

Seeking feedback on AAC services
throughout Scotland: *A project to enable
people who use AAC to give regular
feedback on their services*



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Final Report

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Background

In June 2012 the Scottish Government published “A Right to Speak” (Scottish Government 2012). 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 how 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.

One of the recommendations was that “*local indicators are to be developed by local partnerships and national services*” (Recommendation 8.2). Talking Mats Ltd were commissioned by NHS Education for Scotland to identify potential quality indicators in relation to AAC services in Scotland (NES 2013). From this project, ten quality indicators were identified, under three broad themes:

A. People who work with me:

1. Training: People who use AAC 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).

2. Values: People who use AAC 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 people who use AAC: People who use AAC 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 People who use AAC.

B. How information is provided:

4. Information about the AAC team: People who use AAC 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: People who use AAC 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: People who use AAC 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: People who use AAC and their families felt that information should be provided in a format that was accessible to them.

C. The process (How AAC services work)

8. Equal access to funding and services: People who use AAC 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: People who use AAC 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: People who use AAC 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.

Development of a resource to enable people who use AAC to give feedback about AAC services

Having identified the quality indicators (outlined above), Talking Mats was commissioned by the Forth Valley AAC Partnership to devise a way to consult with people who use AAC in the Forth Valley area to find out how they felt about the services they received.

In particular, the aims of the project were to:

1. Gather patient stories of AAC user's experiences which could be shared with stakeholders and used to help inform service provision.
2. Build sustainability by developing an evaluation tool to be used by professionals to help them really hear the voice of people who use AAC.
3. Produce video clips of people who use AAC telling their stories for a user consultation event, to be held in Stirling.

The Forth Valley project:

We initially developed an interview tool using a Talking Mats approach which, based on previous research (Murphy et al 2012, Gillespie et al 2010), we knew would enable people with a wide range of communication difficulties to participate in giving feedback. We made up three sets of symbols based on the three broad quality indicator themes:

- *People who work with me;*
- *Information*
- *How AAC services work.*

We initially tried these out with a range of service users who had previously been identified by staff from the Forth Valley AAC partnership. Service users were approached by AAC partnership staff in the first instance, and once consent had been gained, we arranged to visit them and interviewed

them using the developing tool. All interviews were filmed so that we could later look at the interactions and assess whether or not the materials were suitable for the people we were working with. We also wanted to be able to use the film clips for raising awareness about gaining feedback from people who use AAC within Forth Valley.

We conducted an initial interview with one participant and then refined the symbols and questions and made up an interview script. We used this with the remaining three participants, although not everyone used all the symbols.

Reflections on our experiences of interviewing people who use AAC in Forth Valley

We used the Talking Mats resource with four people who use AAC in Forth Valley and found that this gave us important insights into services from the perspective of people who use AAC. This uncovered some interesting points of view, which we may not have heard if more traditional methods had been used (such as questionnaires, closed questions, user feedback forms). Using the Mats helped people to give feedback about things that were going well and also enabled them to point out areas that were not going well. Most people who took part appeared to be satisfied overall with the services they were receiving, but there were some areas where improvements could be made. For example, each interviewee raised the issue of training for people in their wider communities.

Once the materials had been piloted, we provided a training session for AAC professionals in Forth Valley. Five people attended the training, during which they were given the opportunity to find out how and why the materials had been developed. Time was also spent reflecting on film clips and going through the interview prompt sheet. Participants then used the materials with volunteers (AAC users from Upper Springland day services where the training took place). This was filmed so that we could watch the footage as a group and spend time reflecting on the process and giving feedback. Participants found this model of training useful and commented that it had made them reflect on their own therapy interventions and think about how they normally gain feedback from individuals. As a result of the training session, AAC professionals in Forth Valley now have the skills and resources to be able to routinely gather the views of people who use AAC about the services they receive. They established a system where individuals who were not directly working with the person with AAC would be the ones to seek feedback. The resources have now been used by those who attended the initial training, and alterations have been made in light of experiences. The original three topics have been merged as it was felt that there was some overlap between the topics of 'information' and 'how AAC services work'. The resource now comprises two main topics:

- People who work with me
- Information and how AAC services work

We have also provided a more detailed script to guide professionals in the questions they ask (see Appendix 1)

Extending the use and reach of the Talking Mats resources to enable people who use AAC to give feedback about services throughout Scotland

Following on from the Forth Valley project, we were commissioned to extend the use and reach of the resources that we had developed. We refined the training course, based on our work with the

Forth Valley AAC partnership and offered training and resources to AAC professionals from all over Scotland.

Half day seminars were arranged and delivered as follows:

Location	Places booked	Attendance with training and resources	Health board areas/organisations represented
Inverness	9	7	NHS Highland, L'Arche, Richmond Fellowship
Glasgow	14	14	NHS Ayrshire & Arran, NHS Greater Glasgow & Clyde, CALL Scotland, NHS Lanarkshire, NHS Highland, Capability Scotland
Dundee	9	9	NHS Tayside, NHS Greater Glasgow & Clyde, NHS Shetland
Edinburgh	11	10	Borders Education, Keycomm, CALL Scotland, Fife AAC partnership, NHS Lothian
Total	43	40	

Range of professionals

The majority of professionals (n= 40) who attended the seminars were speech and language therapists working in AAC services (n = 24). A range of teachers, social care staff, nurses and occupational therapists also attended.

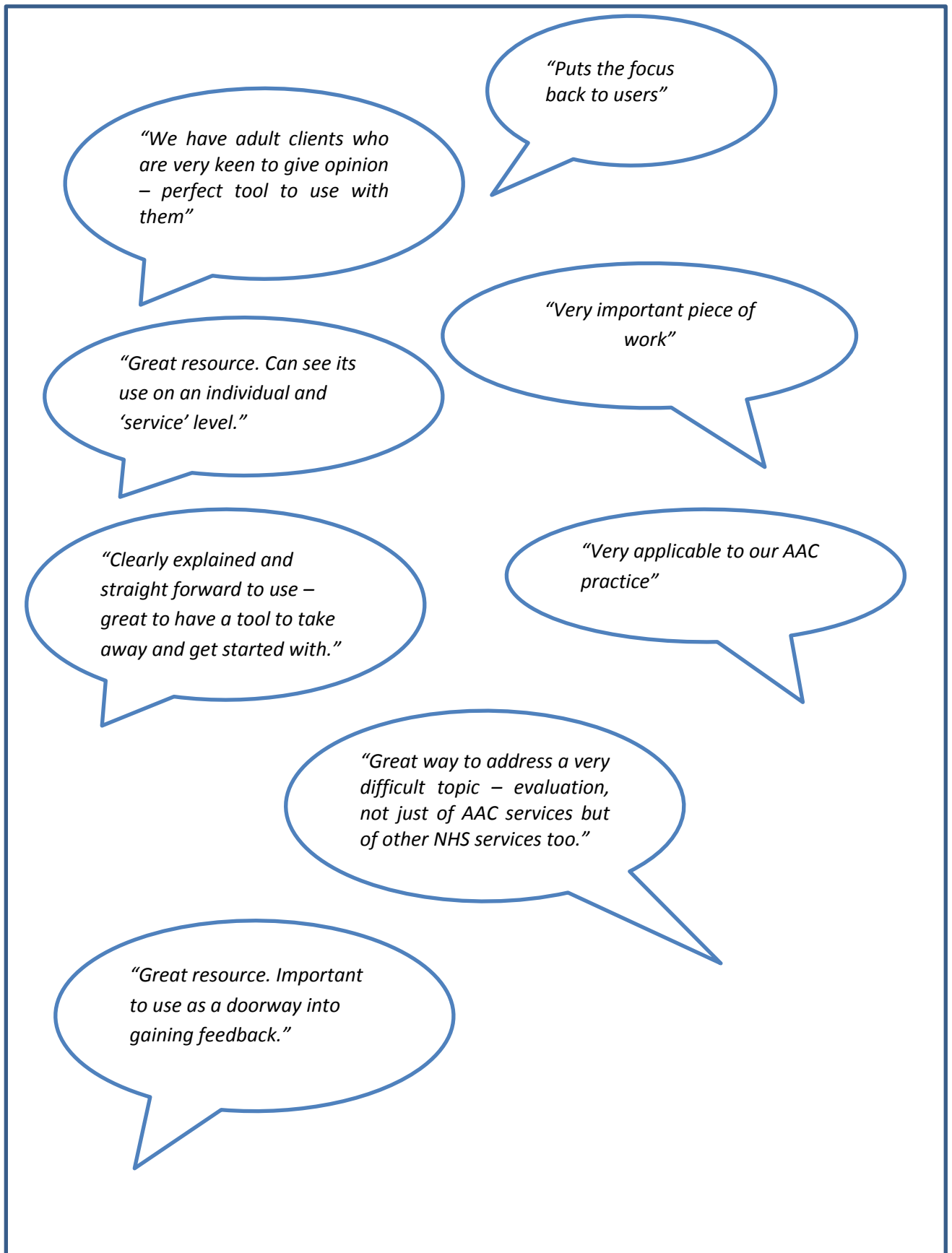
Profession	Numbers
Nurses	2
Occupational therapist	2
Speech and Languages	24
Social care staff	8
Teacher	4

The training

During the training, participants were given background about the original Quality Indicators project and had the opportunity to think about the importance of gaining feedback from service users, as well as some of the barriers to doing this in a meaningful way. Time was spent reviewing the resources, watching DVD examples and using them in role play situations. Consideration was given as to who was the best person to gain feedback from. The model used in Forth Valley NHS where individuals who were not directly working with the person with AAC was promoted.



Feedback from the training was very positive, as reflected in the following comments:



Participants had time and space to plan how they would use the resources after the seminar and gained an awareness of the original Quality Indicators work. They resolved to ensure that these indicators would now be included in their local AAC pathways. Participants went away with plans to use the resource to gain regular feedback from people who use AAC and their families about services. They also thought the resource could be used as an awareness raising tool when working with other professionals who were not so familiar with AAC to illustrate the services issues that were important, e.g. one teacher was going to use it with their head teacher. Participants also had ideas about how use of the resource could be extended and adapted, for example:

- To gain feedback from *parents* of younger children who would find it difficult to understand some of the abstract concepts in the AAC feedback resource;
- To use the resource as a starting point for developing symbols sets to be used to gain feedback about other services such as wheelchair, learning disability and group provision;
- There was acknowledgement that with a little adaptation they could also be used with people to seek views on low-tech AAC support.

Summary

People with complex communication difficulties commonly find it difficult to give feedback about the services they receive. It can be particularly challenging for people who use AAC to use traditional methods of gaining feedback (such as questionnaires, comments forms etc.) due to problems with literacy, cognition and physical limitations. If services are genuinely interested in getting feedback, they should adopt suitable methods to ensure that as many people as possible can take part and have their voices heard and listened to. The Talking Mats materials and training, originally developed with the Forth Valley AAC Partnership provide an innovative way to really hear the views of people who use AAC. Materials have been developed which can be used by those trained throughout Scotland to enable service users to give regular feedback about the services they receive. These materials could be adapted for use within other services (e.g. to support people to give feedback about environmental control or wheelchair services).

As a result of this project, 40 AAC professionals in Scotland have been trained to use the materials developed. This is in addition to the original five that were trained in Forth Valley who also have been given the revised packs. It will now be possible for regular consultation to take place with people who use AAC to find out their views about the AAC services they receive in relation to the people that work with them, information provided and the overall process of assessment and support. This important information can be used to benchmark existing AAC services and to inform how they develop and change in the future throughout Scotland.

Sustainability

The resources will be made available as a pdf and put on the Talking Mats website so that they are freely available to each AAC partnership. This will enable AAC professionals to continue to use the resources in the future.

References

Scottish Government (2012). A Right to Speak: Supporting Individuals who use Augmentative and Alternative Communication. Scottish Government, Edinburgh. Available from:

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NHS Education for Scotland (2013) The Development of Quality Indicators for Alternative and Augmentative Communication: Final Report Cameron, L. Boa, S. and McCulloch, H.

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Appendix 1

Script and prompt sheet for interviews

The interview is divided into 2 sections, based on the ten quality indicators for AAC services: *People who work with you, and how AAC services work* (the process of being assessed, getting equipment etc.)

Start by defining AAC – make sure the person knows that you are talking about the methods they use to communicate (e.g. high-tech AAC, communication book, etc.)

A. People who work with me:




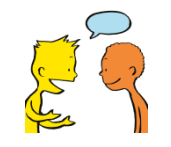






Start by asking: **Who do you think helps you with your AAC?** (to make sure they know who you are talking about)

Write down the person's response here:

Introduce use of the Talking Mat to talk about the people who help you use your AAC (top scale – going well/not going well). 'How's it going?'

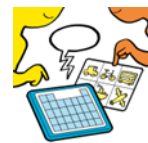
Now use the symbols to ask about people in the AAC team:








How do you feel about information you received about the AAC team	
How do you feel about how your AAC team work together ?	
How do you feel about the AAC team listening to you?	
How do you feel about the AAC team knowing how to communicate with you?	
Check – Did anyone teach you how to use your AAC? How do you feel about it?	




<p>Check – Did your family and friends get any training on your AAC? How do you feel about it?</p>	
<p>Check – Did people in your local environment (e.g. shop keepers, taxi drivers etc.) receive any training about communicating with you using your AAC? How do you feel about it?</p>	
<p>Check – Did your AAC team put you in touch with other People who use AAC? How did you feel about this?</p>	

B. Information and how AAC services work

Introduce the topic which is information relating to your AAC services



<p>How do you feel about the assessment process?</p>	
<p>How do you feel about how long things took? If it didn't go well, how do you feel about the information you got?</p>	
<p>How do you feel about funding for your AAC? If it didn't go well, how do you feel about the information you got?</p>	
<p>Optional, if not going well</p>	
<p>How do you feel about how often you see members of the AAC team – and ongoing support?</p>	
<p>How do you feel about how information is presented – for example, letters and reports being in a format that you can understand</p>	
<p>How do you feel about having information so you know who to contact if things go wrong with you AAC (help in an emergency)?</p>	

<p>How do you feel about what happens when your equipment breaks down?</p>	
<p>How do you feel about the process when you need to get a replacement machine?</p>	
<p>How do you feel about being able to access services if your needs change and you need to be reassessed?</p>	
<p>Check – do you have an environmental control system? If yes – ask: How do you feel about having equipment that works together (for example you AAC and environmental controls working together)</p>	