Augmentative and Alternative Communication Services

Quality Standard for Commissioners

September 2011

Introduction

In 2008 , John Bercow MP reported on services for children and young people with speech, language and communication needs. His report noted good practice in support for those who can benefit from the use of Augmentative and Alternative Communication (AAC) in some local areas. More often, however, provision was poor. Children and young people were not accessing specialist assessment. There were local arguments between the NHS and local authorities about who should provide communication aids. If an aid was provided, too often the 'aftercare' was poor.

Two years later, in my role as government's Communication Champion for children and young people, I reviewed provision to see if it had improved. I found that with a few notable exceptions , local authorities and health providers under-identified needs, lacked the full range of specialist AAC expertise, and did not always make use of the specialist assessment centres available to them. In the words of one teacher, whose local area did not have a budget for communication aids, "Through social care we can get an adapted bed for a child, but not funding to purchase a communication aid that would allow that child to say if they are tired. We can get a special cup, but not the means for the child to say they are thirsty. We can get a new wheelchair, but not the means for the child to tell us whether it is comfortable"'.

In my review, I also noted the problems experienced by young people as they become adults, often losing overnight their right to communicate as aids provided by schools and children's services were withdrawn.

The only way to tackle these problems is better joint commissioning (by health, education and social care) for children and adults, that is guided by quality standards describing what should be happening at each stage in the cycle of identification, assessment, provision of aids, ongoing support and review. The quality standards should be written from the perspective of the people who really matter - those who use AAC.

That is why I welcome this document. The standards published here should inform the commissioners of the future - the new NHS Commissioning Board in relation to the specialised 'hub' assessment services that are their responsibility, GP consortia and local authorities in relation to the vital local 'spoke' services that hubs will need to work with and support.

The standards represent many months of work by people from across the AAC community. They are the result of collaboration, discussion and debate. I congratulate everyone who has been involved, and hope with all my heart that as a result of improved commissioning we will see these standards enacted in the experiences of those who use AAC now, and in the future.

Jean Gross

Communication Champion

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The aim of this document is to provide a quality standard for Augmentative and Alternative Communication (AAC)[1] Services. The quality standard defines a high quality of care within this topic area. It provides specific, concise quality statements and measures as well as identifying those services that should comply with the quality statements contained in this document.

Rationale for developing this quality standard

A person with a communication impairment can be supported to communicate using Speech and Language Therapy or other specialist help, which sometimes includes AAC techniques, equipment and a programme of rehabilitation and learning support. Communication impairment can present through early childhood development as a symptom of conditions such as cerebral palsy, learning difficulties and autism or, for adults, as a symptom of a range of conditions including stroke, cancer, brain injury and neurological diseases such as Parkinson's, Multiple Sclerosis or Motor Neurone Disease. Over the last 20 years the potential for AAC services to support people with communication impairment has increased significantly due to the technological advances of specialist and mainstream communication technologies. However, there is still a postcode lottery that exists with regard to AAC Service provision and equipment. In addition, there is great variation in provision across disability groups and age. The variability and inequality in AAC service provision that exists is a result of:

- under funding
- a lack of commissioning good practice
- lack of support to practitioners (such as Speech and Language Therapists[2]) to develop competence with electronic technologies (and other non-electronic strategies).

This has been noted in relation to children and young people's AAC services in 2008 in the Bercow Report[3] and in 2010 by Jean Gross in the Office of the Communication Champion (OCC) Report[4].

There is a need for more research into the most effective AAC interventions to provide comprehensive evidence on which to base the quality standard. However, service users have voiced[5] their frustration with two key elements of service: poorly co-ordinated working across different AAC services and the lack of funding for equipment. This quality standard therefore addresses the need to clarify roles, responsibilities and shared working practices in AAC services. In recognition of the significant work that is required for some services to reach the quality standard, quality statements are categorised as those that could reasonably be expected to be delivered currently and those for which some services will require a period of development. The quality standard provides commissioners, clinicians, managers and service users with a description of what a high-quality AAC service should look like.

Scope of the quality standard:

The quality standard covers AAC services provided to adults and children by AAC service providers in England, whether in the statutory, voluntary or private sectors.

Prevalence

There is little reliable data on the prevalence or incidence of communication impairment in the population, nor of the proportion of this population who may benefit from the use of AAC techniques and equipment. The OCC Report[4] suggests there would be a significant level of under-reporting of need if prevalence was based on existing service provision figures.

Recent work has been undertaken to estimate the actual level of need:

- Scope[6] suggests that between 0.4 and 1% of the population would benefit from AAC and the figure of 0.6% of the population is the most commonly quoted.

- Blackstone, S. et al refer to 0.4-0.6% of the population requiring AAC based on international evidence[7]
- The mid-2009 population of England was 51,809,700[8,] which would indicate that there were 310,858 people in England who would benefit from AAC of whom 74,330 were 19 or under and 236,533 were 20 years of age or over.
- These figures indicate the broad group that would benefit from low and high technology equipment and strategies. The number of those who might benefit from higher technology, electronic equipment and more complex strategy planning would be lower. The OCC Report[4] provides an estimate of prevalence of 0.05% of children and young people needing high technology AAC, representing an estimated 6,200 children and young people in England. If this prevalence was similar for adults, this would lead to an estimate of 19,710 adults needing high technology AAC.
- Enderby and Pickstone[9] propose that an epidemiological approach may inform the development of models of service delivery appropriate to population needs and contribute to a determination of "unmet" need within the population.

It is likely that these figures will increase as the numbers of adults in the population living with a long term condition increase and as the survival rate improves for children born with complex disabilities.

- Research[10] cited in the OCC Report noted that, in one local area, the numbers of young people aged 15-19 with severe or complex needs increased by 70% over the decade 1998-2008.

Costs and benefits

The 2010 Report from the Communication Champion refers to data obtained from AAC suppliers indicating a total annual spend in 2009 on high tech equipment of £3.28 m, and notes that this indicates a significant underspend relative to the number of children and adults who are likely to need high tech AAC. However, it is further reported that "it has been estimated that every disabled young person whose employment status changes from permanent unemployment to permanent employment as an adult as a result of use of communication aid will realise benefits in the order of £500,000 over a working lifetime".[11]

AAC quality standard development team

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Consultation

Consultation on the quality standard took place between September 2009 and January 2011. The quality standard has been developed by Communication Matters following wide consultation with AAC stake holders, people who use AAC, their families and carers, AAC services, support workers, researchers, professionals working in the field as well as manufactures and distributors of communication and associated equipment.

Communication Matters is a charitable organisation covering the UK. It is committed to supporting people with severe communication impairment requiring the use of AAC **(www.communicationmatters.org.uk)**

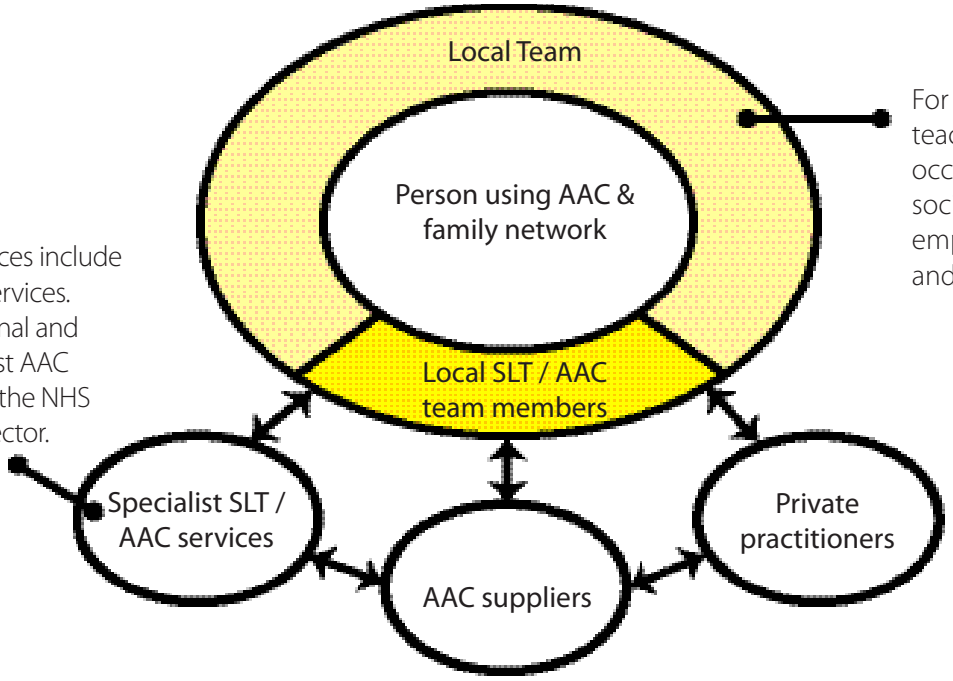
This quality standard will help:

- **Individuals** who use AAC, their families and support workers, to understand what they should be able to expect from current services and the standard that services should aim to achieve after they undertake a reasonable period of development.
- AAC **service providers** to know what standards they are expected to deliver currently and which to aim to deliver in future.
- **Commissioners** of AAC services to understand the sector's view on the quality standard that should be expected today from commissioned services and the expectations commissioners should set as developmental aims for commissioned services in future.

Application of the AAC quality standard

A broad range of individuals and organisations provide AAC services including statutory, third sector and private practitioners (speech and language therapists (SLTs), rehabilitation professionals, educational assistive technology and Access to Work practitioners) as well as equipment suppliers. The models of service vary widely across the country. For the purposes of this quality standard, a generic service model will be used to clarify the roles, responsibilities and communication requirements embedded in the quality statements.

Local teams	The community, local authority or NHS-based team of individuals and organisations who provide a wide range of services to a disabled child or adult, including practitioners working in children's services, adult social care, NHS, further education and employment services.
Local SLT / AAC team members	Most local teams will include SLTs. Some of these local SLTs will have AAC competence, occasionally at a specialist level. A small number of local SLT/ AAC team members will have allocated time to deliver an AAC service and access to a pooled budget for equipment. Many local teams lack funding and time to deliver an AAC service and the OCC Report estimates that around one in five local teams do not have SLT team members with AAC competence.
Specialist SLT / AAC service[12]	Specialist AAC services may sit at local, regional or national levels[13]. Regional and national services are provided by the statutory or voluntary sector from which local teams in health, education and social care commission services.
Suppliers	Most teams, whether at local or specialist levels, will have set up a working relationship with suppliers or retailers of AAC equipment, who provide demonstration services which may include a limited element of assessment, usually restricted to the range of equipment they aim to sell[14].
Private practitioners	Some gaps are filled by private practitioners, often SLTs with AAC competence, who work with local teams and in liaison with suppliers.



For example teachers, teaching assistants, occupational therapists, social workers, employment support and care workers, etc.

Some local services include specialist AAC services. Otherwise regional and national specialist AAC teams sit within the NHS and voluntary sector.

Application of this quality standard:

- Local team members who do not provide SLT/ AAC services and AAC suppliers do not have to comply with this quality standard, but should be aware of and support the quality standard.
- Local SLT/ AAC team members are expected to comply with the quality standard.
- Specialist SLT/ AAC services are expected to comply with the quality standard.
- Independent AAC practitioners are expected to comply with the quality standard and may be expected to do so by private and statutory commissioners of services.
- Commissioners of local and specialist AAC services are requested to support the quality standard as a whole and comply with quality statements specifically referring to commissioning practice.

Policy context informing commissioning of AAC services

Relevant legislation on access to services

- The SEN and Disability Green Paper[15] states:

  5.35 We also want to ensure that local services are able to meet the specific communication needs of children and young people. Some children and young people communicate with other people through electronic communication aids, referred to as augmentative and alternative communication aids (AAC). We know, however, that children and young people who require these high cost, high-tech aids can face a particular struggle to have their needs met under the current commissioning arrangements.

  5.36 Timely provision of such aids, along with the necessary training and aftercare, can make a great difference to a child's quality of life, their relationships and their learning. Subject to parliamentary approval, the commissioning of highly specialised services, including AAC, will become a core responsibility of the NHS Commissioning Board.

- Children's Minister Sarah Teather[16] has written that "my Department is considering the best way to secure support for children who require augmentative and alternative communication with colleagues in the Department of Health following the spending review".

- Under the **Equality Act 2010**[17] schools must not discriminate against pupils in the provision of education or access to any benefit, facility or service. The Act will also extend the reasonable adjustment duty to require schools to provide auxiliary aids and services to disabled pupils. However this duty is not due to come into effect until a later date, following consultation on implementation and approach.
- **UN Convention on the Rights of Disabled People**[18]. The UK government is a signatory to the Convention which establishes internationally recognised benchmarks for disabled people's rights in all areas of life. Of specific note for this topic area are the following clauses:
  - Article 9 - Accessibility: To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems.
  - Article 21 - Freedom of expression and opinion, and access to information: States Parties shall take all appropriate measures ... accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions.
  - Article 24 - Education: States Parties shall take appropriate measures, including: facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication... .

National good practice, policy and regulation

NHS: The Department of Health has published its intention to develop a new outcomes framework for the NHS, supported by quality standards for particular care pathways also developed by NICE and linked to regulation by the Care Quality Commission (CQC). NICE quality standards are based on the best available evidence including existing NICE guidelines and are likely to take into account National Service Frameworks (NSFs).

- **NICE clinical guideline for multiple sclerosis (2010)**[19] 'any person with Multiple Sclerosis who cannot communicate effectively should be assessed by a specialist Speech and Language Therapist for an augmentative aid to communication, which should then be provided as soon as possible'.
- **NICE clinical guidelines for Parkinson's Disease (2006)**[20] speech and language therapy should ensure 'an effective means of communication is maintained throughout the course of the disease, including use of assistive technologies'.
- **The National Service Framework (NSF) for Children** (Standard 8 - Disabled Children and Young People and Those with Complex Health Needs)[21] refers to: 'Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives' and to 'helping disabled children access the equipment they need in all locations'.
- **The NSF for People with Long-term Neurological Conditions**[22] refers to: 'People with long-term neurological conditions are to receive timely, appropriate assistive technology/ equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health, and improve their quality of life' and to 'access to integrated community and specialist assistive technology/ equipment services' and to 'specific arrangements for joint funding of specialist assistive technology provision' (e.g. communication aids..)'.

Current commissioning arrangements

The OCC report contains the most recent and reliable review of current commissioning arrangements for AAC services, though it focuses on children and young people's services. The report details the current commissioning arrangements for AAC services and documents field research undertaken to establish the effectiveness of the current arrangements.

At local level:

- Local service provision and commissioning partners (primary care trusts, which are being replaced by consortia of GPs, local authority children's/ education services, schools and where possible adult social care services) should work to join up services and align or pool budgets for equipment and allied services in order to provide seamless services.

In practice:

- Of the 37 local authority/ Primary Care Trust (PCT) areas visited to undertaken research for the report, the OCC team report that approximately 10 teams follow a model of inter-agency AAC services for children.
- 10-15% of teams at PCT and Local Authority (LA) level include specialist SLTs with AAC competence. Such services do not need to refer to other specialist teams.
- One in five (22%) of the areas visited did not have specialist SLTs with AAC competence, or had a specialist but without sufficient time allocated to assess and support AAC users.
- In 27% of local areas visited, funding is not being allocated by any statutory agency, and in the majority responsibility remains unclear, with ad-hoc arrangements that are dependent on individuals' decisions rather than codified in policy.

At specialist level:

- Current NHS guidance[23] indicates that specialist equipment and services for "adults and children with profound physical disabilities", including communication aids and electronic assistive technology services, should be commissioned regionally by the ten specialised commissioning groups in England using the Specialised Services National Definition No.5.
- The scope of a specialised service is noted as including "expert assessment, followed by demonstration, trial and provision of appropriate electronic and non-electronic communication devices … user training, equipment maintenance, on-going support and periodic review."
- The Definition refers to a hub and spoke model as an effective service delivery model.
- Under the planned changes to the NHS in England, a new national-level NHS Commissioning Board will take over the commissioning of national and regional specialised services, possibly working through regional commissioning groups or clusters of GP consortia.

In practice:

- The OCC team report that only one of ten specialised regional commissioning teams is fulfilling this commissioning function[4].
- It is noted that this situation contrasts sharply with that for a related specialist service, that for environmental control systems, where there are well established regional funding arrangements for the provision of aids and allied services.

Opportunities for improving commissioning of AAC services

The new government is implementing a complete restructuring of the NHS in England under the White Paper, 'Equity and excellence: liberating the NHS'[24]. This provides an opportunity for a fresh look at the commissioning options for AAC services. The need to do so has been clearly stated by the Bercow Report[3] which noted that 'it is critical that health services and children's services, including schools, work together in support of children and young people with SLCN... We believe that a continuum of services is needed. Those services do not just happen. They have to be commissioned. That requires a structure. It is not the exclusive responsibility of the NHS or the education system. Both are involved and services should be jointly commissioned, yet at present they rarely are'.

The recent implementation framework 'Liberating the NHS: legislative framework and next steps'[25] sets out key features on future commissioning practice:

- local healthcare commissioning (80% of total) will be carried out by consortia of GPs, replacing primary care trusts (PCTs), which are being abolished.
- local authorities will have statutory Health and Well-being Boards, which will play a key role in intergrating local commissioning of the NHS, public health, social care and children's services.
- the new national-level NHS Commissioning Board will commission national and regional 'specialised and complex services' which includes AAC.

Although there is a continuation of the approach to commissioning specialised equipment services through the specialised commissioning groups, there is recognition that the proposed restructuring presents an opportunity for change and improvement in commissioning practice. It is noted in the implementation framework that the change to commissioning by GP consortia will require new approaches, for example, in relation to specialised services, GP consortia may require 'support to help them understand the best care pathways and best clinical practice. This was, for instance, an issue raised in relation to many children's services, such as disabled children'.

While not setting out prescriptive models, the implementation framework programme recognises the need for collaborative commissioning across organisational boundaries; 'we will ensure that there is particular emphasis within the 'pathfinder' programme on testing ways of ensuring that consortia quickly develop knowledge and expertise in relation to these areas. This will include exploring joint commissioning with local authorities'.

Options for commissioners to consider in relation to AAC services:

When considering how to implement this quality standard, the following options appear to be open for commissioners to consider in relation to local and specialised AAC services:

- Commissioners in GP consortia, local education teams and social care departments could assess whether current local services are delivering an effective specialist AAC service against the quality standard and, if this is the case, they may choose to continue to commission these services.
- Joint working and joint commissioning across sectors such as health, children's services and possibly social care, through the planned local health and well-being boards, could be developed at a local level. This would be supported by the development of a care pathway that is an integral element of this quality standard.
- If local teams are judged by commissioners to be currently unable to deliver an effective specialist AAC service, the options include commissioning the specialist services from regional 'hub' services or agreeing a development plan with local services to enable them to reach the quality standard for specialist services.
- For those local commissioners who already have a working relationship with specialised services at regional and national level, the quality standard provides a framework which can form the basis of a specification for services and a programme of development work for local teams to develop care pathway programmes where required. A 'hub and spoke' model of regional provision, coordinated by a national organisation, is one of the recommendations of the Bercow Report.
- A useful diagram of the elements of service that need to be considered when developing a commissioning strategy is included in the OCC report and attached as an appendix to this guide (Appendix 1).

Augmentative and Alternative Communication (AAC) Services: Quality Statements

Note that the key principles and the quality statements are written from the perspective of an individual service user and should be taken to mean the individual themselves and/or their family or support worker who is authorised to make a decision with, and on behalf of, that individual if they are a child or someone without the ability to make decisions independently.

Key principles

The following key principles should underpin all AAC Services.

A. 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
   - geographical location
   - economic status
   - linguistic or cultural background

B. I can expect to be involved in an assessment process that is demonstrably impartial, independent and objective.

C. I can expect to receive a high quality, fair and personal service from an AAC service.

D. I can expect the professionals working with me to share information, knowledge and skills.

E. I can expect the professionals working with me to communicate effectively with each other for my best interests.

F. I can expect all members of the AAC service to have the required skills, knowledge and competencies.

G. I can expect my knowledge, skills and experience to be valued and acknowledged.

H. I can expect to be involved as an active participant throughout the whole decision making process.

I. 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 the appropriate knowledge, skills and experience

J. I can expect my local SLT/ AAC team, and the AAC specialist service to have a care pathway that describes their part in the management of my AAC needs.

K. I can expect to be informed where to go for a second opinion if the AAC service does not meet my needs.

The following statements reflect the order and process of the individuals AAC journey.

Developmental 1

Quality Statement

I can expect my local team to identify that I have a need for AAC at the earliest opportunity.

Measure

Local data is collected to monitor the proportion of clients within a local team's patch who are identified early/ late.

A programme of awareness raising activity is regularly undertaken targeting local disability support and universal services teams.

Compliance required /support requested

Compliance: local teams and local SLT/AAC team members

Support: specialist AAC teams to raise the awareness within local teams of SLT/ AAC indicators of need and possible solutions.

Rationale for quality statement

The Bercow[3]: Reference source not found review's recommendation: Early identification and intervention are essential.

Doyle & Phillips (2001)[26] note the critical nature of timing of intervention for AAC users who have motor neurone disease.

Developmental 2

Quality Statement

I can expect my local team to know how to manage my AAC needs or, if they are not able to, know which specialist AAC service to refer to.

Measure

An AAC care pathway process is in place. This should include effective signposting to local and national resources and services.

Compliance required /support requested

Compliance: local SLT/ AAC teams

Support: specialist AAC teams by negotiating a care pathway process with local teams.

Rationale for quality statement

Lund and Light (2007)[27]mention a perceived lack of availability of local AAC services, and in particular a lack of services for adult users. Difficulties in accessing a specialist evaluation are described by parents and AAC users (McNaughton et al. 2008)[28].

Developmental 3

Quality Statement

Members of the AAC team at local and specialist levels have the range and level of competence in AAC required to undertake their role.

Measure

AAC teams have mapped their competencies against those required within a local or specialist team[29]. The team meet, or have a strategy to meet, the competence requirement. AAC team members have training and CPD opportunities to acquire required competencies for current roles and to enable career development.

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams.

Rationale for quality statement

The need for staff coming in contact with AAC users to have adequate levels of skill and knowledge was highlighted by Soto et al. (2001)[30]. Teachers, teaching assistants and parents reported that a lack of training for staff was a significant barrier to successful implementation of systems.

Matthews (2001)[31] In a survey of 320 SLTs working in the UK, 31% reported their skills in high tech AAC as 'none', and 37% reported them at a 'general knowledge/ awareness' level.

Clarke et al. (2001)[32] in an analysis of school records described the amount of official training of other staff by communication specialists as minimal.

Current 4

Quality Statement

I can expect referrals to be made in a timely manner, with comprehensive information provided as agreed in my local team's care pathway planning process.

Measure

Evidence of compliance in terms of timing of referrals as well as the quality and scope of information provided, assessed against the process set out in the agreed care pathway documents.

Compliance required /support requested

Compliance: local SLT/ AAC teams

Support: specialist AAC teams by negotiating a care pathway process with local teams.

Rationale for quality statement

The Bercow[3] review's recommendation: Joint working is critical.

Parette et al. (2000)[33] found that family members appreciated professionals being honest about their level of knowledge, and wanted clear, accurate and trustworthy information, including accurate timelines regarding the process of acquiring equipment.

Current 5

Quality Statement

I can expect that my consent for referral or interventions will be obtained, recorded and regularly confirmed.

Measure

A referral process is in place that documents the consent process.

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams.

Rationale for quality statement

CQC regulation of health and social care is based on high-level 'essential standards of quality and safety'[34]

These include:

- You can expect to be involved and told what's happening at every stage of your care:
- You will always be involved in discussions about your care and treatment, and your privacy and dignity will be respected by all staff.

Parette et al. (2000)[33] highlighted the importance of involving families in decision-making. In Rackensberger et al. (2005)[35] adult users described how they benefitted from taking a lead role in decision-making.

Developmental 6

Quality Statement

At the point of referral, I can expect to receive information about the AAC service to which I have been referred, including the relevant service response timescales.

Measure

Local services have a process in place by which they collect and maintain stocks of service information for all AAC specialist services to which they refer and ensure this information is given to service users at the point of referral.

Specialist services publish information about their services that include service response timescales.

Compliance required /support requested

Compliance: local SLT/ AAC teams

Support: specialist AAC teams by providing information about their service, including service response timescales to local teams.

Rationale for quality statement

Users have requested[36] that AAC services publish and comply with timescales for responding to queries, referrals and requests for assessment appointments.

Current 7

Quality Statement

I can expect that AAC services will comply with their stated service response timescales.

Measure

Services monitor their response timescales against those published in their service information, make this monitoring information available to users on request and take remedial action if necessary. Services covered by this measure are likely to include referrals, reports and interventions such as assessment appointments.

Compliance required /support requested

Compliance: specialist SLT/AAC teams

Rationale for quality statement

The NHS Constitution[37] is in force at the time of publication of this document and includes the following legal entitlement:

'If your GP refers you for treatment, you have the right for any non-emergency treatment that you need to start within a maximum of 18 weeks or for the NHS to take all reasonable steps to offer you a range of alternatives if this is not possible'.

Note: 18 weeks is often considered too long a timescale for someone with a degenerative condition.

Current 8

Quality Statement

Within one month of any assessment that I undertake I can expect to receive a report in clear English, that sets out the agreed action points and plan.

Measure

Evidence of compliance in terms of timing of report production as well as the quality[36] and scope of the information provided, assessed against the process set out in the agreed care pathway documents.

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams

Rationale for quality statement

AAC service users have voiced frustration[34] at the lack of clear, timely communication they have encountered.

Developmental 9

Quality Statement

I can expect 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 to my AAC care plan.

Measure

Local SLT/ AAC teams have a process in place by which a key worker for each service user is identified and all AAC teams along the care pathway are informed of the key worker's contact information, role and each team's communication responsibilities. This key worker may not be located in the local team and may change over the course of the assessment process (in negotiation with the service user where possible).

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/AAC teams.

Rationale for quality statement

Users have requested[36] key worker support to manage a sometimes complex and confusing AAC care pathway process. Lund and Light (2007)[27] outlined limited expertise of local professionals and a lack of collaboration between professionals.

The Bercow Report[3] recommendation: A continuum of services designed around the family is needed.

Developmental 10

Quality Statement

I can expect roles and responsibilities to be made explicit throughout the assessment process, with key contacts identified within each team.

Measure

AAC teams have a process in place by which roles are explained to service users and documented and key contacts are identified.

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams.

Rationale for quality statement

As above

Current 11

Quality Statement

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.

Measure	The plan for the assessment process is drafted and amended on a regular basis and agreed and shared with all involved.
Compliance required /support requested	Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams.
Rationale for quality statement	Sector consensus.

Current 12

Quality Statement

I can expect that the AAC team will apply their knowledge and skills to consider the broad range of AAC options that are available, to meet my requirements.

Measure	AAC assessors demonstrate that they have knowledge of an appropriately broad range of AAC options through their CPD and self directed learning plan.
Compliance required /support requested	Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams.
Rationale for quality statement	McDonald (2008)[39] notes that achieving outcomes depends in part on identifying an appropriate AAC device or strategy for each individual: 'the major consequence, however, is the need for detailed assessment and provision appropriate to the individual needs of each child.'

Current 13

Quality Statement

I can expect that the AAC service can provide me with the opportunity to physically interact with a range of AAC equipment and strategies.

Measure	Local and specialist AAC teams can demonstrate how they provide access to an appropriate range of AAC equipment and strategies.
Compliance required /support requested	Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams.
Rationale for quality statement	Sector consensus.

Developmental 14

Quality Statement

When required as part of the assessment process, I can expect to be offered a trial of equipment for a period of time sufficient to indicate how effective it will be.

Measure	Local and specialist AAC teams can demonstrate how they provide access to equipment for trial, including agreements with suppliers, etc.
Compliance required /support requested	Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams.
Rationale for quality statement	Sector consensus.

Current 15

Quality Statement

I can expect that the equipment that I trial, or which is recommended for my use, will be provided to me with adaptations and programming in place to meet my needs.

Measure

Local and specialist AAC teams can demonstrate that, within the team or by accessing external expertise, they have the competence to appropriately set up equipment for trial or provision, including making hardware and software adaptation, and that they have the processes in place to do so.

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams.

Rationale for quality statement

The barrier of limited availability of technical support was outlined by Bailey et al., (2006)[40], Rackensberger et al. (2005)[35], Parette et al. (2000)[33] and Soto et al. (2001)[30]. Family members described their own limitations in regard to technical aspects of equipment and need for support to be readily available (Bailey et al. 2006[40], Parette et al. 2000)[33].

Current 16

Quality Statement

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 this is on a trial, loan or permanent provision basis.

Measure

Local and specialist AAC teams have a programme in place to provide training to the person using AAC, their family, support workers and the wider local team. Local and specialist AAC team members have the competence and skills and time available to provide adequate training.

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams.

Requested support: team managers of the wider local team to allow sufficient time for local team members to prepare resources and maintain AAC.

Rationale for quality statement

Murphy et al (1996)[41] identified that a person learning to use an AAC device receives an average of 40 hours of therapy per year. In comparison, it is estimated that in order to learn English as a foreign language to the level of holding a basic conversation, approximately 200 hours of input is required.

Adult AAC users with Cerebral Palsy in the Smith and Connolly (2008)[42] paper reported that their own knowledge and skill level was a barrier to usage.

Lund and Light (2007)[27], and Parette et al. (2000)[33] reported a need for family support. McNaughton et al. (2008)[28] identified the important role of parents in teaching usage of a device.

Current 17

Quality Statement

I can expect a clear rationale to be given for the AAC strategies and / or equipment that are trialled and recommended.

Measure

Targets are set for any resource trial with measurable outcomes that are gathered and reported. The rationale for recommendations for strategies/ equipment are documented in assessment reports and provided to the person with AAC and all relevant teams.

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/AAC teams.

Rationale for quality statement

Sector consensus.

Current 18

Quality Statement

I can expect that, when a decision is made about equipment for long-term provision, a plan of implementation is agreed.

Measure

Implementation plans are produced. The range of support activity covered by the implementation plan is likely to include: maintaining the device, maintaining relevant vocabulary (including required languages), the provision of appropriate voices for VOCAs, the provision of a stimulating communication environment, opportunities for the individual to participate using their AAC, and access to role models or peer support.

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/AAC teams

Rationale for quality statement

Evidence from Norway[43] shows that 'it is not sufficient to invest in additional equipment without a clear framework for multiagency planning and delivery and the essential speech and language therapy and other support services required to make equipment optimally functional for the AAC user.'.

A study by Smith and Connolly (2008)[42] reported that few users had assistance with programming or maintenance when they were provided with their devices.

CQC regulation[44] of health and social care is based on high-level 'essential standards of quality and safety'

- 'You will be given opportunities, encouragement and support to promote your independence.'

Current 19

Quality Statement

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.

Measure

Local SLT/ AAC team members have a process in place to support the implementation plans of their AAC clients. This will include a process to avoid, and manage the consequence of, technical failure of the device. This is likely to include access to loan equipment while users' devices are under repair.

Compliance required /support requested

Compliance: local SLT/ AAC team members

Requested support: the wider local team

Rationale for quality statement

International research has indicated that nearly one third of all AAC equipment is abandoned if there is insufficient support available in its use[45].

Teachers in the Soto et al. (2001)[30] paper, identified back up services and support being in place as requirements for successful introduction and use of AAC.

Hodge (2007)[46] found that technical problems were a common cause of frustration, particularly with the more sophisticated devices.

Development 20

Quality Statement

I can expect my AAC teams' proactive support when seeking the funding or resources that are required to implement their recommendations.

Measure

Local and specialist AAC teams have standardised resources to document the case for funding or to support the implementation of AAC recommendations, plus signposting to external sources of support.

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/AAC teams.

Rationale for quality statement

Service users have voiced[47] their frustration the lack of funding for equipment. Parents in the Golbart and Marshall (2004)[48] paper perceived that there were demands on parents to fund AAC resources themselves.

Development 21

Quality Statement

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 on the use of the budget.

Measure

Local commissioners publish their strategy for commissioning AAC equipment and services that meet the AAC quality standard.

Compliance required /support requested

Compliance: commissioners

Rationale for quality statement

The Bercow Report[3] notes that commissioning AAC services "is not the exclusive responsibility of the NHS or the education system. Both are involved and services should be jointly commissioned, yet at present they rarely are".

Current 22

Quality Statement

I can expect to receive periodic review aimed at ensuring the equipment/ support is proving useful and effective.

Measure

Local AAC teams have a review process in place for all current clients and their personal support network. Teams demonstrate that they carry out reviews using a range of methods, with face-to-face (or equivalent) review likely to be required by most clients.

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams

Rationale for quality statement

Murphy et al[41] state that 'to learn to use an alternative method of communicating, particularly when one has a physical and/or learning disability, is a far more difficult task, yet there is comparitively little time allowed for it and far to few adequately trained personell.'

Current 23

Quality Statement

I can expect to be able to recommence the assessment process as my needs, circumstances and AAC practice and technologies change.

Measure

Local AAC teams publish clear information about the process for requesting a re-assessment or follow-up support to all current clients on a regular basis, including signposting to information about innovative AAC practice and technologies.

Compliance required /support requested

Compliance: local SLT/ AAC team members, specialist SLT/ AAC teams

Support: specialist AAC teams by providing information about innovative AAC practice and technologies

Rationale for quality statement

Sector consensus.

Current 24

Quality Statement

I can expect my local commissioners to ensure continuity of AAC services between children and adult services and between AAC services and other relevant specialised AT services.

Measure

Local commissioners publish their strategy for commissioning AAC equipment and services that meet the AAC quality standard across adult and children services. This will include co-ordinated working with wheelchair, posture and seating and environmental control services.

Compliance required /support requested

Compliance: commissioners

Rationale for quality statement

Kent-Walsh and Light (2003)[49] examined the perceptions of teachers in the USA who had AAC users in their mainstream class. The participants described the importance of a range of factors including a specific need for careful transition planning.

A study by Hodge (2007)[45] of parents of children using AAC and adult users described how devices needed to be secured to a wheelchair in order to use them successfully. Rackensperger et al. (2005)[39] echoed this, reporting how for some users physically operating a device was a challenge, with devices difficult to use apart from seated in a customised wheelchair.

Endorsement and publication partners

The quality standard will be disseminated through the Communication Matters website and comments on the document should be sent to **admingroups@communicationmatters.org.uk.**

The aim is that this quality standard will become the accepted standard for AAC services against which services can be measured.

Definitions used in this document

The OCC report[4] sets out a useful description of AAC services:

1. "AAC[50] describes methods of communication which can be used by children, or adults, who find communication difficult because they have little or no clear speech. It adds to (augments) or replaces (is an alternative for) spoken communication. AAC can also help the user's understanding, as well as provide a means of expression.
2. There are two main types of AAC: unaided or aided. Most people who use AAC combine both methods. Unaided communication does not require additional equipment. People use many unaided methods to communicate; for example, body language, pointing, eye pointing, facial expressions, vocalisations, gestures. Some people use different types of signing. Aided communication requires additional equipment, ranging from simple picture materials to a computer or special communication device.
3. Aided methods may be low technology or high technology i.e. Voice Output Communication Aids (VOCAs). Low technology devices include anything that is not powered; for example, everyday objects, charts and communication books with pictures, symbols or photos, alphabet charts as well as pen and paper. High technology devices require at least a battery to operate. High-technology communication systems also known as Voice Output Communication Aids (VOCAs) range from simple (e.g. single message devices such as a Bigmack, Go Talk, pointer boards, toys or books which speak when touched) to very sophisticated systems (e.g. specialised computers and programs, electronic aids which speak and/or print).
4. Some people may use alternative devices to control their aided AAC system, such as a switch, light pointer or a device to control an on-screen pointer. People who normally use a high technology device will usually have a low technology communication system in place. For example, a speech output device is suitable for using over the telephone, or in normal conversation. A paper-based communication system would be more appropriate for a private conversation, in a noisy place, or where a high technology device is inappropriate, for example at a swimming pool or perhaps when travelling, or in those instances where the technology breaks down. Increasingly, communication aids and computer technology can be integrated with other equipment, such as mounting systems, specialist seating and environmental controls.

Additional key policy papers and good practice documents

Policy:

1. Equality Act 2010 and the Disability Discrimination Act 1995: http://www.odi.gov.uk/disabled-people-and-legislation/equality-act-2010-and-dda-1995.php
2. Under the Equality Act 2010 Schedule 10: http://www.legislation.gov.uk/ukpga/2010/15/schedule/10 local authorities in England and Wales must, in relation to schools for which they are responsible, prepare an accessibility strategy to increase the extent to which disabled pupils can participate in the schools' curriculums, improve the physical environment of schools, and improve the delivery to disabled pupils of information.
3. [Pending update in February]: Part IV of the Education Act 1996 http://www.legislation.gov.uk/ukpga/1996/56/contents covers special educational needs including duties of local education authorities and school governors, assessments and statements of SEN and provision of services.
4. Office of Disability Issues (ODI) Independent Living Strategy (ILS) which contributes towards the government's work to implement the United Nations Convention on the Rights of Disabled People: http://www.odi.gov.uk/odi-projects/independent-living-strategy.php .
5. ODI leads on the Right to Control Trailblazers, pilot projects for personal budgets for disabled people bringing together various strands of government funding: http://www.odi.gov.uk/odi-projects/right-to-control-trailblazers.php
6. Personal budgets for social care are being rolled out across England and have to be universally available by April 2013 under the government's vision for adult social care: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121508
7. The Department of Work and Pensions (DWP) is responsible for the Access to Work employment programme for disabled people, which can be used to fund AAC equipment: http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/DG_4000347
8. The Department for Culture, Media and Sport has launched the eAccessibility Plan, a detailed package of measures towards a more inclusive digital economy for disabled people: http://nds.coi.gov.uk/Content/detail.aspx?NewsAreaId=2&ReleaseID=415918&SubjectId=2

Good practice documents:

9. Better Communication Action Plan: http://www.dcsf.gov.uk/slcnaction/
10. AAC Care Pathway document: West Midlands ACT service: http://www.sbch.nhs.uk/about-us/divisions-and-directorates/specialist-services/rehabilitation/west-midlands-rehabilitation-centre/services/act/
11. The Consumer Expert Group's 'Report into the use of the internet by disabled people: barriers and solutions'(2009): http://www.culture.gov.uk/reference_library/publications/6378.aspx
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14. Royal College of Physicians (2004) 'Specialist equipment services for disabled people: The need for Change' http://bookshop.rcplondon.ac.uk/details.aspx?e=153
15. Royal College of Speech and Language Therapists 'Clinical Guidelines' include references to AAC: http://www.rcslt.org/members/publications/clinicalguidelines

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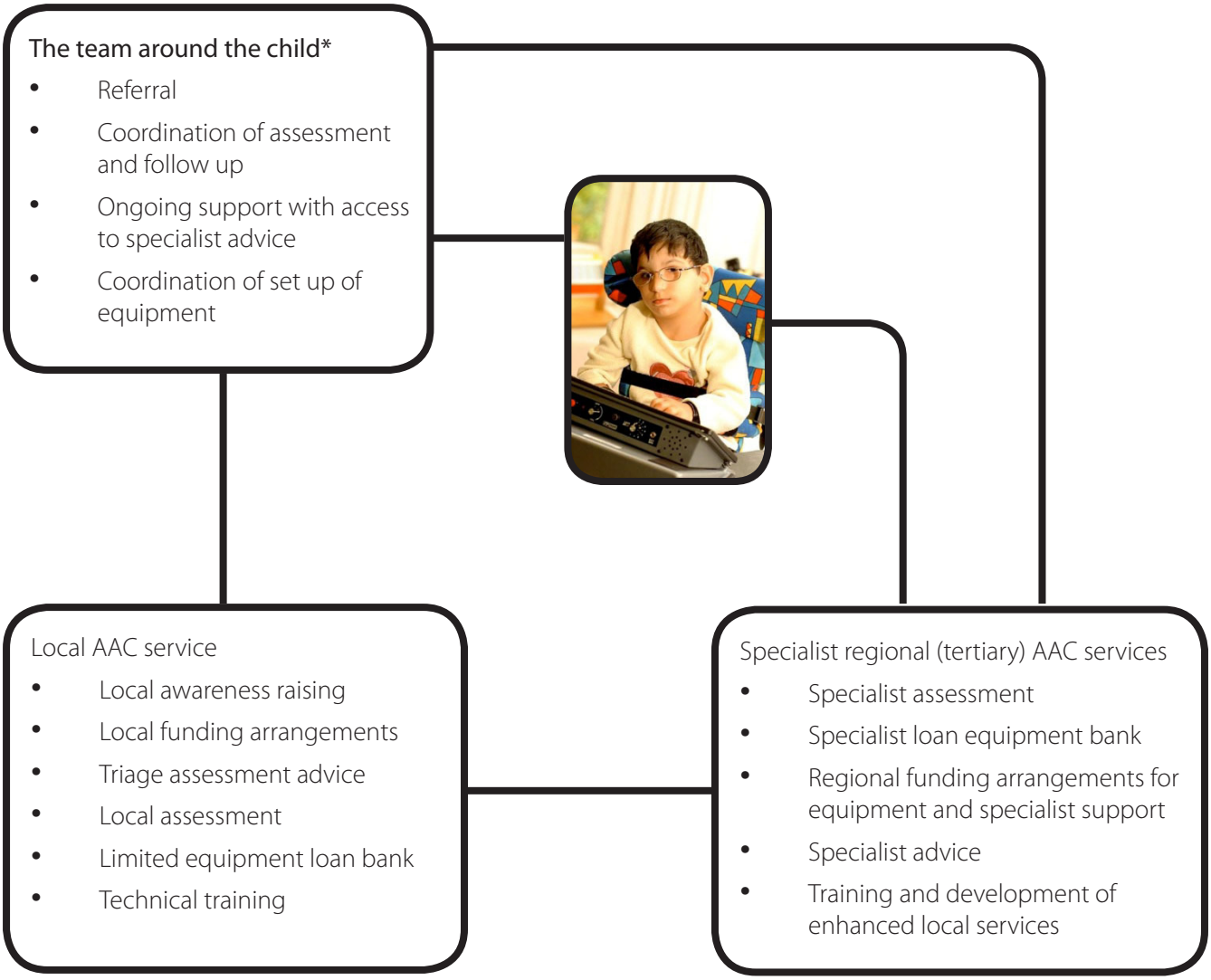
Appendix 1: Elements of local and specialist service that need to be commissioned to secure a full AAC service

Source: The Office of the Communication Champion Report[4]

Figure 1

The interface between local and tertiary (regional) services



*This diagram makes reference to a child in the source document. However, the diagram is also applicable to adults

Appendix 2: Statistics for prevalence of AAC need

	Total population in England (mid-2009)[51]	Scope estimate[5] that 0.6% of the population need a level of AAC support	The OCC report[4] estimates that 0.05% of people in England would benefit from high technology AAC equipment and strategies
	'000s	'000s	'000s
	51,810	311	26
By age group:			
0-19	12,387	74	6
20-90+	39,422	237	20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