

The Development of Quality Indicators for Alternative and Augmentative Communication

Final Report

December 2013

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**The study was commissioned and funded by NHS Education for
Scotland**

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NHS Education for Scotland: Report Introduction

In June 2012 the Scottish Government published “A Right to Speak: Supporting Individuals who use Augmentative and Alternative Communication”. This report outlined a vision for Scotland as a place where:

“Individuals who use augmentative and alternative communication (AAC) are included, free from discrimination, and live in an environment that recognises their needs and adapts accordingly” (Scottish Government, 2012: 10)

In order to achieve this vision eight recommendations were made, each of which is about something that needs to happen to help make sure that people who use AAC can:

- Be fully included in society
- Have equal access to AAC services
- Get access to AAC equipment when they need it

NHS Education for Scotland (NES) was identified as a key partner in facilitating the delivery of the education, training and development aspects of the report. As such, NES was responsible for commissioning a range of research projects which contribute to the delivery of the recommendations contained in the report. This report relates to one of the four research projects NES commissioned in the financial year 2012-2013. Together these research projects contribute to the delivery of action 1.1 of the report which is “Develop a National AAC Research Strategy” (Scottish Government, 2012: 3).

During the final year of the project NES will be funding further research as part of its work to improve provision for individuals who use AAC in Scotland. NES intends to use the findings of this and the other three research projects commissioned in 2012-2013 to inform and define future research needs. The findings from this report will also be used to support the development of the core values, commitments and AAC specific knowledge and skills described in IPAACKS.

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Overview and summary: *The Development of Quality Indicators for Alternative and Augmentative Communication June 2013*

Talking Mats was awarded funding by NHS Education for Scotland (NES) to conduct research aimed at developing quality indicators in relation to Alternative and Augmentative Communication (AAC) services. The objectives of the project included the achievement of several recommendations made in the Scottish Government's Right to Speak: Supporting Individuals Who Use AAC' Guidance. In particular, the project focused on recommendation 8.2 of the Right to Speak which states that "*local indicators are to be developed by local partnerships and national services*".

Talking Mats worked with Capability Scotland's Disability Equality Associates (DEAs) to gather the views and experiences of AAC users across Scotland about the services they access. In particular, the team aimed to find out what aspects of AAC services were particularly important to AAC users and their families.

Existing statements of good practice (which had been developed by Communication Matters in 2011) were used as a starting point from which to develop materials and questions to allow AAC users across Scotland to engage meaningfully in the project. The existing Communication Matters statements were subdivided into three categories; *people who work with me, how information is provided and the process (how AAC services work)*. These categories were then used to develop survey questions and communication support materials which were used to gather views from a wide range of AAC users. Once materials had been developed, engagement took the form of:

- An electronic survey gathering the views of 27 AAC users and their families;
- Four focus groups with a total of 25 AAC users, including both adults and children;
- 12 face to face interviews with AAC users and their families across Scotland.

The findings of this engagement, as well as the observations of Talking Mats team and the DEAs have resulted in recommendations in relation to the development of indicators of good practice for AAC services in Scotland. We have used pseudonyms throughout this report in order to maintain participants' anonymity.

Quality Indicators for AAC services in Scotland

The objective of the project was to identify potential quality indicators in relation to AAC services in Scotland. Ten specific quality indicators were identified, each relating to the three categories from the original Communication Matters quality statements.

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A. People who work with me:

1. Training: AAC users and their families highlighted the importance of being provided with high quality training on using and understanding their AAC systems. Many believed that training should be provided at an individual level as well as within their own and the wider community (for example in respite and in their local communities).

“It’s easier with my Mum and Dad...when I’m out people don’t understand me”.
(Focus Group)

“It’s really important that my sons and the nurses who come in to look after me understand my machine.”
(Interview)

“Well my son is just a child and in his life people just turn up and do things”
(Interview)

“Everyone is an individual and Language is ever changing. AAC has to be able to change to meet daily needs.”
(Survey)

“it’s more important to have one single point of contact who deals with his AAC.”
(Interview)

2. Values: AAC users and their families believed that it was important for AAC professionals to understand, know and value them so that their views could be taken into account when decisions about AAC were made.

3. Being put in touch with other AAC users:

AAC users and their families in remote settings indicated that at times they felt isolated. Most people agreed that they should be given the opportunity to have contact with other AAC users.

B. How information is provided:

4. Information about the AAC team:

AAC users and their families felt that it was important to be given information about who was working with them, and what each professional’s roles and responsibilities were. Many agreed that having a named AAC keyworker would be helpful.

5. Information about timescales, the assessment and funding process:

AAC users thought it was important that they be kept informed about their plan, how long things would take and how their AAC would be funded.

6. How information is shared:

AAC users and their families felt that their information should be treated confidentially, but also believed that at times it would be important and necessary for AAC professionals to share information with each other.

7. How information is presented:

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AAC users and their families felt that information should be provided in a format accessible to them.

C. The process (How AAC services work)

8. Equal access to funding and services: AAC users and their families felt that there should be equity of access to funding and provision of AAC, regardless of where they lived, age or health condition.

9. Access to equipment and expertise: AAC users and their families felt that they should have access to AAC professionals who had the right knowledge and skills, and that local services should be able to access advice and training from regional specialist centres. They agreed that there should be access to a range of equipment which should be available during assessment and when an individual's AAC system breaks down.

10. Ongoing support: AAC users and their families felt that it was important that they were provided with on-going support from AAC professionals, particularly at times of transition (e.g. between school/adult services; between AAC systems). They also felt that AAC professionals should work together across agencies.

Increased risk factors

In addition to these quality indicators endorsed by AAC users, Talking Mats and Capability Scotland staff made several observations relating to risk:

a. Adults living in residential care appear to have less communication support and less access to high tech equipment than those living with their family or independently in the community. Discussion with AAC users, their families and staff suggested that this was in part because of uncertainty as to who has legal and financial responsibility for ensuring an individual's communication support requirements are met. Individuals who live with or who have close contact with family members appear more likely to have access to suitable AAC support. This may be as a result of the fact that family members play an important role in advocating on behalf of the individual and, where necessary, fundraising to pay for high-tech devices.

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“Joe has no other means of communication when his Lightwriter isn't working. He doesn't even use an alphabet board to communicate.”
(Focus group)

“Being in a remote location it might be unrealistic to have a local service, but strong local knowledge is brilliant, with the support of national service” **(Survey)**

“David told the group that he had his new Pathfinder in the house for three months before he really knew how to use it properly.”
(Focus group)

“It's important that the people I work with can understand what I'm saying and this takes a while to develop”
(Interview)

“Karen said that it was really important to her that her Talker was purple, because that is her favourite colour.”
(Focus group)

I'm going to respite this weekend and I'm worried people won't understand me”.
(Focus group)

“Freda explained that her Dad had had to pay for her communication device because the NHS felt they did not have responsibility.”

(Focus group)

“Sarah is the only person in her day centre or area with AAC needs and she is very isolated. Although meeting other AAC users is one of the highest importance this isn’t happening for Sarah as she is the only person in the area using AAC and therefore is very isolated and shunned by others at her learning disability day centre.”

(Interview)

“My machine cost over £6,000. Despite the cost I’m luckier than some people. An SLT helped me get funding for my machine. Some people have to pay and that isn’t right

(Interview)

b. Adult versus children’s services: There appears to be disparity between the high standard of communication support enjoyed by children in specialist schools and the lack of such support at adult residential services. There is a concern this is the result of a lack of investment in adult AAC services, poor communication between health boards and service providers and poor coordination of the transition between children’s and adult services

c. Rural versus urban settings: AAC users living in rural areas appear to be at risk of feeling isolated. They would benefit from opportunities to meet other AAC users. This group valued access to national AAC services which provide support for local AAC specialists.

We recommend that consideration is given to the development of a toolkit which allows services in contact with AAC users to assess and improve their own performance in relation to the identified Quality Indicators.

1. Background

In June 2012 The Scottish Government published “A Right to Speak”. This report recognised that people who use Alternative and Augmentative Communication (AAC) access a range of services including those from health, social care, education, employment and the voluntary sector. The report made eight recommendations about what needs to happen to ensure that people who use AAC can:

- Be fully included in society
- Have equal access to AAC services
- Have access to AAC equipment when they need it.

This project was commissioned by NHS Education for Scotland (NES) and will contribute in part (along with three further research projects funded by NES) to the delivery of action 1.1 of the report (*“Develop a National AAC Research Strategy”*). It will also contribute to delivery of action 8.2 (*“Local quality indicators to be developed by Local Partnerships and National services and to be monitored by appropriate agencies including the Scottish Government”*).

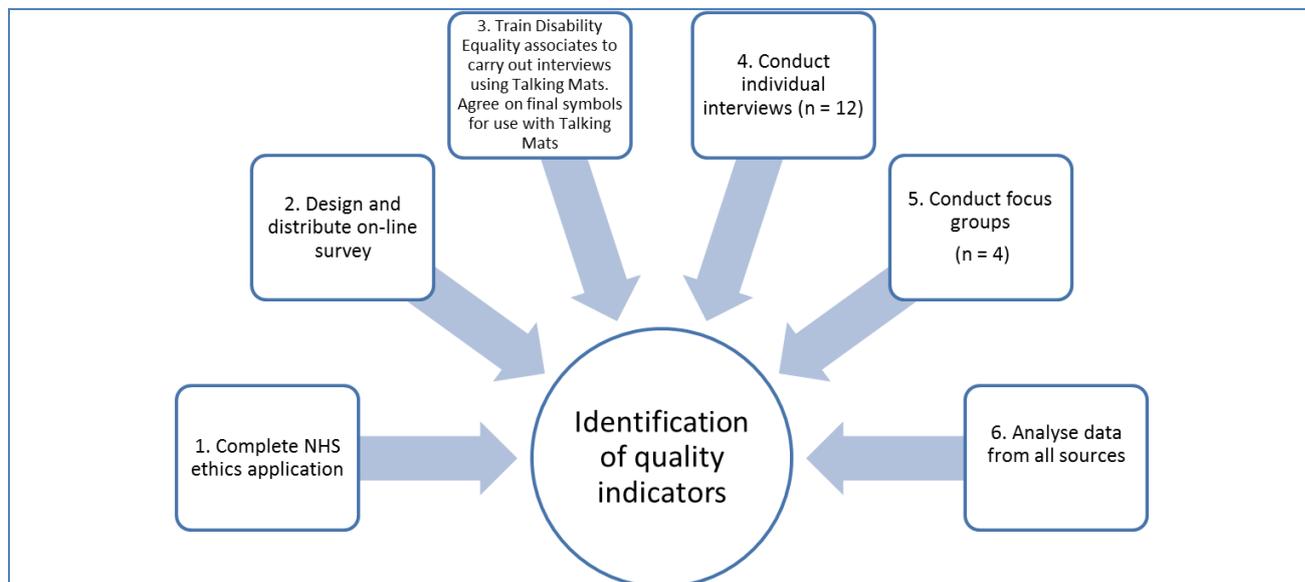
Communication Matters (CM) published a report on Quality Standards for AAC services in 2012. This is a piece of work which originally began in 2007 and involved consultation with AAC users, their families and professionals. This national document provides an overview of what AAC users have the right to expect from AAC services and provides service providers with a benchmark for measuring the quality of their services. The CM consultation was conducted predominantly with AAC users who attended the annual National AAC conference held by Communication Matters. These AAC users tend to be a particularly active group of well-informed AAC users. The consultation work done by CM resulted in the development of 42 quality statements. We have used these as a foundation for consulting a wider group of AAC users in Scotland and have endeavoured to widen the opportunities for people who use AAC but who do not necessarily actively participate in national AAC networks, to express their views about AAC services. We have used a novel approach to this service evaluation, working in partnership with adults who have a disability, who have shaped the project and conducted interviews and focus groups. The benefits and barriers which we have encountered in using this approach are discussed in section 3.1.

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Figure 1 shows a summary of the phases of this project.

Figure 1 Overview of the project



2. Aims

To develop, in partnership with individuals who use AAC, a set of quality indicators relating to the AAC service in Scotland. Our specific objectives were:

- To establish whether the quality statements, identified through the work of Communication Matters, fit with AAC service user's views of what an AAC service should look like in Scotland.
- To establish whether there are additional quality indicators which are of importance to Scottish AAC users and their families.

In carrying out this project, we endeavoured to:

- Engage with a broad cross section of individuals who use/have used AAC, and their communication partners.
- Offer a range of response options (online survey, individual interviews, focus groups) in order to collect views using an individual's preferred method.

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3. Design

3.1 Partnership working

We worked in partnership with Capability Scotland's DEAs, who are skilled in working with a range of disabled people during consultation events. Carrying out user-led consultation provides an equal and authentic consultation and provided AAC users with the opportunity to provide honest feedback on an equal footing. Our partnership with the DEAs added a significant value to the project. The benefits of co-production as outlined by the Department of Health (2011) include:

- access to first-hand experience of disabled people;
- publicly demonstrating the value placed on the views of customers;
- creating credible relationships by working together to identify solutions to difficult problems.

The DEAs are employed on a sessional basis by Capability Scotland to carry out audits and present to groups. Each DEA attended two training sessions where they received training in the use of Talking Mats and had the opportunity to shape the wording of the interview questions, as well as comment on the images. This was very valuable as it provided us with a different perspective and made us think about our use of language and choice of images. Prior to conducting the project, some people had expressed concern about disabled people interviewing AAC users, but in practice, interviewees clearly valued being interviewed by people who had a shared understanding of their situation.

3.2 Consulting people with communication difficulties

Consulting people who have communication disability is inherently difficult, and this group of people are often left out of research and consultations (Cameron and Murphy 2007). In order to include people with a wide range of communication disabilities, we developed a range of communication supports. Interviews and focus groups were structured so that, if people had no formal method of communication, they could at the very least, express their views using Talking Mats. This format allowed people to expand and comment on specific issues if they were able to.

4. Methods

Given that we wanted to reach as wide an audience as possible, we used three different methods to collect our data:

1. *Online survey*

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The online survey was aimed at AAC users who could access a computer and had literacy skills. It could also be completed by parents and carers of AAC users. We hoped that, using this method we would be able to access the views of people who might not be well enough to attend interviews or focus groups, for example, people with Motor Neurone Disease (MND) and Multiple Sclerosis (MS).

2. *Individual interviews*

The DEAs conducted individual interviews using the Talking Mats framework with a total of 9 AAC users and 3 families of AAC users. Hanna McCulloch from Capability Scotland was present at each interview except one so that detailed field notes could be written. After each interview, both the interviewer and Hanna debriefed and wrote and agreed on notes.

3. *Focus groups*

Four focus groups were conducted in Capability Scotland establishments. Each group was facilitated jointly by one member of the Talking Mats team and a DEA. Communication supports were prepared in advance to ensure that all members could participate to the best of their abilities.

5. Procedure

The project is outlined in the five phases below.

5.1 Phase one: Ethical approval

Prior to starting the study, we developed all project documentation and liaised with appropriate Research Ethics Committee and Research and Development departments to obtain appropriate ethical approvals. Initial discussions with East of Scotland Research Ethics Committee (EoSREC) indicated that the project might be considered a service evaluation. In order for this to be assessed, the following documents were prepared and submitted to EoSREC on the 14th of Feb to for their consideration:

- Protocol
- Patient information sheets – individual/focus/online
- Consent forms (appendix 2)
- Advertisement and invitation to participate

On the 12th of March we received a reply from the EoSREC stating that this project did not fall under the remit for the Governance arrangements for Research ethics committee, provided that we were not recruiting NHS patients and we were not interviewing on NHS premises (appendix 1). Whilst we were happy that we were not planning to do the former, we felt that we would be recruiting for the individual interviews through the NHS, so we

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sought further clarification. The response to this query was received on the 13th March: *'Although you are recruiting participants through NHS contacts you are not recruiting NHS patients, this being the case I don't think you require an amended letter'* and provided confirmation that this is a service evaluation. We proceeded with the project on that basis.

5.2 Phase two: Question design and development of communication supports

We completed an in-depth analysis of the Quality Statements which had been developed by Communication Matters. This involved consideration of how these statements would be perceived and potentially discussed by AAC service users. The Quality Statements were developed with input by people who use AAC but we had significant concerns about making them accessible to people who use a range of AAC systems. These concerns related to:

- The complexity of vocabulary and language used e.g. *'demonstrably impartial services'*
- The professional slant of the concepts used *'I can expect referrals to be made in a timely manner with comprehensive information provided as agreed in my local team care pathway planning process'*
- The overlap of the concepts used: Quality statement 4 *'I can expect the professionals working with me to share information, knowledge and skills'*; Quality indicator 5 *'I can expect professionals working with me to communicate effectively with each other for my best interest'*.

When we looked in detail at the Communication Matters report, it was difficult to translate the Service Quality Statements into questions which could be used in a survey or in interviews and focus groups which would be accessible to people with communication support needs. In order to do this, we carried out the following process:

1. Each Service Quality Statement was read and put onto a mind map.
2. We began to group questions under categories and identified any duplicate questions. At this point we also simplified the language used.
3. Three main categories were identified: 'People who work with me'; 'Information provided' and 'Process (how AAC services work)' (Table 1).

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Questions for Survey, interviews and focus groups – Mapping from CM Quality Statements

Table 1 Main categories from Service Quality Statements (Communication Matters)

1. People who work with me	2. Information provided	3. Process (How AAC services work)
1a. Know about me	2a. Outcomes of assessment and plan for implementation	3a. Stick to a care pathway
1b. Keep up to date with AAC and have access to training	2b. In a way that I can understand	3b. Gaining funding
1c. Know about AAC	2c. Who is who and contact details	3c. Local services
1d. Work as part of an AAC team	2d. named person/keyworker	3d. National services
1e. Talk about me to other members of the team	2e. Timescales	3e. Provide long-term support
1f. Take my preferences into account	2f. Funding	3f. Access to a second opinion
1g. Have time for me	2g. My care pathway	3g. Clear about when to refer on
1h. Put me in touch with other AAC users		3h. Work with Health, Education and Social work
1i. Involve me in decisions		3i. Provide trial equipment
1j. Involve me in target/goal setting		3j. Access to a range of equipment
1k. Look at my needs regularly		3k. Early introduction to AAC
1l. Provide training for me		3l. Clarity about who is keyworker
1m. Provide training for my family		3m. AAC is adapted to suit my needs
1n. Provide training in my wider environment		3n. Equal access to Assessment and intervention
1o. Check they have my consent to work with me		
1p. Work on their own		

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The Service Quality Statements were then cross checked against each of the above statements/ideas, to make sure nothing was missed out (Table 3, Appendix 2).

This ground work formed the basis for the development of the questions for the on-line survey, focus groups and individual interviews. During discussions with the DEAs, we further refined the wording of questions and agreed which concepts were abstract or concrete. This was important to ensure that we could select appropriate questions for participants during interviews and focus groups, depending on their cognitive abilities.

In addition to this, we spent a session discussing the topics with Janet Scott from the Scottish Centre of Technology for the Communication Impaired (SCTCI), who was leading on a competencies education project. During this discussion we found that some important issues such as confidentiality and support when AAC breaks down were missing from our topic sets. We also agreed that it was important to ensure that issues such as assessment and support were included. We spent some time discussing national versus local services as, currently, national services (such as those provided by CALL and SCTCI) are provided in people's local area. We felt that we would need to phrase our question to reflect the level of expertise provided by different types of service.

At the end of this process we developed a set of questions under the three categories: 'people who work with me'; 'information provided' and the 'process (how AAC services work)'. We made symbols to represent each question so that they could be made accessible to people using AAC and be used with Talking Mats for the individual interviews (see Appendices 3 and 4). These were piloted with DEAs during their training (see section 5.4). These questions were used as the basis for all parts of the evaluation (i.e. the survey, focus groups and individual interviews).

5.3 Phase three: Survey design

We designed an on-line survey using the questions identified through the process described in section 5.2. We used Survey Monkey and distributed the survey through the national AAC leads as well as contacts and networks developed through Talking Mats and Capability Scotland. We also used social media (Facebook and Twitter) to publicise the survey as widely as possible. AAC users and their families and carers from all over Scotland were encouraged to complete it.

5.4 Phase four: Individual interviews

Four DEAs from Capability Scotland were trained as Talking Mats interviewers. Each DEA attended two half day training sessions. During the training, the interview questions were further refined and participants were given the opportunity to practice asking the interview questions using Talking Mats. By the end of the sessions, all participants were confident that they would be able to use Talking Mats as a method of interviewing a range of AAC users.

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Participants for the individual interviews were recruited through Capability Scotland's networks as well as the AAC leads. We aimed to recruit a range of participants representing different regions in Scotland and a range of aetiologies.

5.5 Phase five: Focus groups

Resources and questions for the four focus groups were devised in collaboration with the DEAs. Questions were based on a sub set of statements outlined in section 5.2.

6. Participants

The three different methods allowed people to participate from a variety of backgrounds and locations, including more remote parts of Scotland. We have been able to collect the views of AAC users and families from all Scottish health boards apart from Dumfries and Galloway, Grampian, and Orkney. We have used pseudonyms throughout this report in order to maintain participants' anonymity.

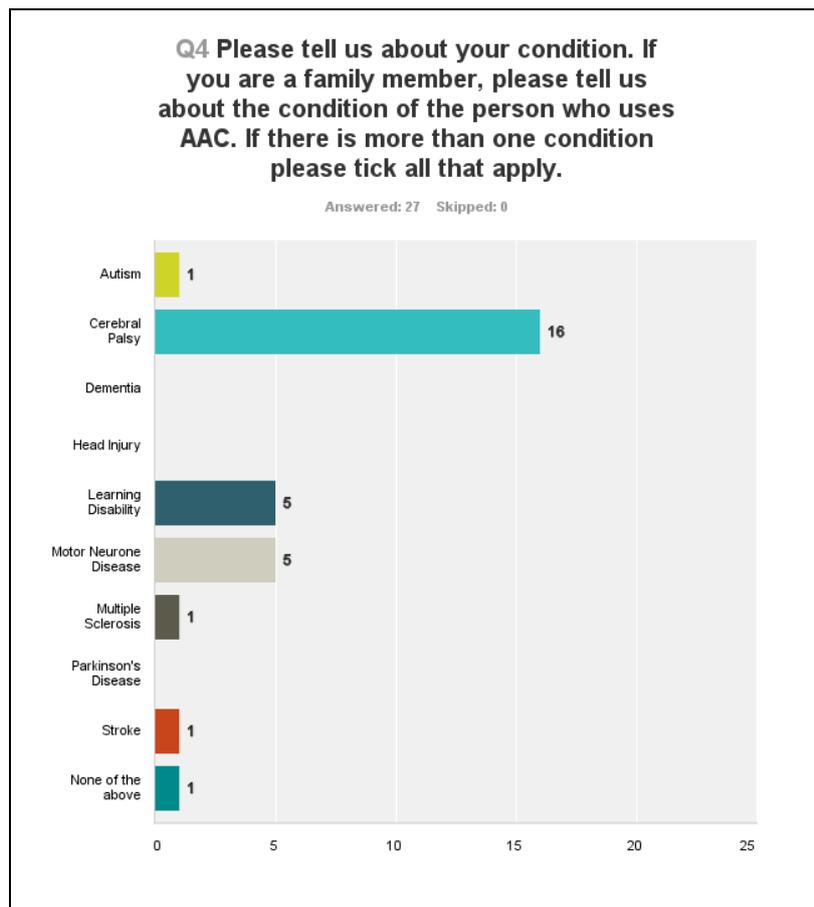
6.1 Survey participants

A total of 27 people completed the survey. 19 respondents were AAC users and eight were parents or carers of AAC users. Answers were written by or on behalf of four children. All Scottish healthboard areas, apart from Dumfries and Galloway, Grampian, Highland and Orkney were represented. People who responded had a range of conditions (Figure 2).

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Figure 2 Conditions of participants



The majority of respondents had cerebral palsy, and none had dementia, Parkinson's Disease or a head injury. This fits with recent research (Communication Matters 2013) which found that low numbers of people with head injury currently benefit from AAC. The research also reveals a discrepancy between the numbers of people with dementia and Parkinson's Disease who could benefit from AAC, compared to those who were actually using it.

The numbers who responded to the survey are small, so it is not possible to carry out meaningful statistical analysis. However, the purpose of using survey methods was to provide an opportunity for AAC users who were unable to take part in focus groups or interviews to express their views about AAC services in Scotland. With this aim in mind, we designed the survey so that people could answer questions using free text as well as standardised answers.

6.2 Individual interview participants

Twelve AAC users and their families were interviewed (table 2)

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Table 2 Interview participants

AAC users		Carers/families
Children	Adults	
1	8	3

The majority of people interviewed had cerebral palsy (n= 8), but we also interviewed the family of a child with autism and someone with aphasia.

6.3 Focus group participants

Four focus groups were conducted in a range of Capability Scotland's residential establishments. Two were conducted with children and two with adults. A total of 25 people took part over the four focus groups. All of them had cerebral palsy and the age range of participants was 11 to 65. The reason why all participants from this group had cerebral palsy was because we were recruiting from Capability Scotland's service users, who are predominantly people with cerebral palsy.

The cognitive and communication abilities of participants varied. Prior to asking the questions about AAC, we ensured that participants understood the concepts of 'AAC' and 'importance'.

7. Data analysis

Data from the survey, focus groups and interviews were organised into themes using Framework analysis (Framework). This type of analysis is particularly relevant to healthcare research where data is being gathered from a variety of sources (Lacy & Luff 2001).

The key stages of Framework analysis are outlined below:

- Familiarisation
- Identifying a thematic framework
- Indexing
- Charting
- Mapping and interpretation

(Lacey & Luff 2001:11)

Data from each source was originally analysed separately. Similar themes emerged from each source, so we report on the data as a whole, using examples from different sources to illustrate points which arise.

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8. Findings

We report on findings under the three categories, corresponding to the questions we asked: *people who work with me; information provided* and the *process* (how AAC services work). We use direct quotes, when available from all three data sources.

8.1 People who work with me

Comments about what AAC professionals should provide were grouped under three themes: *training; values and what AAC professionals do*.

Training (Quality Indicator 1)

All participants felt that the people who worked with them should provide training at different levels. Firstly, everyone agreed that AAC professionals should spend time teaching them how to use their AAC devices:

“If a person does not know how to work their AAC aid then the speech therapist isn’t doing their job” (Interview 8)

Participants appeared to value input from AAC professionals and felt that it was important that they received individual training in the use of AAC.

Participants also felt that training should be provided for family and friends, although not everyone agreed that this was as important as individual training:

“someone has to learn and then they are the person that tells the others - family user is less important than the main user” (Interview 1)

Focus group participants (focus group 2) unanimously agreed that it was important for friends and family to be provided with training to help them understand and know how to use their equipment. Participants in focus group 1 clearly benefited from being in a ‘total communication’ environment where everybody appeared to know how to use their AAC. Throughout the session, their support workers actively encouraged use of AAC and provided appropriate communication supports to help both understanding and expression.

The issue of training for the wider community promoted much discussion among focus group participants, particularly one of the school aged groups. One participant commented that she found it was easier to use her AAC with familiar people

“I can use my machine with nice people” and “It’s easier with my Mum and Dad”. She then went on to say, “When I’m out people don’t understand me”.

Another commented:

“it’s easier to use AAC in school.”

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The importance of providing training for staff in respite was raised, and this was an important issue for all participants in focus group 2:

“I’m going to respite this weekend and I’m worried people won’t understand me”. She then explained this is her first weekend at a particular respite centre and she is anxious that people won’t understand what she is saying. (participant from focus group 2)

Participants in focus group 4 agreed that people in the local community should have an awareness of using AAC, and one participant said that she thought it would be easier to go out and do things if people such as shopkeepers could understand what she was saying.

Values (Quality Indicator 2)

Participants in focus groups, interviews and the survey all agreed that it was important for AAC professionals to listen to their views:

“If they don’t hear what you are trying to say they won’t know you as a person.” (Interview 8)

They also thought that AAC professionals should involve them in the decision making process when working with them. This included target setting:

“somebody has to have awareness of what is realistic in time scales and help you set realistic targets” (Survey respondent)

One participant commented that AAC professionals should be flexible and, as part of valuing individuals, should have the scope to work flexibly them:

“We found that SLTs can get locked into a way of doing things. This is done here.” (Interview 1)

Another participant commented about the importance of working with AAC professionals who knew them:

“They can’t provide for your needs if they don’t know you” (Survey)

Being put in touch with other AAC users (Quality Indicator 3)

Participants were asked if they thought it was important for them to have the opportunity to meet other AAC users. This met with a variety of responses. Some people thought this was very important:

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“We live on a remote island with few AAC users. Opportunities to attend conferences and parent groups provided essential networking and learning and friendship”
(Survey)

For some this isolation could present real challenges for example the carer of one person who was interviewed from a remote rural location commented:

“Sarah is the only person in her day centre or area with AAC needs and she is very isolated. Although meeting other AAC users is one of the highest importance this isn’t happening for Sarah as she is the only person in the area using AAC and therefore is very isolated and shunned by others at her learning disability day centre.” (Interview 12)

Others felt meeting other AAC users was less important:

“It’s good for Paul to have friends but how they communicate isn’t necessarily important. It is good for Paul to know that he’s not the only person who is a bit different though.” (Interview 5)

8.2 Information provided

Comments about information have been categorised under four themes: *information about the AAC team; information about timescales, assessment and funding; how information is shared and how information is presented.*

Information about the AAC team (Quality Indicator 4)

Participants felt that it was important to have information about the AAC professionals who were working with them. A key worker was seen as an important person who could coordinate services:

“There are always so many different professionals involved in all aspects of AAC users – who is going to drive forward the AAC development. Who can you work with?”
(Survey)

Some alluded to confusion about the roles and responsibilities of different professionals:

“Really need to know about roles and responsibilities – who does what – what does the teacher do, what does the SLT do and what does the parent do” (Interview 1)

In this case there was agreement that having an identified keyworker would help people to navigate their way through services. This was particularly important for the parents of a child with autism:

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“This is particularly important to Paul because he likes to know who everyone is. This is related to his autism.” (Interview 5)

Focus group participants were less concerned about having a keyworker to promote the importance of AAC, but in one of the establishments that we visited, there were two people who had hi-tech AAC systems. One person had very strong family links, and he had an up to date lightwriter which was in good working order (his support worker reported that his family had a strong role in ensuring that his AAC was kept up to date). The other had a lightwriter that was over 12 years old. It had been broken for at least a year. He did not appear to have anyone advocating for his need to have a formal method of communication, and relied on informal gestures to get his message across. One of our observations was that it may have been helpful for this individual to have a named keyworker to coordinate his AAC provision.

Information about timescales, the assessment and funding process (Quality Indicator 5)

Participants appeared to be resigned to the fact that being assessed and provided with AAC was often a long, slow process:

“You kind of assume that everything will take a long time” (Interview 1)

However, there was also a level of frustration about time scales:

“time lost in politics, decision making, is time lost in learning how to use a method of communication and allow you the right to communication” (Survey)

Participants were clear that they should be given information about how long things were going to take so that they could make plans:

“That you should know how long thing will take. People who are disabled have to plan, therefore it is really important to know how long things will take.” (Interview 8)

In the focus groups, participants talked about some of their experiences of waiting for AAC and they felt that it was really important to be given information about how long they should expect to wait:

Sarah explained that when she was waiting for her current machine she used to ask staff every day when it would arrive. They could never give her an exact answer and this really annoyed her. She agreed that it was important for people to be told exactly when they were going to get their equipment delivered. (Focus group 2)

There was agreement between participants that they should be provided with information about how long things were going to take.

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Participants were asked whether or not they thought it was important to have information about their AAC care pathway. Only 52% of participants knew what this was, but those that were aware did feel that it was important that they were given information about this. However, one survey respondent pointed out that there should be flexibility around care pathways:

“If it’s working – have to be flexible and willing to change if not.” (Survey)

Participants perceived a variation across the country regarding funding for AAC. We discuss this in more detail under ‘how AAC services work’. Participants felt that they should be provided with information about funding so that, if necessary, they could raise funds themselves:

“funding can be a major problem and difficulty for many family. It has to be clear in case they need to have a fund rising drive. However, in order to maximise and develop communication – and to meet the communication needs of the user – funding should be an irritation, not an obstacle” (Survey)

“we had to fund our son’s own AAC as the one provided by our local NHS trust was unreliable” (Survey)

How information is shared (Quality Indicator 6)

Participants were asked whether or not they felt it was important for their information to be treated confidentially. Although they felt confidentiality was an important issue, there was also an awareness that at times, information should be shared, and that this might help to ensure that people were kept informed about what was happening:

“if you want to maximise and develop communication people need to know.”
(Survey)

“I don’t mind sharing of information if it helps him and helps people work together”
(Interview 1)

One participant also pointed out that at times it would be important for professionals to share information in order to protect individuals:

“Sometimes need to share info if someone is going to hurt themselves.” (Interview 8)

How information is presented (Quality Indicator 7)

Participants felt that they should be presented with information about funding, their AAC plans and timescales in a way that they could understand. It was acknowledged that this might mean that information would have to be adapted to suit the needs of individuals:

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“It has to be clear to the user and in a format they can understand. Also that the other family or support team can understand and share together.” (Survey)

Understandably, school age participants felt that information about funding was less important, perhaps because they may not have been involved in securing funding for their equipment.

One participant appeared resigned to the fact that her child did not always receive information about what was happening or who was working with him:

“well my son is just a child and in his life people just turn up and do things” (Interview 1)

Participants agreed that they should be kept informed about what was happening in relation to their AAC, especially if there were going to be delays in funding or if they would have to fund raise themselves. It was agreed that efforts should be made to make any information provided accessible to individuals.

8.3 The Process (How AAC services work)

Comments about the process and how AAC services work have been categorised under three themes: *Equality of access to services and funding; Access to equipment and expertise and on-going support.*

Equality of access to services and funding (Quality Indicator 8)

Participants believed that people should have equal access to AAC services, and funding for AAC, regardless of where they lived:

“it shouldn’t matter where you live or how much money you have there should still be the same access to services.” (Interview 5)

There appeared to be some variation regarding how or if people were able to secure funding for High-tech AAC systems. One participant described how securing funding had depended on a ‘lucky’ event and a good relationship with a member of staff who was in the position to influence budgetary decisions:

“we were lucky we had a really great SLT who saw the underspend and got it but not everybody is that lucky.” (Interview 1)

Other people were less fortunate and told us that they had to raise funds themselves. This seemed to be particularly true for people who lived in residential settings and had no family support to advocate for their needs. In both of the adult centres where we ran focus groups, participants and support workers told us that it was very difficult to access local speech and

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language therapy services, and that residents in these institutions did not seem to be able to access statutory funding for AAC:

Freda explained that her Dad had had to pay for her communication device because the NHS felt they did not have responsibility. It seemed that this is because Freda attends a centre run by a third sector organisation and, as a result, her speech and communication requirements are viewed as being the responsibility of that organisation's Speech and Language Therapists.

David then commented that it was easier to get a Pathfinder if you live 30 minutes away. When asked whether David meant that the quality of the service you get depends on where you live he said, yes, this is what he meant. (Focus group 3)

This seemed to be the case in the other adult residential care setting where we conducted a focus group, and the support worker confirmed that there were difficulties accessing local speech and language therapy services and funding for high-tech AAC.

Access to equipment and expertise (Quality Indicator 9)

Participants believed that during the process of being assessed for AAC, they should be given the opportunity to try equipment out before it was purchased. However, during one of the focus groups, one participant told us that in his case, having a trial of equipment had not been very useful because he needed his vocabulary and shortcuts programmed into his device in order for him to be able to explore its' full potential. Another participant in focus group 3 shared her experiences:

Janet was formerly a very effective LLL (Language Living and Learning, a Minspeak-based programme) user on her Delta Talker. She then moved on to a Vantage system. This was partly because her occupational therapist thought having a smaller device would give her a better range of movement. The new system had fewer keys than Janet was used to. Since getting her new device, Janet has found it extremely difficult to learn to use. It is particularly difficult for her to re-learn the placement of the buttons and how to access the correct 'layers' on the new system. As a result, Janet prefers to use her communication book or to spell words out on her hi-tech device. (Focus group 3)

The above example illustrates the importance of having a trial of equipment with the relevant programmes installed and over a realistic time scale, giving AAC users full experience of the benefits and draw backs of potential systems. It also highlights the importance of different professionals working together during the assessment process.

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Participants were asked if they felt it was important to have support when their AAC breaks down. Unsurprisingly, responses to this question depended on whether people used High or low-tech AAC systems. Those who used high-tech AAC felt strongly that they should be provided with support when their systems broke down:

“Who else can ‘give you a voice’. When positive work has been done to provide you with AAC, you are more disabled if it breaks down and you are left with nothing and unsupported” (Survey)

Discussion about support when AAC systems break down led focus group 3 to talk about funding for AAC repairs and extended warranty agreements. One of the participants told us that he had been in a dispute about who should pay for repairs. Fortunately, this had been resolved by his speech and language therapist who was an AAC specialist and managed to secure funding for a ‘rescue’ service which meant that he was provided with a replacement system whenever his AAC device broke down. A participant from focus group 4 used a lightwriter communication aid as his main method of communication. He indicated that it was very difficult for him to communicate when this broke down, as he did not have a system (such as an alphabet chart) to use as a back-up.

Discussion about having the opportunity to try out equipment led on to debate about the importance of having access to support when transitioning from one system to another. One participant told us that it had taken him three months to learn how to use his new system, and that he had needed lots of support during this transition phase. Participants in the focus group agreed that transitioning to new AAC systems was challenging and that in an ideal world they needed access to their old systems while they got used to their new ones. The support worker at the focus group pointed out that this was potentially difficult to do, given that often, new devices are not provided until an old one has stopped working.

Participants felt that any AAC system should be tailored to meet their needs and that systems they be flexible and have the potential to be adapted if necessary:

“Everyone is an individual. Language is ever changing. AAC has to be able to change to meet daily needs.” (Survey)

One participant told us that professionals did not always acknowledge that families of AAC users were often experts themselves:

“Services argue that you need to start on a low tech system as you will always need a back up system. What they don’t understand is that most families already have their back up systems established and it should not prevent the early introduction of technology”. (Interview 1)

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Participants in focus group 2 (a group of young people) had a lot of discussion about the importance of AAC being the right colour, shape and size as these excerpts illustrate:

Katie said that it was really important to her that her Talker was purple, because that is her favourite colour. All the other participants agreed and indicated that they had chosen the colour of their equipment and that this was really important to them. Robert gestured that he would have thrown away his Talker if he had been given a pink one. (Focus group 2)

Jane was also asked whether it important to her that her technology was light enough for her to carry around when she was walking rather than using her chair. She answered by saying '3', which had come to mean 'very important ' during the course of the session. (Focus group 2)

In addition to having access to the right kind of equipment at the right time, participants valued having access to professionals with the right expertise. People talked about their experiences of agencies working together and the importance of being able to call upon national services for advice:

"We have been referred several times to other professionals and agencies. It is helpful to local services, particularly in remote locations, to have the support and advice of others" (Survey)

Participants appeared to value the way that national and local services worked together, and could see the benefits of local AAC services working in partnership with national centres who could keep up with advances in technology:

"Being in a remote location it might be unrealistic to have a local service, but strong local knowledge is brilliant, with the support of national service" (Survey)

On-going support (Quality Indicator 10)

A strong theme from interview, survey and focus group data was the importance of having access to on-going support. People were aware that their needs would change over time and that they might need to be reviewed in light of this and because of advances in technology:

"In our particular case AAC support is lifelong. It has to be able to change according to the challenges and continuum of life. Also the quickly changing world of AAC in a modern technological age." (Survey)

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During the focus groups, we observed a striking difference in the level of support to use AAC available for adults compared to children. Within schools, all focus group participants had access to one or more AAC system, and support workers were readily available to support children to use them. In the adult establishments, very few participants had any formal AAC methods and relied on eye pointing, gesture and 'yes'/'no' responses. Several participants were unable to communicate with us independently because their AAC systems were not available or they were broken. One participant commented that he felt he had had access to more support in using his AAC when he was at school compared to adult services. Other members of the group agreed that this was the case (Focus group 4).

Limitations

During this project we aimed to consult a wide range of people with communication disability throughout Scotland. We succeeded in including people from all Scottish health boards apart from Grampian, Dumfries and Galloway and Orkney. However, we managed to consult with people from a range of locations, including the more remote parts of Scotland, and this has been useful in adding a different perspective to our findings. We endeavoured to consult with people with a range of aetiologies, but participants were predominantly people with cerebral palsy. Although this group represents only 4.5% of the UK population who could benefit from AAC, recent UK research (Communication Matters 2013) found that people with cerebral palsy appeared to make up *"the largest single user group of powered aided communication"* (CM 2013:18) and it was very likely that respondents in our study would include a large proportion of people from this group. Future studies could take account of this and try to actively engage with other types of AAC users (for example, people with MND and MS).

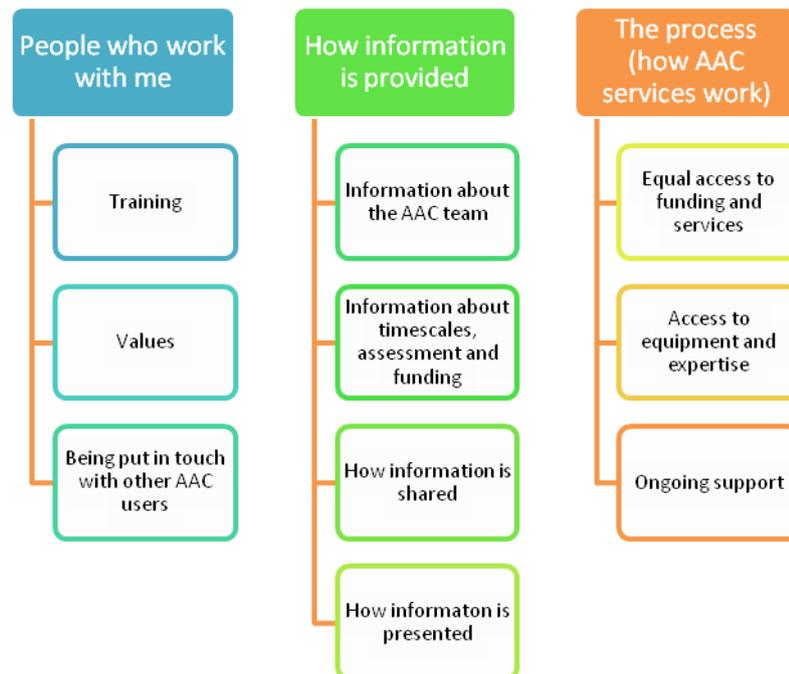
Recommendations

Ten Quality Indicators have been identified by the AAC users and families who took part in this consultation, which are summarised in figure 3:

Figure 3 Quality Indicators

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It is our recommendation that these should be taken into account in the design, delivery and evaluation of AAC services in Scotland. Recommendations should be considered at both service level (AAC service managers and providers) and strategic level (those who plan and commission services). Three main recommendations have arisen from the project:

1. We recommend that consideration is given to the development of a toolkit using the 10 Quality Indicators which have been identified in this project (pages 4-6). This will allow services in contact with AAC users to assess, reflect on and improve their own performance. For example, the Quality Indicators could be used to form the basis of annual service evaluation. Accessible materials, based on the 10 quality indicators, could be developed to enable service providers to consult with AAC users and their families about how they are performing in relation to the Quality Indicators.

Inclusion and involvement of AAC users themselves should be at the heart of any relevant toolkit. The toolkit should be fully accessible to accommodate the needs of people who use AAC and should provide a way of comparing the views of AAC users and service providers.

This toolkit should be linked to the AAC education and development framework (IPAACKS) and used as a resource to support development of core values, commitments and AAC specific strands.

2. Services should be aware that there are increased risk factors for AAC users, particularly at times of transition:

- a. between services (e.g. children/adult services)

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- b. between AAC systems
- c. between home and respite services

Services should make provision to provide support for AAC users in these situations.

3. This project identified several issues that require a strategic change and these need further consideration:

- I. The perceived post code lottery and the need for equitable funding across Scotland
- II. The inequity of service provision between child and adult services
- III. The increased risk for AAC users in rural areas of isolation has been highlighted and requires particular attention
- IV. It appears that being in residential accommodation without strong family support adds to increased risk for AAC users. This requires further examination, and if this is the case, should be addressed.

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Appendix 1

EoSRES

Research Ethics Service

East of Scotland Research Ethics Service (EoSRES)

Tayside Medical Sciences Centre (TASC)
Residency Block C, Level 3
Ninewells Hospital & Medical School
George Pirie Way
Dundee DD1 9SY

Mrs Morag Place
Talking Mats Centre
2 Beta Centre
Stirling University
Innovation Park
Stirling
FK9 4NF Scotland

Date: 28 February 2013
Your Ref:
Our Ref: **CYA/AG/13/GA/013**
Enquiries to: Mrs Caroline Ackland
Extension: Ninewells extension: 83839
Direct Line: 01382 383839
Email: Caroline.ackland@nhs.net

Dear Mrs Place

Re: The Development of Quality Indicators for Alternative and Augmentative Communication

You have sought advice from the Research Ethics Office on the above project. The Senior Co-ordinator and I have considered this and can advise that this does not require ethical review under the terms of the Governance Arrangement for Research Ethics Committees (GAfREC) in the UK. The advice is based on the following documentation provided:

Document	Version	Date
Emails	N/A	various
Protocol	1	14 February 2013
PIS – Focus Groups	1	14 February 2013
PIS- Online Survey	1	14 February 2013
PIS- TM Interviews	1	14 February 2013

- You are not recruiting NHS patients
- You are not using NHS premises

Please note that this advice is issued on behalf of the Research Ethics Service Office and does not constitute an opinion of a Research Ethics Committee (REC). It is intended to satisfy journal editors and conference organisers, who may require evidence of consideration of the need for ethical review prior to publication or presentation of your results.

You should keep a copy of this letter within your project file.

Yours sincerely,

Caroline Ackland
Scientific Officer, East of Scotland Research Ethics Service

cc Dr Allyson Bailey, R+D Manager NHS Forth Valley

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Appendix 2

The Service Quality Statements were then cross checked against each of the above statements/ideas, to make sure nothing was missed out, as follows:

Table 3 Quality Service Statements mapped against themes from table 1

Service quality statement	Mapped against which theme in Table 1
1. I can expect to have the right to equal access to an AAC Service regardless of: • age or time of onset of impairment • severity of impairment • geographic locations • economic status • linguistic or cultural background	3n
2. I can expect to be involved in an assessment process that is demonstrably impartial, independent and objective.	1a, 1b, 1d, 3a, 3g, 3j, 3m
3. I can expect to receive a high quality, fair and personal service from AAC Services.	1a, 1b, 1c, 1d, 3m, 3j
4. I can expect the professionals working with me to share information, knowledge and skills.	1e, 3a
	1e, 3a
6. I can expect all members of the AAC Services to have the required skills, knowledge and competencies.	1c, 1b
7. I can expect my knowledge, skills and experience to be valued and acknowledged.	1a, 1f, 1i, 1j
8. I can expect to be involved as an active participant throughout the whole decision making process.	1i, 1j
9. I can expect that if my needs for AAC cannot be addressed by my current team, a referral will be made to a team with appropriate knowledge, skills and experience.	3a, 3g
10. I can expect the local SLT/AAC and specialist AAC Service to have a care pathway that describes their part in the management of my AAC needs.	3a
11. I can expect to be informed where to go for a second opinion if the AAC Service does not meet my needs.	3f
12. I can expect my local SLT/AAC team to identify that I have a need for AAC at the earliest opportunity.	3k
13. I can expect my local team to know how to manage my AAC needs. If they are not able to, then they need to know which specialist AAC Service to refer to without delay.	3a, 3g
14. At the point of each referral, I can expect to receive information about the AAC Service to which I have been referred, including the relevant service response timescales.	2b,2c, 2e, 2g
15. I can expect referrals to be made in a timely manner, with comprehensive information provided, as agreed in my local team care pathway planning process.	2a, 2b, 2g
16. I can expect that my consent to participate in the assessment process will be obtained, recorded and regularly confirmed.	1o
17. I can expect that AAC Services will comply with their stated service response timescales.	3a.

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Service quality statement	Mapped against which theme in Table 1
18. I can expect to my local team to ensure I have a named AAC key worker who will act as a point of contact for all AAC teams involved in my care and who will regularly keep me informed of changes. This key worker may change over time.	3l
19. I can expect roles and responsibilities to be made clear to me throughout the assessment process, with key contacts identified within each team.	2c
20. I can expect the timing, length, venue and format of the assessment will take into account my needs and preferences and be structured to ensure that I can participate to my full potential.	1k, 2b, 3c
21. I can expect that the AAC Service will apply their knowledge and skills to consider the broad range of AAC options that are available to meet my requirements.	1b, 1c, 1f, 3j, 3m
22. I can expect that the AAC Service can provide me with the opportunity to use a range of AAC equipment and strategies.	3a, 3j, 3l
23. Where required, as part of the assessment process, I can expect to be offered a trial of equipment and/or strategies for a period of time sufficient to indicate how effective these will be.	3a, 3l
24. I can expect that the equipment that I trial and/or which is recommended for my use, will be provided to me with adaptations and programming in place to meet my needs.	1f, 3m
25. I can expect that I, my family, support workers and, my local team, will be offered training on the techniques, devices and systems provided, whether on a trial, loan or permanent provision basis.	1m, 1l
26. I can expect a clear rationale to be given for the AAC strategies and / or equipment that are trialed and recommended.	2a, 2b, 2g
27. I can expect that, when a decision is made about equipment for long-term provision, a plan of implementation is agreed.	1j, 2a
28. I can expect my local SLT/ AAC team to support my use of the AAC equipment that is provided, whether on a long-term loan or permanent provision basis.	3e
29. I can expect to have my local SLT/ AAC team's proactive support when seeking funding and resources required to implement AAC recommendations made for me.	2f, 3b
30. I can expect my local commissioners to work across organisational boundaries to set up a budget for AAC equipment and services, and have a transparent policy agreed by all agencies on how decisions will be made about the use of the budget.	3b, 3h
31. Within one month of any AAC assessment that I undertake I can expect to receive a report in plain English, that sets out the agreed action points and implementation plan.	2a, 2b, 2e

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Service quality statement	Mapped against which theme in Table 1
32. I can expect to receive periodic reviews aimed at ensuring that the equipment/strategies are proving to be useful and effective.	1k, 3e
33. I can expect to be able to re-enter the assessment process at any time as my needs, circumstances and AAC practice and technologies change.	1k, 3a, 3b, 3m
34. I can expect my local commissioners to ensure continuity of AAC services between Children and Adult Services, and between AAC Services and other relevant specialist AAC Services.	3h
35. I can expect that the AAC team supporting me will receive training, as necessary, to ensure that I can use the equipment and strategies recommended.	1l
36. I can expect to have a team to provide me with clear information and guidance to support me in learning to use my communication system and to continue supporting me as I develop my AAC skills.	1l, 2b, 3c
37. I can expect there to be SMART (but flexible) targets to develop my AAC use. These aims and objectives will be discussed and agreed by the whole team.	1j, 1i, 3a
38. I can expect that Total Communication will be actively encouraged in my environments so I receive sufficient support to enable me to express myself.	1n
39. I can expect my team to arrange appropriate opportunities for me to meet AAC Role Models.	1h
40. I can expect that the local team supporting me will have sufficient time, over time, to prepare resources and maintain my communication system.	1g, 3e
41. I can expect my team and I to receive a rolling programme of training to support me in learning to use my AAC system.	1l, 3e
42. I can expect there to be specifically agreed roles and responsibilities for the team, so I know who to go to for support as I learn to use my new equipment/strategies fully.	2c

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Appendix 3

Figure 4 Examples of symbols used with Talking Mats



All symbols copyright Adam Murphy2013 and owned by Talking Mats Ltd.

Appendix 4

Information about Talking Mats:

Talking Mats is an established communication framework with a strong research evidence base. The framework uses a mat with three sets of symbols (a top scale, a topic and options). It is designed to help people:

- Consider and think about issues discussed with them
- Provide them with a way to effectively express their opinions.

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Talking Mats can help people arrive at a decision by providing a structure where information is presented in small chunks supported by symbols. The example below shows a photograph of a mat completed by one of the project participants. He was asked to consider how he felt about the information he received about AAC services. The top scale was 'importance', with three stars being 'really important' and one star being 'not important'.



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