**

Information on powered  
communication aids

Assessment

Loan equipment  
for trial

Provision of powered  
communication aids

Repair of powered  
communication aids

Replacement of powered  
communication aids during repair

Maintenance of powered  
communication aids

Customising or manufacture  
of hardware

Customising or manufacture  
of software

Customising or creation  
of vocabularies

Training for people who  
use powered communication aids

Training for  
conversational partners

Training for professionals  
working with powered  
communication aids

Follow up reviews  
of powered communication  
aid use

Ongoing support for  
powered communication  
aid use

Other

Please indicate services and other organisations that  
refer clients to you within the text box.

Please also indicate whether you get referrals from  
clients themselves.

**33 How many total referrals to you or your service  
have you received in the past year related to  
powered aided communication use?**

In this section, please provide estimates of values where it  
is not possible to provide verified data.

**34 What is the total number of people who use  
powered aided communication that you or your  
service have on your current caseload?**

**35 What is the total number of people who use  
powered aided communication known to you  
or your service? Please also split this number  
into aetiologies.**

Please fill this in for your current caseload if you are  
unable to answer about all clients known to you or your  
service. Please also list any other aetiologies not covered  
in the table in the box labelled "other".

Number of clients

**Total**

Stroke

Head injury

Cerebral palsy

Profound and Multiple  
Learning Difficulties

Autistic Spectrum Disorder

Developmental delay

Other learning difficulties

Multiple sclerosis

Motor neuron disease

Parkinson's disease

Muscular dystrophy

Head and neck cancer

Cleft palate and  
craniofacial malformations

Dementia

Other

**36 Of those clients known to you or your  
service, how many do not have English as their  
first language?**

☐ 0

☐ 1- 5

☐ 6- 10

☐ 11- 20

☐ 21- 30

☐ 31- 40

☐ 41- 50

☐ Over 50

Please fill this in for your current caseload if you  
are unable to answer about all clients known to you or  
your service.

**37 Please list the powered communication devices which are used by the clients known to you or your service. Please include as much detail as possible (e.g. 1 x Powerbox with CallTalk vocabulary, 2 x iPad with Predictable).**

This research project is led by Communication Matters (ISAAC UK), a registered charity, no. 327500, and a company registered in England and Wales, no. 01965474. The project is funded by the National Lottery through Big Lottery Fund. The research partners are Barnsley Hospital NHS Foundation Trust, Manchester Metropolitan University and the University of Sheffield. Thank you

**38 How did you obtain the data for this survey?**

- ☐ Estimates from my experience
- ☐ Estimates based on having previously extracted this data
- ☐ Data extracted from a database
- ☐ Other:

**39 Any further comments or questions?**

**40 Service information contact**

We would like to contact you or your service again to gain more detailed information on provision of aided communication and the processes involved and data about your caseload. We would like to access your anonymised data to get really accurate information that will fully capture the current use and provision of AAC services across the UK. Please can you state in the box who is the best person to contact about providing us with this information and how best to contact them.

Thank you for taking time to complete the survey. If you have any questions about the survey or would like more information about how you can contribute further to the study, please email Sarah Creer at [S.Creer@Sheffield.ac.uk](mailto:S.Creer@Sheffield.ac.uk) or telephone 0114 222 2978.

Please return the survey either in person, electronic submission or by post to:

Sarah Creer,  
School of Health and Related Research,  
Regent Court,  
30 Regent Street,  
Sheffield,  
S1 4DA

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# Appendix 10

## Mapping AAC provision: 2012-13 v8.3.1 (22/11/12)

This tool contributes to the objectives set out by the Department for Education funded grants for Augmentative and Alternative Communication. This tool aims to map teams, departments and services who provide services for people with AAC across England so that all stakeholders will have a clearer idea of the resources and services available outside of the specialised and tertiary services. It aims to provide a clear understanding for commissioners of the need for and the cost of local and specialised AAC provision. The data gathered will contribute to identifying priority areas (across geographical areas, sector and caseload) for service development which will address existing inequities in provision.

**Inclusion criteria** (please refer to glossary for definitions):

1. Services with a universal remit across a defined geographical area (e.g. SLT service, including AAC, in Barnsley).

OR

2. Other services with a universal remit across a defined population and area (e.g. people with MND in Yorkshire, school pupils with SLCN in a special school in Huddersfield).

AND

3. Provide, or are involved in the provision of AAC services, equipment or support OR have a caseload including people with speech, language and communication needs where it would be expected that there would be an AAC need.

**Exclusion criteria:**

1. Services without a universal remit across a defined geographical area (i.e. tertiary services, independent practitioners, companies)

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### Glossary of terms:

Section A – General terms

Section B – Service components

Section C – Examples of types of communication aids

#### (A) General terms:

##### Aided Communication

Aided communication is a subset of AAC which refers to those methods of communication which involve using additional equipment, such as picture, letter or word boards or books and technology based systems such as voice output communication aids.

##### Augmentative and Alternative Communication (AAC)

AAC covers a range of techniques which support or replace spoken communication. It includes gesture, signing, symbols, picture, letter or word boards or books and technology based systems such as voice output communication aids.

##### AAC key worker

The key worker's role is to ensure effective communication between the local and specialised services for AAC and any other allied services that may be required and to keep the person who uses AAC and their care and support network fully informed.

##### Care pathway

A care pathway is a sequenced programme of care (support) placed in a timeframe which defines the process and professionals involved from entry into the service until transfer out. In terms of services for AAC, a care pathway would define the programme of care (support) for a person from the identification of need to provision of any AAC equipment required and any review or follow up procedures.

##### Caseload

The number of people that are currently receiving or have been identified to receive one or more of the service components for AAC listed in section B of the glossary.

### Communication aid

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

### Discharge

The point at which the 'episode of care' (period of responsibility) for a person is ended. This can be when the goals set at the beginning of the intervention are met or agreed as no longer appropriate. After this point a person would need to be re-referred to have further input from the service. This does not, however, include ongoing responsibilities such as planned preventative maintenance etc.

### Equipment refresh

Refresh of equipment is the procedure of keeping issued equipment or stock up to date in order to maintain and improve functionality in the long term.

### High-tech aided communication

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

### Installation

The set up of equipment to a specification provided in the location where the person who will be using it can access it appropriately.

### Low-tech aided communication

These systems are those which do not require power to function such as picture, letter or word boards or books.

### Planned preventative maintenance

Planned preventative maintenance refers to scheduled, planned maintenance of equipment which ensures that the equipment is functioning correctly. This is carried out regularly following a pre-planned schedule rather than in response to malfunctions or equipment breaking down.

### Service

Service refers to the team or department or sometimes individual who provide services (e.g. deliver care, support, training or resources) for people who could benefit from AAC.

### Specialist skills in AAC

Specialist skills refers to someone who has advanced skills in the assessment or provision of AAC. This would normally include specialist knowledge and skills in the types of equipment available and the requirements for using that equipment. This person would be able to, and would often, make decisions independently on the most appropriate intervention for people with AAC needs.

### Unaided communication

Unaided communication is a subset of AAC which refers to those methods of communication which do not involve additional equipment, such as signing, body language, facial expression and gesturing.

### Warranty

A warranty is a guarantee written by the manufacturer of a bought product that assures the repair or replacement of the product if there is a problem in its functioning that fits a certain criteria. A warranty usually lasts for a defined time period after purchase.

### (B) Service components (see Care Pathway section):

#### Identification of need for AAC

The identification that a person could benefit from further assistance with their spoken communication either through unaided techniques or additional equipment.

#### Information/advice for AAC

This may be as part of general awareness raising process for people and their families which could contribute to the identification of need. This may also be in order to provide information once a need has been identified. Information could be provided on types of device or strategies that could benefit a person or services available to assist with any stage of the process of care for AAC.

#### Training for people who use AAC

Training involves a period of time potentially over multiple sessions to help those involved learn about using the device with an expected outcome of an awareness of how to operate the device and integrate it with their current communication strategies to the extent which is useful for them.

### Training for conversational partners

Training involves a period of time potentially over multiple sessions to help those involved learn about using the device with an expected outcome of an awareness of how the device works and how best to help the person using it maximise the effectiveness of their communication during an interaction.

### Training for professionals working with AAC

Training for professionals includes raising awareness and updating knowledge of AAC. This may include some or all of: information on AAC strategies, research and practice; AAC equipment and potential customisation and access options; and how to use and prepare the equipment for use. Training may also include information on any other aspects of providing a service for AAC and people who use AAC.

### Follow up AAC reviews

Review occurs in a separate period after an initial intervention. It is a process where a communication strategy employed since the previous intervention is considered and evaluated. The review will consider if this strategy is still appropriate and meets the needs of the person who uses AAC. A review may involve further assessments of the person's communication strategies, abilities and access methods and address any changes that have occurred in the person's situation.

### Ongoing support for people who use AAC

The provision of any type of support for the person who uses AAC after the provision of the equipment or strategy. This could include further customisation, information or advice on effectiveness of use or suggestions of alterations to meet minor changes in the needs. Where there are more distinct changes in the needs of the person a review may be required.

### Assessment for aided communication

Assessment is an evaluation of the suitability of aided communication to match a person's skills and capabilities for use. The assessment takes into account some or all of the cognitive, communicative, language, speech, physical and sensory abilities and needs including those that affect the method of accessing the devices for the person. It may also include equipment loan and trial.

### Loan trial of equipment

Equipment loaned to people for a period of time to allow trial of the equipment within the person's everyday context. This refers only to the period of loan, trial and evaluation before equipment is fully recommended as that which meets the needs of the person. The period of time may vary but is regarded as short term. The equipment has to be left with the person, not just used with the AAC professionals in attendance.

### Long term provision of equipment

Equipment can either be loaned or provided by a service for AAC on a long term basis – normally until the person has no use for the equipment or the equipment requires refreshing. This may or may not result in the recipient owning the equipment and in cases where a service retains ownership, the equipment may have to be returned at the point where the person transfers out of the service (due to age or the person moving out of the area). In either case, long term provision is for use of equipment for longer than a trial period for assessment purposes.

### Repair of equipment

Repair of equipment is required if the equipment is no longer fully functional. Repair means to make this aspect functional again by replacing or fixing the affected part (which is outside routine maintenance of the equipment).

### Positioning and mounting of equipment

This is provided when the person has other assistive equipment which may interact physically with the positioning of the communication aid. This process maximises the effectiveness of the equipment in terms of its placement and also carries out the manual attachment or mounting of the equipment. This component is purely relevant to the physical hardware provided and not any software that may need integration or installation.

### Replacement of equipment during repair

When the equipment is in need of repair, the service provides a replacement of the equipment to enable the person to continue to be able to communicate with those around them. The equipment does not necessarily have to be exactly the same model or have the same content of vocabulary but it should be similar enough for the person to be able to communicate in the same way with very little alteration or training.

### **Maintenance of equipment**

Maintenance refers to carrying out tasks to keep the equipment in working order. This may include: making routine updates to the software or operating system or keeping the hardware functional; cleaning; routine repairs to any fixings or mountings which could impede the equipment's functioning. Maintenance can be on request or can be 'planned preventative maintenance'.

### **Equipment Customisation (software)**

Customisation of software is distinct from customisation of vocabularies. Customisation of software is altering or developing software which is housed on the device (either a dedicated device or other technology) which changes a core component of how the software works rather than the individual vocabulary content.

### **Equipment Customisation (vocabulary/content)**

Customising vocabularies is the ongoing alteration of the content of the communication aid. This includes changing the accessible content in terms of words and phrases available for use on both high and low tech equipment.

### **Equipment Customisation (hardware)**

Customisation consists of altering the hardware to match the requirements or preferences of the person using the equipment. This may be through combination of commercially available hardware components, or modification of the hardware. This would not include attaching access devices such as switches or keyboards to the main device

### **Creation of low tech resources**

This is the creating of aided communication resources for people, such as communication boards or books. This is the initial stage of creation. Any ongoing changes would come under customisation (vocabulary).

### **Custom manufacture**

Equipment made, or modified outside of its original intended purpose to meet a person's specific needs. Custom equipment would not be used in the same configuration for another person as it is specific to that person. Custom equipment may be classified as a 'custom made medical device'.

### **Equipment management**

This is the systematic management of some or all of: logging loans and provision; de-contamination, commissioning, re-commissioning and decommissioning of equipment; managing equipment software and hardware updates; equipment acceptance and functional testing; equipment evaluation; equipment repair; refresh and recycling.

### **Recycling of equipment**

Equipment returned to the service that is re-commissioned ready to be used either by another person or by the service in some way. Equipment may also be recycled for use for parts.

### **Research and development into AAC**

Research and development into any aspect of AAC use, need or provision. This may or may not lead to the development of new technology, recommendations for best practice, collection and synthesis of evidence or changes in any procedures involved in any aspect of AAC.

### (C) Examples of types of communication aids (see Skills and Resources section)

#### Medium to large sized communication aids:

(with displays and large output vocabulary) These aids usually have a synthesised computer voice.

e.g. Smartbox PowerBox, Techcess Tellus, Liberator Accent, Dynavox Maestro, Tobii C12

#### Small or hand held communication aids

(with displays and large output vocabulary) These aids usually have a synthesised computer voice.

e.g. TCL Lightwriter, Dynavox DynaWrite. Tobii C8, Tellus Mobi SmartPhone devices and applications such as: Predictable, Proloquo2Go

#### 9 or more message communication aids

(with static overlays) These aids usually have a digitised or recorded voice.

e.g. GoTalk 9/20, TechSpeak 32, Tobii S32,

#### 1-8 message communication aids

(with static overlays) These aids usually have a digitised or recorded voice.

e.g. BigMac, Partner2/4, TechTalk 8

Other communication aid

Any other AAC equipment which is powered and does not come under the above categories.

## Part 1: Service provision

### Section 1: Contact information

- 1 Contact name: \_\_\_\_\_
- 2 Name of department/  
service/team (see glossary A): \_\_\_\_\_
- 3 Address: \_\_\_\_\_
- 4 Email address: \_\_\_\_\_
- 5 Service contact email  
address (if different from above): \_\_\_\_\_
- 6 Telephone number: \_\_\_\_\_
- 7 Service contact telephone  
number (if different from above): \_\_\_\_\_

### Section 2: Service information

- 8 Name of employing organisation  
(e.g. Sheffield Teaching Hospitals  
NHS Foundation Trust, Derbyshire  
County Council): \_\_\_\_\_

- 9 How is your service commissioned?  
Please indicate the proportion of funding provided by each organisation using a percentage:

	%
Primary Care Trust (PCT)	
GP consortia	
Regional specialist commissioning group	
Local educational authority	
Social care	
Charity	
Other (please state):	

- 10 We want to identify specialist services and services with AAC integrated into them. In order to help us identify this, please indicate the approximate percentage of time your service spends providing services for AAC.

- ☐ Less than 10%
- ☐ 10-29%
- ☐ 30-59%
- ☐ 60-90%
- ☐ over 90%

- 11 How many people do you provide services for AAC to? Please indicate the following:

a number of people on your current caseload using AAC

b the number of new people seen in the past twelve months (now) using AAC

and

c the number, if any, seen in the past twelve months who do not currently use but who could benefit from using aided AAC.

Please estimate if you do not have exact figures and indicate how you got the figures:

- ☐ Estimates from my experience
- ☐ Estimates based on having previously extracted this data
- ☐ Data extracted from a database
- ☐ Other

	a. Caseload	b. In past 12 months	c. Do not use but could benefit from using this type of AAC
Total			
Unaided AAC			
Aided (low tech only)			
Aided (high tech)			

- 12 Are those who do not use but could benefit from AAC referred on to another service?

- ☐ Yes (please state which service):
- ☐ No (please state reason(s) why):

- 13 What is the geographical area covered by your service?

- 14 Who do you provide services for? (Please choose all that apply)

- ☐ All age groups
- ☐ Pre-school age
- ☐ Primary school age
- ☐ Secondary school age
- ☐ Further education
- ☐ Adults
- ☐ Other (please state):

15. What is the location of your service provision?

	Frequent provision	Infrequent provision	Never
Healthcare settings			
Education establishments			
Person's own home			
Residential care			
Day care settings			
Other (please state):			

16 Please list the members of the team providing AAC by job title, their whole time equivalent (WTE) and indicate whether they have specialist skills in AAC.

[illegible]

### Section 3: Access

17 Do you have any eligibility criteria for access to your services for AAC?

☐ Yes (please state criteria):

e.g. types of people seen, conditions, geography, funding

☐ No

18 Who do you accept referrals from to access services for AAC?

	Frequently	Infrequently	Never
Self-referral			
Family/conversation partner of individual			
Speech and language therapist			
Occupational therapist			
GP			
Teacher			
Social worker			
Other healthcare professionals (please state):			
Other education professionals (please state):			
Other social care professionals (please state):			
Other services for AAC (please state):			
Anyone			
Other (please state):			

19 Please rank the top 10 primary conditions of those listed below of people who you see most frequently in your service who use AAC or aided AAC (where 1 is most frequently seen).

Rank 1-10		
Condition	AAC	Aided AAC
Multiple sclerosis		
Motor neurone disease		
Parkinson's disease		
Dementia/Alzheimer's		
Other progressive neurological disorders		
Stroke		
Head injury		
Other non-progressive neurological disorders		
Head/neck cancer		
Autistic spectrum		
Other learning disabilities		
Cerebral palsy		
Physical disability		
Specific language impairment (including dyspraxia Progressive neuromuscular disorders		
Sensory impairment		
Genetic disorders		
Other (please state):		

The following sections are only to be filled in by services who provide for people using aided communication.

Section 4: Care pathway

- 20 Is there a documented care pathway for AAC in your area?
- ☐ Yes
- ☐ No

21 Please indicate how your service provides the following (see glossary B):

For individual people:	Service provides	Service has access to (please state which service and how in the box)	Service does not provide	Comments (e.g. criteria for using own service facilities or accessing other services?)
Identification of need for AAC				
Information/ advice for AAC				
Training for people who use AAC				
Training for conversational partners				
Training for professionals working with AAC				
Follow up AAC reviews				
Ongoing support for people who use AAC				
Assessment for aided communication				
Loan trial of equipment				
Long term provision of equipment				
Repair of equipment				
Positioning and mounting of equipment				
Replacement of equipment during repair				
Maintenance of equipment				
Equipment Customisation (software)				
Equipment Customisation (vocabulary/content)				
Equipment Customisation (hardware)				
Creation of low tech resources				
Custom manufacture				

For service

Equipment management

Recycling of equipment

Research and development into AAC

22. Do you have any other links with services not listed above?

- ☐ Yes (please state who and the reason or use for the links):
- ☐ No

23 Are there procedures in place for when people transfer out of your service but still use or require aided communication?

- ☐ Yes (please state):
- ☐ No

24 Is your service involved in any social or participation groups for people who use AAC and their communication partners?

- ☐ Yes (please state):
- ☐ No

## Section 5: Skills and resources

25 How many days of AAC training from each of the following have your staff received in the past twelve months? (Please give a number on average per staff member)

	Days per staff member
AAC suppliers	
Accredited training	
Self-directed learning	
Within team	
Conferences/exhibitions/events	
Other (please state):	

26 Does your service provide or have access to a loan bank or library of equipment? (Please choose all that apply)

- ☐ Yes – within service (go to Q27)
- ☐ Yes – from other sources outside of the service (please state):

Go to Q29 if this is the only answer selected)

- ☐ No access to any loan equipment (go to Q31)

27 Please list below the number of high tech communication aids that your service currently has available for loan (see glossary C):

	Total
Medium to large sized communication aids (with displays and large output vocabulary)	
Small or hand held communication aids (with displays and large output vocabulary)	
9 or more message communication aids (with static overlays)	
1-8 message communication aids (with static overlays)	
Other	

28 Do you have access to funding for equipment for loan bank or library items via your service budget?

- ☐ Yes (please state total amount available per year for loan bank equipment):
- ☐ No

29 Please indicate which sources have been accessed for funding loan bank or library equipment and the cost over the past twelve months:

Funding source	Amount
NHS	
Local authority	
Charities	
Private purchase	
Other (please state):	

30 How sufficient is the content of the loan bank for you to deliver your AAC services?

- ☐ Insufficient – limited range or size
- ☐ Satisfactory – items are usually available
- ☐ Sufficient – never have a situation where an item cannot be loaned

31 Do you have access to funding for equipment for long-term use by a person on your caseload via your service budget?

- ☐ Yes (please state total amount available per year for long-term equipment provision):
- ☐ No

3 Please indicate which sources have been accessed for funding equipment for long-term use by people on your caseload and the cost over the past twelve months:

Funding source	Amount
NHS	
Local authority	
Charities	
Private purchase	
Other (please state):	

33 In general, when you buy equipment do you also buy the following?

- ☐ Installation
- ☐ Warranty
- ☐ Planned preventative maintenance
- ☐ Equipment refresh

34 Does your service use facilities for remote service delivery for example videoconferencing and or other methods?

- ☐ Yes (please state which videoconferencing or other system(s) you use):

(Go to Q35)

- ☐ No (Go to Q37)

35 How frequently are the following delivered remotely?

	Never	Less than once per month	Approx- imately once per month	2-3 times month	More than 3 times per month
Assessment					
Training					
Review					
Ongoing support					
Staff meetings					
Staff case conferencing					
Other (please state):					

36 Are the remote delivery facilities accessible by people who use AAC on your caseload?

- ☐ Yes
- ☐ No

37 Does your service follow documented guidelines or written guidance for best practice for any aspect of your provision of services for AAC?

- ☐ Yes (please state what is used):
- ☐ No

38 Do you know of any other AAC Services in your area that we should be contacting as part of the project?