

Specialised AAC provision Commissioning national services

Office of the Communication Champion and Council November 2011





This report was commissioned by the Office of the Communication Champion and Council, and authored by Keren Down MBE, Director of the Foundation for Assistive Technology, with support from Anna Reeves, Communication Coordinator.

The Communication Coordinator was appointed by government to help to ensure that the Augmentative and Alternative Communication sector provides strong, sustainable services which meet the needs of local authorities and primary care trust commissioning services.

The Communication Champion was appointed by government to provide a strong independent voice for children with communication needs, driving improvements in services by working with national, regional and local partners.

The Communication Council is an advisory body, set up by government to monitor, support and advise on initiatives to improve services for children and young people with speech, language and communication needs.

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Executive Summary

This report was commissioned by the Office of the Communication Champion and Council. It follows an earlier report in September 2010,¹ which proposed improvements to the system for commissioning services for children and adults who need augmentative and alternative communication aids (AAC). This second report aims to operationalise the earlier proposals, so as to inform arrangements for commissioning of specialised AAC services under new NHS arrangements.

It provides:

- a proposed model of care for specialised and local AAC services
- a care pathway that identifies the interdependence of specialised hub and local spoke AAC services
- quality standards for AAC, developed by the Communication Council in wide consultation with the AAC sector
- a proposed tariff for services and equipment, and costings over a three year period.

Provided separately is a model Service Specification for specialised AAC services.

The prime purpose of this report is to inform specialist commissioning. The report will, however, also support clinical commissioning groups and Health and Wellbeing Boards in developing specifications for local AAC services.

Recommendations

It is recommended that:

- the models proposed in this report are adopted by the NHS Commissioning Board and by local NHS and local authority commissioners
- the NHS Commissioning Board commissions the specialised regional 'hub' AAC services described in this report, so that they are in place in all four regions by no later than April 2013, and can deliver services which comply with the sector's Quality Standard
- Around £14,000,000 is made available for these specialised services from NHS budgets in the 2013-14 financial year
- Clinical Commissioning Groups , working with Health and Wellbeing Boards, commission effective local 'spoke' AAC services which comply with the sector's AAC Quality Standard
- Clinical Senates include members with relevant expertise in AAC, such as specialist speech and language therapists, so that they can advise on how best to commission the AAC Pathway linking local and specialist AAC services.

Background

The provision of services for children and adults with communication impairment has recently been described as 'unacceptable'² with families perceiving there to be a 'post-code lottery' and service providers acknowledging that national coverage is 'variable' and 'ad hoc'¹. For children and their parents, for adults who need equipment by which to achieve

¹ The Office of the Communication Champion (OCC) report, September 2010. <u>http://www.thecommunicationcouncil.org/council/communication-council-papers/meeting-on-16-</u> september-2010/

² The Bercow Report, July 2008. Available from the DfE website: <u>http://www.education.gov.uk/publications/standard/publicationdetail/page1/DCSF-00632-2008</u>

their communication goals, and for professionals who work with them, the current situation appears unclear and unfair.

"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."

Teacher in a special school, quoted in One Year In, Communication Champion, 2011³

"I am currently trying to get funding for an assessment and a new communicator more suitable for my developing needs. I am unable to get any help either from the NHS or Social Services – both saying it is the other's responsibility. My only option seems to be the charitable route – yet again."

Scope, No voice, no choice campaign, Communication Aids Survey respondent, 2007⁴

John Bercow MP has urged government, commissioners and service providers to recognise that: 'Communication is crucial. Recognising that is right in terms of equity for those in need and right in the national interest as we all wish to cut the costs of failure and to increase the productiveness of our country.' Many people with communication impairment testify to the empowering role of technology:

"My aid has enabled me to live independently in my own home, employ my own care staff, set up my own business (self-employed), earn enough to come off meanstested benefits, earn enough to buy my next new AAC device soon." Scope's No voice, no choice Communication Aids Survey respondent, 2007

There are a range of strategies and interventions that aim to support people with a communication impairment, one of which is the use of augmentative and alternative communication aids (AAC). AAC is an umbrella term for devices, systems and interventions that include an element of technology, ranging from 'low technology' devices and systems (such as paper and pen and picture, symbol and phrase boards) to 'high technology', powered devices and systems that produce vocal or displayed communication.

Stakeholders in the AAC sector, including service users, professional bodies, service providers and charities such as Scope⁴ and Communication Matters, have for many years raised concerns about inequality of access to local AAC services, to the more specialised regional AAC services and to AAC provision. The previous government recognised that there were problems in access to all types of support for children and young people with speech, language and communication needs (SLCN). It asked John Bercow MP to carry out a review² which reported in 2008, and led to the appointment of the Communication Champion for children and young people aged 0-19 in England.

On AAC the Bercow Review found that 'children and young people who require AAC face a particular struggle to have their needs met under the current commissioning arrangements' and that there was no consistent or equitable system (locally, regionally or nationally) for ensuring that those who need communication aids receive them. The Review recommended a 'hub and spoke' model for AAC services, whereby local services would be supported by regional centres, and that the Communication Champion should review the effectiveness of AAC provision across the country.

³ One Year In. Office of the Communication Champion, January 2011.

http://www.thecommunicationcouncil.org/champions-reports/

⁴ No voice, no choice campaign, Scope, 2008. <u>http://www.scope.org.uk/help-and-information/communication/no-voice-no-choice</u>

The Office of the Communication Champion (OCC) report *Augmentative and alternative communication: a report on provision for children and young people in England* published in September 2010¹ found some good practice in AAC provision: some primary care trusts and local authorities were providing local multi-agency specialist teams with specific budgets and some local services were supported by regional centres of excellence. However, available data indicated that the estimated level of need was not being met and, while NHS guidance indicated that specialised equipment services should be commissioned regionally,⁵ only one of ten NHS regional commissioning teams was fulfilling this function for AAC services. The OCC report endorsed Bercow's vision of a 'hub and spoke' model for AAC services and included recommendations to improve the commissioning of local services⁶ and develop AAC quality standards.⁷ Recognising that under planned changes to the NHS,⁸ the proposed NHS Commissioning Board would take over responsibility for the commissioning of specialised services, it recommended that:

- government ask the new NHS Commissioning Board, once established, to take forward the commissioning of regional AAC 'hubs' as a matter of urgency;
- government consider commissioning regional AAC hub services on an all-age basis, that also includes the full range of high technology assistive technology as well as communication aids'.

The government's Special Educational Needs (SEN) Green Paper *Support and aspiration: a new approach to special educational needs and disability*,⁹ published for consultation in March 2011, aims to reinforce the role of local authorities in working with health services. Service users will have a single assessment process and a combined education, health and care plan to run from birth to 25 years old. The Green Paper includes these commitments on the commissioning of AAC services:

'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.'

According to the latest plans, the NHS Commissioning Board will operate in shadow form from October 2011, taking over its full responsibilities, including specialised commissioning,

⁵ Definition No. 05: Assessment and provision of equipment for people with complex physical disability (all ages), Edition 3, 2010. <u>http://www.specialisedservices.nhs.uk/doc/assessment-provision-equipment-people-with-complex-physical-disability-all-ages</u>

OCC recommendations on commissioning of AAC. <u>www.thecommunicationcouncil.org/commissioning</u>
 Quality standard for AAC services, Communication Matters, 2010:

http://www.communicationmatters.org.uk/page/resources/national-standards-aac-services
 The NHS White Paper 'Equity and Excellence: Liberating the NHS',

http://www.dh.gov.uk/en/Healthcare/LiberatingtheNHS/DH_122624

⁹ Support and aspiration: a new approach to special educational needs and disability, Department for Education, March 2011.

https://www.education.gov.uk/publications/standard/publicationDetail/Page1/CM%208027

in April 2013.¹⁰ In this transitional phase specialised regional commissioning will be carried out through four clusters of strategic health authorities. A more uniform approach to this work across the country will be developed, which will include national standardisation for access to services and convergence of contracts, policies and service specifications.¹¹

Specialised NHS commissioning is based on the 'Specialised Services National Definitions Set'. Definition No. 5⁵ which covers the 'assessment and provision of equipment for people with complex physical disability (all ages),' including environmental control services, other electronic assistive technology services, and communication aid services. Specialised Services National Definitions Set (SSNDS) Definition No. 5 refers to a hub and spoke model as an effective service delivery model.

Local AAC services

While focusing on the service model for specialised AAC services, the importance of comprehensive, well resourced local spoke AAC services is emphasised throughout this report. 90% of the needs of a local AAC population for assessment and for a range of interventions, including low tech AAC, should be met by the local AAC spoke services operating across health, social services and education. 100% of the needs of the local AAC population for on-going support, including for the implementation of high tech AAC, will need to be met by local AAC spoke services. It will be important that Clinical Commissioning Groups (subject to legislation), working with the Health and Wellbeing Boards, consider the potential for Joint Strategic Needs Assessments as a vehicle for commissioning local AAC spoke services, in line with the proposed model of service set out in this report.

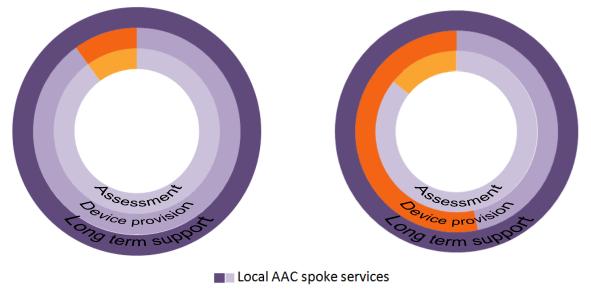
Given the current pressures on budgets available to local NHS, social care and education commissioners, it must be emphasised that any investment by the NHS Commissioning Board in specialised AAC hub services will not be effective without adequate resourcing of local AAC spoke teams. The Office of the Communication Champion has previously highlighted the common experience of children falling 'down the metaphorical cracks between two systems (health and children's services)'. The need to communicate underlies every activity undertaken by an individual – social and community, learning and employment – and agencies have often disputed their 'share' of the costs. This report clarifies, for adults and children, the share of responsibility between different agencies at local and regional levels so that such disputes do not continue.

The proposals in this report do not constitute a case for reduced provision at local level, rather they emphasise the crucial role of local AAC spoke services, for children and adults, particularly for providing long term support for 100% of their local AAC clients, including those using high tech AAC systems. In terms of activity, local commissioners will bear sole responsibility for 90% of the total AAC population for assessment (representing approximately 86% of total budget required for assessment services) and 100% of the total AAC population for low tech AAC device provision (representing approximately 47% of the total budget required for AAC device provision). The report therefore identifies an activity plan and required budget for local services and recommends that local Clinical Commissioning Groups, working with Health and Wellbeing Boards, establish local spoke AAC services that have the capacity to deliver these activities and can comply with the sector's Quality Standard for AAC services.

¹⁰ Developing the NHS Commissioning Board, DH, 2011: <u>http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH 12811</u>

¹¹ Director of Provider Policy to PCT Chief Executives, August 2011. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128894.pdf

Diagram indicating relative proportion of activity in low and high tech AAC assessment, device provision and long term support at local and regional levels. Diagram indicating relative proportion of resources required to fund low and high tech AAC assessment, device provision and long term support at local and regional levels.



Regional AAC hub services

A phased approach

Taking into account the under-provision of local and regional services in relation to the estimated size of the population who require AAC services and the need to build capacity within specialised and local AAC services, the report proposes a phased approach to commissioning of specialised AAC hub services. The primary role of the specialised AAC hub services in the first two years will be to work with local commissioners to establish a comprehensive coverage of local AAC spoke services across their region.

The specialised AAC hub services will work with the developing local AAC spoke teams to provide training and to establish a collaborative approach to outcomes measurement and data gathering on which to base quality assurance, service development and to inform future commissioning practice. Over the three years this work will reduce as a comprehensive coverage of local spoke services is established and collaborative care planning processes are put in place.

Specialised AAC services will work with their local AAC spoke teams to build their capacity to manage directly the needs of 90% of the region's AAC population and to jointly manage the needs of the 10% of the region's population that require specialised AAC services. As this level of development work reduces, the AAC local and hub services will work with an increasing proportion of the AAC population that require services. This phased approach means that at the end of year three the specialised AAC hub services and local AAC spoke services will be working to capacity and within 5 years will have been able to address the needs of the total population that require AAC.

The report therefore recommends the development of strong collaborative working between local and specialised AAC services within the four regions aligned with the SHA cluster boundaries. During the three year development phase we recommend that the four specialised AAC hub services work collaboratively with other regional services to establish

an approach to procurement that maximises value for money while sustaining a dynamic and innovative UK manufacturing base.

Having established the evidence on prevalence, using estimated average costs for equipment provision and assuming a phased approach to building capacity to deliver services, we propose that a specialised commissioning budget is required of approximately £14 million in year one, £23 million in year two and £35 million in year three (when 100% capacity should be reached) to establish specialised AAC hub services and to support the development of a comprehensive coverage of local AAC spoke services across England.

This report offers concrete proposals for taking forward the Communication Champion's recommendations for the commissioning of specialised AAC services as regional hubs supporting local services, and for meeting the commitments in the SEN Green Paper. It is based on the Specialised Services National Definitions Set No. 5. and is informed by the Quality Standard for AAC services which has been endorsed by the AAC sector. Commissioners of specialised NHS services can use this report, and the model service specification which accompanies it, to establish a more uniform, standardised and equitable approach to the commissioning of specialised AAC services.

Alongside these proposals is a recommendation that local commissioners in the emerging Clinical Commissioning Groups and Health and Wellbeing Boards consider the report, the proposed interdependency between local and specialised services, the activity plan and the estimated budget required to establish local AAC spoke services. To this end, it will be essential that Clinical Senates, in their role as advisors on the commissioning landscape, should have members (such as specialist speech and language therapists) with relevant expertise to advise on how best to commission the Pathway linking local to specialised AAC services. The proposals for specialised AAC hub services depend on getting local services right and for local services to work in partnership with specialised services to support adults and children with communication impairment so that they have the opportunity to participate fully in our society.

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The context for commissioning specialised AAC services

Specialised AAC services deliver high-cost, low-volume interventions that aim to restore a degree of communication for severely or profoundly communication impaired people. Communication impaired people in this context means those adults and children who have an impairment that impacts on their ability to communicate using speech and/or language or written communication. This does not cover those people with communication problems arising primarily from hearing or vision impairments.

Communication impairment may result from physical, sensory, intellectual, learning or cognitive disabilities. This would include children born with a communication impairment (for example and in no order of precedence, those resulting from cerebral palsy, developmental disorders and learning disabilities such as autism) and children and adults who become communication impaired (for example through stroke, cancer, brain and spinal injury and neurological diseases such as Parkinson's, Alzheimer's, Multiple Sclerosis or Motor Neurone Disease).

There is no agreed approach to distinguishing between low and high tech AAC and for the purposes of this report we refer to any powered communication device as high tech. In service delivery there will be a less rigid distinction and a more appropriate categorisation approach is likely to be developed over time. Other terms for this range of equipment include: assistive technology (usually this is used to indicate a wider range of technology for disabled and older people); electronic assistive technology (a sub-set that includes powered wheelchairs, environmental controls, telecare, etc); and voice output communication aid (VOCA) a term which indicates dedicated devices to produce vocal utterances.

The high tech AAC referred to this in this report indicates a range of systems based on powered devices that use a microprocessor or a computer that uses language and communication software designed to produce communicative utterances, either spoken or displayed. AAC systems may additionally include any of the following elements:

- access and control by switches and control devices operated by hand, foot, body, head, breath and eye;
- mounting systems for securing devices, switches and control devices onto wheelchairs or other equipment;
- positioning and support systems provided to the individual (often using a wheelchair) in order to access the AAC system.

The high tech AAC systems may additionally be used to control sensors and switches which are installed in the physical environment, such as door opening controls, etc. and so can provide an element of an environmental control system.

There is therefore a complex set of issues to be considered during the assessment and decision making processes that lead to an effective communication intervention and an AAC device recommendation. Benchmarked against the complexity of a decision making matrix for related electronic assistive technologies, that for AAC provision is amongst the most complex.

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 specialised and mainstream communication technologies. There is also the potential for much of the technology to reduce in price, particularly if procurement opportunities are used creatively, in close co-operation with manufacturers and suppliers. Meanwhile new innovations, such as eye-gaze technology are increasing the opportunities for people with profound

communication impairments to communicate for the first time. Such innovations tend to come down in price at larger volumes. The report proposes a model of care that can cost-effectively exploit available and emerging technologies to maximum benefit.

Evidence base

The evidence base regarding the use of high tech AAC has been well set out in a recent systematic review which was commissioned by Communication Matters¹² and undertaken by the University of Sheffield School of Health and Related Research (ScHARR).¹³

The review identifies 133 papers published in peer reviewed journals and draws conclusions from the available evidence, noting caveats based on the lack of large-scale, well-designed studies. In summary the review notes the following conclusions in relation to benefits:

- A disparate range of outcome measures had been used in the studies including increases in narrative, word flow, longer utterances, requesting, responding, communication effectiveness, engagement, spelling a target word, and yes/no indication. In addition to these evaluations of the content of communication, authors considered take up of devices, degree of usage, use in a functional setting and views of users and their family members.
- The outcomes of intervention were mostly reported as positive including 5 of the 6 papers using linguistic analysis, 21 of the 27 using number of initiations or attempts to communicate, both papers using measures of communicative effectiveness, and all 12 using the percentage that were correctly selected as an indicator. Papers which reported usage/ take up suggested that 30-50% of devices offered were accepted and used successfully. A range of benefits were identified by users and their families including increased social and educational opportunities, independence and employment, as a means of participation and enabling choice.
- Those reporting mixed outcomes included those studies which used outcomes of verbal comprehension/ correct selection, standardised language measures and intelligibility and the use of speech generating software.
- There were also a few papers which compared high versus low tech devices which indicated that low tech may be preferable for some clients, notably for those people with Alzheimer's.

Factors relevant to this report that have been identified in the studies and which impact on take-up and use of high tech AAC include:

- the ease of use of the device; reliability; availability of technical support; the voice/ language of the device; the time taken to generate a message;
- the process of making decisions regarding choice of a device; fit between user and system; level of staff training; the availability of specialised services;
- family attitudes, perceptions and roles; other people interacting with an AAC user; and other factors such as attitudes of realism and ownership.

Evidence regarding service delivery models is reported as limited but includes:

- studies that suggested that the training of staff in schools may impact on outcomes, together with the degree of team working.
- Indications that speech and language therapists perceive that they have limited knowledge and skills regarding high tech AAC, from which may be inferred a need for greater training.

¹² Communication Matters is a UK 3rd sector organisation for people who use AAC, their families, care networks and the professionals who support them. <u>http://www.communicationmatters.org.uk/</u>

 ¹³ Baxter, S. et al., 2011. Barriers and facilitators to use of high technology augmentative and alternative communication devices: a systematic review and qualitative synthesis. International Journal of Language & Communication Disorders, (In press).

The Office of the Communication Champion (OCC) report additionally notes the following estimate of economic benefits of providing high tech AAC: "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".¹⁴

A consistent recommendation from the studies, literature reviews and sector analysis that has been undertaken is the requirement for better data collection to create a robust evidence base to inform good practice and good commissioning of services.

General overview

Need/ prevalence

The data on the prevalence or incidence of communication impairment in the population, or of the proportion of this population who may benefit from the use of AAC techniques and equipment at any level, is not extensive. Existing levels of service provision are a poor indicator of need due to lack of specialised service provision. Analysis of the evidence base has been undertaken to establish the most robust indicators of the level of need:

Total AAC population

- Blackstone, S. et al indicate that between 0.4 and 0.6% of the total population (children and adults) require AAC, based on international evidence.¹⁵ These figures indicate the broad group that would benefit from low and high technology AAC equipment and strategies.
- For the purposes of this report we have used a figure of 0.33% for children (0-15 years) and 0.54% (16+ years) for adults, for the proportion of the population who require AAC at some level, low or high tech. These figures together approximate to 0.5% of the total population. The higher figure for adults reflects an assumption that those using AAC in childhood will continue to do so as adults, and be joined by those who become communication-impaired in adulthood, for example through stroke, cancer, spinal injuries and neurological diseases.

Proportion of population requiring high tech AAC

- There appears to be little significant national or international research on the proportion of the AAC population who might benefit from high tech AAC compared to low tech AAC. This is compounded by the lack of clear categorisation approaches.
- The OCC Report¹ provides an estimate of prevalence of 0.05% of children and young people needing high technology AAC, i.e. 10% of the total number of the AAC population. This estimate was derived from the following information:
 - In 2008, under Scottish Ministerial direction, a Short Life Working Group was set up to address the needs of children and adults using AAC in Scotland. The remit of the group included a scoping activity to provide cost projections and involved an audit of existing provision across Scotland. An analysis of the data by the Communication Co-ordinator indicated that 0.05% of the total population (adults and children) had been provided with a high tech communication aid. (This was extrapolated to indicate 10% of the AAC population.)
 - Similar data from Norfolk, where there is an established budget for high tech AAC, was analysed by the Communication Co-ordinator. This also indicated that

¹⁴ DfE figures in the impact analysis for the clause relating to inspection of special educational needs in the Children, Schools and Families Bill 2009-10 identified that, if 2 pupils benefit from that clause to the extent that during their working lives their employment status changes from permanent unemployment to permanent employment, this would realise benefits of £1 million

¹⁵ Blackstone, S. (1990) Populations and Practices in AAC Augmentative Communication News Vol. 3 No.4

this budget met the need for 0.05% of the population of children aged 4 to 19 years. (This was extrapolated to indicate 10% of the AAC population.)

- The ScHARR literature review notes that some studies indicated a need for high tech AAC of 12% and 19% of the AAC population for children and adults respectively.
- This figure was supported by 28% of current specialised AAC services when consulted. 19% did not agree with this figure and 53% did not know whether this figure was accurate or not. There was no consistency in the responses from services that did not agree with this figure except that they felt this was too low a proportion, with proposed proportions ranging from 10% to 60%.
- In this report a prevalence figure of 10% of the AAC population is being used to indicate the proportion of people who required high tech AAC (i.e. 0.05% of the total adult and child population).

Proportion of the population who require specialised assessment and low tech AAC

- There is also no evidence on the proportion of the AAC population who require specialised AAC assessment due to complex needs who go on to require low tech AAC interventions or who already have a low tech AAC device but for whom expert assessment is required to establish the most effective intervention and support programme.
- Given the lack of data we propose that referrals for individuals who fall into this category are accepted by specialised AAC hub services and that data is collected on the service need. Adjustments to activity plans in relation to this service need should be assessed and made at the end of year two.

The recommendation is therefore that 90% of adults and children requiring AAC can be dealt with effectively at a local level, and that 10% of the AAC population are likely to require a referral to specialised AAC services for a high tech or specialist AAC intervention. As a benchmark, under the original plans for NHS reform in England⁸ local healthcare commissioning was proposed as covering around 80% of total, with 20% of commissioning relating to specialised services.

Statistics for prevalence of AAC need (figures indicate total, not annual, need for service)

			AAC Population: Est. 0.5% average of whole population who		Low tech AAC needs: est. 90% of AAC pop would		High tech AAC needs: est. 10% of AAC pop would		
			Adults						
		(0-15)	(16-90+)	(0-15) (approx. 0.33%)	(16-90+) (approx. 0.54%)	(0-15)	(16-90+)	(0-15)	(16-90+)
	51,092,100	9,655,800	41,436,400	31,864	223,599	28,678	201,381	3,186	22,360

Expected outcomes

Expected outcomes from the delivery of specialised AAC services are:

- to support clients to attain their personal communication goals;
- to provide timely access across England for the estimated population that require specialised AAC services;
- to increase adoption and use of appropriate high tech AAC interventions and minimise abandonment of these AAC systems;

¹⁶ Population figures are based on mid-2007 census: latest available SHA cluster population figures which are used in later analysis

• to support the development of effective local AAC teams and care pathway procedures by which to manage referrals to specialised AAC services.

It is currently difficult to identify the best approach to measuring the benefits to clients of a specialised AAC service as there is no consensus on the best way to do this. Outcome measures such as PIADS, TOMS or Goal Attainment Scaling are currently in use in some specialised AAC services. Further guidance on appropriate outcome measures should be available in 2012 as a result of activity by a Communication Matters AAC Outcome Measures working group.

It will be expected that specialised AAC services will put in place mechanisms to measure relevant activity such as access to services, high tech AAC system adoption and abandonment rates across the region, as well as activity undertaken to implement local care pathway processes. It would also be expected that specialised AAC hub services would measure indicators of activity to meet the quality standards noted in Appendix 1.

The OCC report notes¹⁷ a requirement for specialised hubs to undertake data collection, including data on regional prevalence and the impact of AAC provision and allied support (outcome measurements), in order to inform the work of the NHS Commissioning Board.

Service scope

In line with the recommendations from the Communication Champion¹ regional services should provide specialised AAC interventions, including the provision of high tech AAC, to people of all ages across England. In line with government policy^{18 19 20} the services may be provided by statutory, voluntary or private sector organisations, or by a consortium of organisations, dependent on compliance with the required standards and capacity to meet commissioners' expectations of service delivery.

Service descriptor

Using the basis of good practice and the approach indicated in the Specialised Services National Definition Set (SSNDS)⁵ the proposed AAC specialised service model will be based on a hub and spoke model of service delivery.

- The term 'specialised AAC hub service' indicates a range of activities to be undertaken (see service model section) rather than a presumption that there must be a centralised hub location or provision of hub services by a single organisation.
- The service has to be sustainable based on the size of its geographical catchment area and population which makes cost-effective a level of specialism (where specialism indicates both the focus on AAC (high tech AAC particularly) and a more expert level of competence).

- ¹⁸ Procurement Guide for Commissioners of NHS-Funded Services, Department of Health, July 2010. Available from:
 - http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_11821

¹⁷ The OCC report (footnote reference 1) page 22

¹⁹ The Principles and Rules for Cooperation and Competition, Department of Health, July 2010. Available from:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_11822

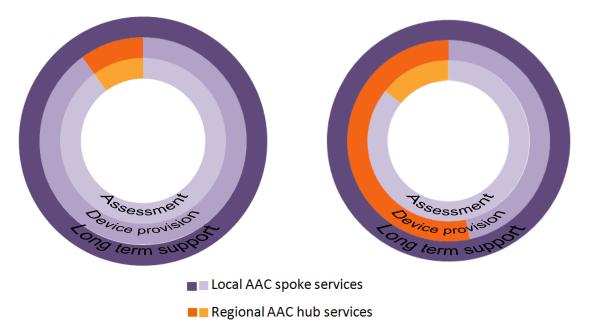
²⁰ The NHS standard contracts for acute hospital, mental health, community and ambulance services and supporting guidance 2011-12 (effective from 1 April 2011). Available from: <u>http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_12432</u> <u>4</u>

Funding model

The SEN Green Paper⁹ notes a commitment, subject to Parliamentary approval, that the commissioning of highly specialised services, including AAC, will become a core responsibility of the NHS Commissioning Board. This follows the commissioning model for environmental controls, wheelchairs, prosthetics and other specialised services in the SSNDS Definition 5. In the period before the NHS Commissioning Board is established, this commissioning role will be undertaken by the SHA Cluster Special Commissioning Groups.

The proposals in this report do not constitute a case for reduced provision at local level, rather they emphasise the crucial role of local AAC spoke services, for children and adults, particularly for providing long term support for 100% of their local AAC clients, including those using high tech AAC systems. It is essential that local spoke services build on existing joint commissioning arrangements, with NHS clinical consortia working closely with social care and education services to meet the needs of their local AAC child and adult population.²¹ In terms of activity, local commissioners will bear sole responsibility for 90% of the total AAC population for assessment (representing approximately 86% of total budget required for assessment services) and 100% of the total AAC population for low tech AAC device provision (representing approximately 47% of the total budget required for AAC device provision).

Diagram indicating relative proportion of activity in high and low tech AAC assessment, device provision and long term support at local and regional levels. Diagram indicating relative proportion of resources required to fund high and low tech AAC assessment, device provision and long term support at local and regional levels.



Consultation undertaken in drafting this report indicated a significant level of concern about the use of the referral process to shift responsibility for funding AAC systems from local to regional commissioners. This has been a feature of previous funding initiatives and arises from a failure to put in place a whole system approach to AAC service provision, from local to regional levels. It is proposed that the issue of budget management through inappropriate

²¹ The OCC report notes (p23) 'In this model, 'spoke' AAC services would continue to be commissioned locally, alongside other community children's services, in ways that fit particular local needs and resulting service configurations. In some areas, for example, GP consortia together with the local authority might commission integrated services for disabled children which work out of special schools. In others, the services might be provided differently.'

referrals is managed through rigorous employment of the care pathway process. The specialised AAC hub services will monitor local teams' referral rates and referral rationale and work collaboratively with local teams and commissioners to address significant variance from the proposed levels of sole management by local spoke teams of 90% of the AAC population.

It would also be appropriate for specialist AAC hubs to re-charge local commissioners for their services, when referrals are made inappropriately due to lack of effective local spoke services.

The NHS Commissioning Board should commission specialised assessment services and high tech AAC system provision for individual use. Present ad hoc arrangements and funding sources for AAC system provision, such as Access to Work, Disabled Students Allowance (DSA), and compensation payments, should in future be used for AAC system needs relevant to those specific environments or tasks, e.g. employment, education, social, etc. It is proposed that an individual carries the 'core' device and portable elements of the system with them and the non-portable elements such as environmental sensors, peripherals, switch and access components, and mounting systems, that cannot feasibly be portable and re-set up in their key environments, are replicated in relevant environments. The individual would therefore require a system set up at home for personal use, the high tech AAC elements of which would be commissioned by the NHS Commissioning Board, but those non-portable high tech AAC elements required within school, college or work environments would be funded by the relevant education or access to work commissioners.

Elements of the system, including vocabularies or software, that relate to specific tasks such as learning or work, should also be commissioned through these funding routes. Coordination of these replicated elements of the system should always be through the local spoke AAC service, who will refer to the specialised AAC hub service where required and may use the procurement arrangements provided by their specialised AAC hub service.

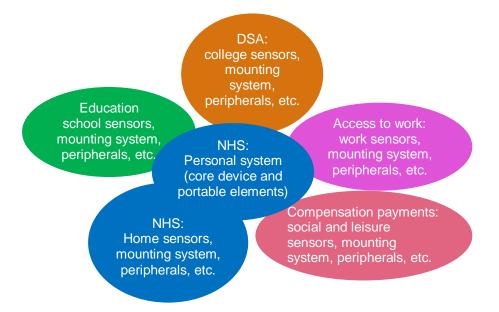


Diagram to indicate the commissioning relationship for the provision of AAC systems and elements.

The Department for Education is considering²² the provision of auxiliary aids (more widely known as assistive technology) for disabled children by schools / local authorities. This enquiry is consequent to the queries raised in the Lamb Inquiry into parental confidence in the SEN system and the amendment to the Equality Act which ceases the exemption of schools from the requirement to make reasonable adjustments to provide auxiliary aids for disabled children. The proposals in this report would mean that education commissioners, in addition to ensuring the physical structure of the building and curriculum, ICT and learning tools are fully accessible to any disabled child would have, in relation to AAC system provision, sole responsibility for funding:

- low and high tech AAC systems within a school environment which are intended for use by multiple children;
- elements of any child's personal AAC system, such as switching, mounting and access elements, that are not easily portable and need to be replicated within the school environment;
- software and vocabularies that relate to the task of curriculum learning, including home access to the curriculum;
- sensors and environmental control peripherals (door opening mechanisms, etc.) that need to be provided within the school in order to provide control by the child using their AAC system.

Local education, health and social care commissioners, including schools, would be jointly responsible for provision of all low tech AAC devices and interventions for the local AAC population.

These local commissioners would also have responsibility for ensuring that all those in regular contact with those who use high or low tech AAC (at home, at school or college, in short break provision) have training in how to support optimum use of the communication aid. In school settings this will involve the funding and training of teaching and support staff to ensure the individual can fully access curriculum materials and can use learning tools and that their learning and development needs are being supported by their communication strategies. It will also require supplementary work, for example, to provide training to communication partners, including other children, to ensure they are supportive of communication by the individual using their AAC system. The relative costs of this activity are likely in many cases to be of a greater order than the costs of the device. Such implementation support is probably the most significant factor in securing the outcome of effective communication and, consequently, maximising the learning and educational potential of the child.

A similar scope of funding would be relevant to DSA and Access to Work commissioners.

It is highly unlikely that it will be possible to implement a system of commissioning via personal budgets for high tech AAC systems and specialist intervention. The setting of a personal budget relies on a non-specialist being able to apply a relatively straightforward method to correlate impairment or capability with a restricted range of off-the-shelf systems. Unlike for relatively standardised, single unit systems, such as hearing aids, it is not possible to identify on an individual basis a client's potential requirement for different elements of an AAC high tech system, including vocabulary, switch and access control, interoperability solutions, and mounting and positioning supports. Providing averaged costs for devices and setting out related activity plans is only possible on a population basis due to averaging

²² Department for Education consultation document: <u>http://www.education.gov.uk/consultations/index.cfm?action=conSection&consultationId=1774&dId=1127</u> <u>&sId=7234&numbering=1&itemNumber=1&menu=1</u>

between clients (e.g. a small number may require an eye-gaze system at £10k-15k while significantly greater numbers of clients may require a PC-based system at £800).

There may be the potential to use personal budgets for some categories of AAC intervention at a non-specialist level. The assessment for this would be most likely to be effective at the point at which the local AAC spoke team undertake the initial assessment of the requirements of each individual. Given the lack of standardised approach and poor understanding of the variation in need on a population basis, it is recommended that no blanket decisions are made with regard to the use of personal budgets for any AAC requirement until the specialised AAC hub services and local AAC spoke services have been running for two years. At this point there is likely to be sufficient information available to estimate the proportion of clients for whom personal budgets might be an effective approach.

Accessibility/ acceptability

In line with the definition of specialised services, "it is the complexity and severity of the person's condition, and the expertise required to assess/ support and provide/ maintain equipment for each individual that defines a requirement for a specialised AAC service as opposed to the nature of the equipment itself. However, currently there are no standard tools available to distinguish between specialised and non-specialised service activity."²³

Without standard tools, the requirement for a specialised AAC service must arise when the task of matching the individual to the most effective solution is judged, by the local team themselves, as beyond their capability. It is proposed that self reflection and judgement of capability by local teams will be supported by training and professional development support from the specialised hub teams.

The breadth of issues to be considered when assessing the individual for AAC are shaped²⁴ by the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF)²⁵ and include:

- the individual, their impairment(s), predicted progression, abilities, learning and communication requirements, preferences, life experiences and attitudes;
- the tasks that the individual wishes and needs to undertake;
- the individual's care networks and the social, cultural and physical environments in which the individual and their system will have to operate.

It is likely that much of this information will be gathered by the local team and will inform the decision to refer for specialised assessment and will be documented and passed on with the referral request. Based on this information, the specialised AAC hub service should be able to have in mind a sub-set of interventions and AAC systems that are likely, based on expertise and experience, to meet the individual's needs. It is the process of testing the initial hypothesis and then establishing the most effective of this sub-set of interventions and systems that are indicated by the use of the term 'specialist assessment'. As noted in the AAC quality standard 17, local spoke services and specialised hub services must be able to present a clear rationale for the AAC strategies and/ or equipment that are trialled and recommended, based on the information gathered from the client. This precludes assessment by trying every system on the shelf.

The sector's Quality Standard for AAC Service also indicates that it is not acceptable²⁶ for the assessment or trial of equipment to be restricted by the assessor's access to stocks of

Royal College of Speech and Language Therapy (RCSLT) Standards for AAC (submitted for publication at October 2011)
 This experimentation at a standard standar

²⁴ This approach was unanimously supported by the AAC specialised services consulted during the drafting of this report.

²⁵ World Health Organisation (WHO) International Classification of Functioning, Disability and Health: http://www.who.int/classifications/icf/en/

equipment, confidence, habits or preferences, unless the restriction in interventions and systems trialled are demonstrably in the best interest of the client. An example of this may be where the client has minimal capacity, time or motivation to learn a new system and their existing system can be replaced without significant negative impact on budgets, organisational resources or the future communication strategy for the individual or care network.

There is no relevant standard or guidance relating to the detailed assessment of the individual's communication impairment and this remains to be considered in detail by the sector. The requirement would be for specialised AAC hub services to implement best practice as an organisation and then for all specialised centres to develop a common approach over time, based on evidence.

The issues that are likely²⁷ to require referral to a specialised AAC service in relation to the possible technology solutions also include:

- the features of available and emerging technologies, an assessment of upfront and lifetime costs and interoperability issues;
- software requirements, interoperability with related electronic assistive technologies and mainstream technologies;
- access and control methods;
- the need for custom made devices and equipment;
- mounting of equipment or switches and positioning of the individual.

Whole system relationships

Interdependencies

With allied services: The sector's agreed Quality Standard for AAC services⁷ notes a requirement for continuity of AAC services between child and adult services and between AAC services, other relevant local and specialised electronic AT services, including wheelchair and environmental control services and allied services such as for posture and seating. The SSNDS Definition 5 also highlights the importance of these linkages. With some functions common between environmental control systems and high tech AAC systems, it would be sensible to exploit this as far as possible in terms of alignment if not interworking of NHS electronic AT (eAT) services. This would be likely to enable cost savings and quality improvement through sharing facilities and specialist staff, for example sharing maintenance and installation engineers or technologists skilled in custom manufacture.

Whether or not NHS electronic AT services chose to be part of any consortium that tenders to provide specialised AAC hub services, arrangements need to be put in place to ensure electronic assistive technology services are provided in an integrated way.

Between local and specialised services: The care pathway proposed in this report indicates the close interdependence of local spoke AAC teams and specialised hub teams. Specialised AAC hub services are not viable without local spoke AAC services that will be the source of all referrals in to the specialised AAC hub services.

The OCC report looked at the current arrangements by which local AAC services are commissioned, noting good practice²⁸ and indicating the tasks that should be carried out by

²⁶ See Quality Standard for AAC Services no. 13.

²⁷ 92% of specialised AAC services agreed with this range of issues, with no comments or amendments put forward by the 2 respondents (representing 8% of the respondents) who noted that that did not agree.

local teams. A diagram from the OCC report that outlines the interface between local and specialised AAC services is shown in Appendix 2. Based on the OCC proposals, on guidance in the commissioning tools²⁹ for speech, language and communication needs that have been published by the Commissioning Support Programme as an outcome of the Bercow Pathfinder programme, and on standards noted in the sector's AAC Quality Standard, we would suggest that the following activity is undertaken by local spoke AAC teams:

- Local awareness raising of the need and benefits of AAC interventions with primary and community care teams, schools and colleges, short break providers, NHS consultants and hospital based teams, social service teams, residential and care homes, etc.;
- Establishing local funding arrangements between health, social care, education and other relevant commissioners including the negotiation of an appropriate version of the care pathway process with their specialised AAC hub teams;
- Managing the receipt of referrals and making appropriate onward referrals to specialised AAC hub teams and other services;
- Undertaking assessment for low tech AAC and for those clients with non-complex needs, including establishing the goals and outcome measures by which to assess the impact of the intervention;
- Trial and long term provision of low tech AAC equipment;
- Implementation and support for trial and long term provision of low and high tech AAC systems, including technical training for individual AAC users, their families and communication and support networks;
- Monitoring and recording outcome measures using the regional database and, using information extracted from the database, reviewing the impact of individual care plans and analysing and reporting data in relation to the local AAC population to commissioners at local and regional levels;
- Collaboratively co-ordinating the care of their AAC population with their regional specialised AAC hub services.

Relevant networks and screening programmes

As with all other specialised services, as noted in the SSNDS, ⁵ there are no standard tools available to distinguish between specialised and non-specialised service activity and therefore there is no standardised screening programme for referral to specialised services. Providing services at a local level for the majority of the population who need AAC requires local teams to:

- be confident and knowledgeable within their area of competence;
- know when the boundaries of safe practice have been met;
- be familiar with the services offered by specialised services;
- be familiar with the processes to follow to make a referral to specialised AAC services.

The development of this level of knowledge, skills and competence within the local team is crucial to managing clients' appropriate, timely access to specialised services and to managing costs. The objective of this activity is to ensure the AAC population is appropriately and cost-effectively managed at the right level, local or specialised.

²⁸ Brief papers and local case studies on the commissioning of local services for children with SLCN. Available on the Champion's website at: www.thecommunicationcouncil.org/commissioning and www.thecommunicationcouncil.org/case-studies.

²⁹ Commissioning Support Programme website: http://www.commissioningsupport.org.uk/thecommissioners-kitbag/in-depth-publications.html

Service delivery

Taking into account the SSNDS document and the OCC report recommendations, explicit and implied, on the activities to be undertaken by specialised AAC hub services, it is proposed that the following areas of service will be undertaken:

- Specialised assessment of AAC needs;
- Regional management, including procurement, of high tech AAC systems;
- Training and service development of local spoke AAC teams;
- Regional co-ordination of care planning, service standard development, quality assurance and improvement of local AAC teams.

In order for a specialised AAC hub service to deliver the required range of activities, and based on the SSNDS³⁰, the report from the Communication Champion³¹ and AAC Synthesis for Commissioners from the RCSLT,³² in addition to those administrative and management staff required by any organisation, the hub team should include staff with the following competences:

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

The hub team should also be able to evidence that it has processes and contracts in place to access, in a timely way, staff with the following competences:

- Competence in personalisation and customisation of equipment (software, electronic and mechanical);
- Cognitive assessment competence to support AAC assessment and intervention service to older clients;
- Health informatics,³³ quality improvement and research methodology competence;
- Training and workforce development competence to support the development and competence of local AAC spoke services.

There is no framework of competence that sets out the scope and levels of competence required to deliver any assistive technology service at either local, non-specialised or regional, specialised levels.³⁴ A mapping of the required competences, in consultation with the health, social care and education sectors, would need to be undertaken by a Sector Skills Council to establish an agreed competence framework. This would then enable education providers across the UK to establish accredited courses at a range of levels. In the meantime there is work underway by a special interest group of Communication Matters to establish a provisional, informal framework for AAC services. This framework will be set at

³⁰ The SSNDS notes that "a specialised communication aids service team includes speech and language therapists working closely with colleagues from education (specialist teachers), occupational therapists and engineering (clinical scientists and clinical technologists).

³¹ The OCC report notes on page 14 the competences required by hub as: Skilled assessment of the young person's communication needs, and subsequent after-care, will typically involve a speech and language therapist with specialist expertise in AAC, an occupational therapist, a technician and teaching staff working closely with the young person, their family and staff in education and care settings.

AAC Synthesis for Commissioners, RCSLT, 2011. Section 7.

Health informatics further information: http://www.nhscareers.nhs.uk/details/Default.aspx?ld=767

³⁴ Assistive Technology Workforce Development, a feasibility study for Skills for Health and Skills for Care, July 2007, FAST: www.fastuk.org

four levels,³⁵ rather than benchmarked against the complete knowledge and skills frameworks relevant to health and education. The four level framework will use indicative titles to indicate levels of competence, such as: foundation; developing; independent; advanced. Without external examination and nationally established benchmarks this would be a self-certified approach to competence development. There are unlikely to be a sufficiently differentiated level of training and courses that correspond to the informal framework that could also be used as a workforce development mechanism. While this approach is not satisfactory, there is no alternative until a mapping exercise is undertaken by the Sector Skills Councils.

Within a team working in a specialised AAC hub service, there would be a range of levels of expertise as staff develop more expert competence. The specification would be that there is a level of expert oversight and responsibility taken by the relevant senior member of staff to ensure the service that is provided is of an appropriate standard. The consensus of specialised services when surveyed was that a regional specialised hub service should be consist of, or be able to draw on, staff with the required areas of competence noted above, at levels three and four (independent and advanced).

Service model

The proposed service model is based on:

- existing good practice in services operating a hub and spoke model;
- a size, scope and capability for service delivery as noted above;
- alignment with the proposed four Strategic Health Authority (SHA) cluster commissioning groups which are replacing the ten regional specialised commissioning groups in the transition to the NHS Commissioning Board.³⁶

There are some key issues that need to be considered in relation to the four proposed areas of service within the service model:

- Specialised assessment of high tech AAC needs;
- Regional management, including procurement, of high tech AAC systems;
- Training and service development of local spoke AAC teams;
- Regional co-ordination of care planning, service standard development, quality assurance and improvement of local AAC teams.

Specialised assessment of high tech AAC needs,

The term specialised assessment of high tech AAC needs does not indicate a 'one-off' consultation but covers a period that is likely to include: information gathering; consultation with the individual and their care network, demonstration of low and high tech AAC systems, observation of the individual trying out systems or elements of systems, and short-medium term trial(s) to gather evidence on effectiveness of a system or approach. These short-medium term trials may, for some individuals, need to be repeated several times before a recommendation can be made for long term provision.

Assessment should be undertaken in consultation with the care network and care and communication partners, such as family, education providers, care providers, etc, and each stakeholder will require specific outcomes, such as social, curriculum or professional communication, from the intervention which will need to be considered by the assessment

³⁵ The RCSLT recognise differing levels of competencies for SLTs working with AAC and have developed a set of competencies for AAC knowledge specifically: learner, competent with support, competent and experienced, and the specialist SLT (RCSLT Competences for AAC: status: submitted for publication at October 2011).
³⁶ Development AMUS Competencies Deced AUL 0011

³⁶ Developing the NHS Commissioning Board, DH, 2011. <u>http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_12811</u> <u>8</u>

team. The goals of the assessment will vary between stakeholders and the assessment service will seek to manage the varying expectations and desired goals of each stakeholder, and build consensus on the approach to achieving the primary goal of increased involvement in life situations for the client. Sharing this goal will avoid a technology-driven approach to assessment.

The length and approach to assessment, and use of short term trial(s) as part of the assessment process, will vary quite considerably in practice, with some systems, or elements of systems that need a significant level of customisation and personalisation requiring time for the AAC team or teams in allied services to undertake the work. Examples of where this may be relevant are for the development of a complex vocabulary, for customised programming, to develop customised mounting and posture solutions and to undertake safety and risk assessments on these elements. For such systems, or elements of systems, the requirement for an effective set up is more important than undertaking the assessment phase over a defined time period.

For the purposes of commissioning and service planning, a specialised AAC hub service assessment is proposed as constituting an average of 5 days work by the multi-disciplinary team and will include the following activities:

- Reviewing the referral information, seeking further information including, potentially, observation;
- Consultation with client and care network, including demonstration of systems and observation of client trialling systems (this may take place over more than one face to face consultation);
- Report writing, referrals to other services, outcomes setting, documentation;
- Initial follow up (review / conclusion of trial, discussion with the local team to assess their training needs and to discuss outcomes measurement);
- 6 month review jointly undertaken with the local team.

High tech AAC system procurement and loan management

This is not an activity that has been consistently undertaken by specialised AAC services and it is therefore an area for which there are few guidance documents. The SSNDS notes the scope of a specialised AAC service to include "on-going, life-long maintenance/ replacement and user support." The document also notes that "individually targeted assessments should make it possible to harness developments in electronic technology to link multiple control functions by a single system.⁵

The clusters of equipment that make up the full scope of a high tech AAC system can be categorised according to current procurement patterns as:

- Devices (hardware), software, vocabularies
- Switches, access and control methods
- Mounting for switches and access and control methods
- Device mounting (both off the shelf and customised)
- Interoperability systems and cabling
- Environmental sensors, actuators and receivers
- Positioning of the client (joint working with wheelchair services may be required)

Standards 12-15 from the sector's Quality Standards document are based on a consensus within the AAC specialised services that a broad range of devices and systems should be available at the point of assessment; that the individual should have the opportunity to handle and use an appropriate range of systems as part of the assessment process; that a short term trial is often required to establish the benefits of the recommended system; and that the system should be made available to the client for long term loan appropriately set up, integrated with other technologies and programmed to meet the individual's needs.

High tech AAC systems are not implemented in isolation. In practice, and within the sector's Quality Standard for AAC services, there is a requirement for AAC services to undertake close working with wheelchair services and environmental control services where required, and for there to be joint consideration of issues relating to the mounting of equipment and the positioning of the individual. The care pathway may therefore be complex.

There is also a variation in the need for an extended assessment, undertaken through short term trial of systems or elements of the system. This will impact on the complexity of the care pathway. For some ranges of equipment, the AAC system that is used for assessment may be left with the individual for trial and then, if the trial is judged successful, left with that individual on long term loan. For other ranges of equipment or elements of the system this is not possible and there may be a need to trial different systems or to customise a bespoke solution, for example, when the assessment is not straightforward, when the individual has needs that are not catered for by standard off the shelf systems, and when circumstances change or become apparent during the trial.

This implies a range of timescales and provision paths that will vary depending on individual circumstance. For the purposes of this report, the care pathway will be structured around three phases, which in practice may blur into each other or require repetition until a successful system is established: assessment, short term trial, longer term loan.

The breadth of the range of equipment that will be required by an AAC specialised hub service and the quantities required will depend on the intended use of the equipment at these three stages of the care pathway and the timescale within which it must be provided.

- Assessment/ consultation AAC systems for use in assessment need to be available to hand to be used for demonstration and trial during the assessment/ consultation process. Systems or elements of systems, such as mounting, used for assessment may be generic equipment that provides a sufficiently close approximation to the intended final product to enable evaluation.
- 2. Trial if the system is fairly standard this needs to be available shortly following assessment (within 5 working days) while customised or personalised systems or elements of systems should be available as soon as possible, ideally no later than 20 working days following ordering. These systems or elements of systems to be used for trial can be relatively generic, as long as they provide a sufficiently close approximation to the intended final system to enable evaluation, such as mounting using a floor-based stand. For an effective trial, however, it may be required to customise the system (i.e. software, vocabulary, mounting or hardware). The level of customisation need only to match that required to allow successful evaluation of the assessed element or facility. This equipment, if not intended as a long term solution, must be chosen to be robust and useable over the trial period and suitable for use by multiple clients with diverse needs. The need for training by the local team may lead to some delay in the proposed timescales. This needs to be documented as a variance to the care pathway and, if occurring regularly, addressed by the specialised hub team through their training programme. The length of the trial, if required, is likely to be between six weeks and three months, therefore averaged as eight weeks. A justification of any extension of the trial beyond three months should be documented to prevent unnecessary delay to implementing the long term loan.
- 3. **Longer term loan** needs to be available at a maximum of six weeks post the conclusion of the trial phase and must be adapted, customised and set up to match the individual needs of the client as closely as possible.

Equipment supply for assessment/ consultation and short-term trial arrangements

• **Stock levels:** It is proposed that, for the purposes of assessment and short term trial (approx. and averaged as 8 weeks), the regional centres would hold a stock of low and high tech AAC devices, switches, postural support and mounting equipment sufficient in breadth to enable the team to reach a conclusion on which would be the most effective solution for any client. Stocks of low tech devices would be for the purposes of assessment, with long term loan of low tech devices to be arranged by local AAC spoke services. Stocks of AAC systems for assessment purposes could be held in closely located equipment stores but the requirement is for a wide range of equipment to be readily to hand at the point of assessment/ consultation.

For standard systems which are likely to be in relatively high demand, it makes sense for centres to leave systems used for assessment with the individual for trial and, if the trial is judged a success, to then use these systems with the client for long term loan. Re-ordering would be to replenish centrally held stock levels in anticipation of future demand. Alternatively, assessment devices may have a number of software and vocabulary packages loaded on them for the purposes of assessment, which may make them inappropriate for leaving on loan.

For those clients requiring customised or specially adapted systems (or elements of the system such as mounting) this would require a level of stock to be held which could approximate to the element which would eventually be custom-made. There would be disadvantages to having high levels of stock as this would reduce the opportunity to take advantage of emerging technologies. The stock levels, and/or arrangements to rapidly access stocks that are agreed with suppliers, should enable specialised AAC teams to have ready access to sufficient numbers of each element of the technical system to enable some to be out on trial and still have ready access to stocks.

- Access to stocks: The stocks of equipment held for the purposes of assessment and short term trial would also need to be sufficient to enable a dispersed, outreach team to have equal access across a potential large geographical area. Stock management and transportation systems will have to be put in place by the specialised hub teams to enable ready access, from centrally-held stocks or from manufacturers, for the purposes of assessment and short term trial.
- **Product lifetime**: The assumption is that all AAC high tech equipment has a 5 year maximum product lifetime³⁷ (4 years for children given the greater chance of breakage and wear and tear) before it becomes too expensive to cover under warranty, too prone to breakdown to be worth recycling, too difficult to integrate with related electronic systems and software, and to offer significantly less benefits to the individual than products that have come onto the market at lower cost in the intervening 5 years since the point of provision.³⁸ It is proposed that, if stocks of equipment are used for the purposes of assessment and short term trial, shorter product lifetime periods are assumed, bearing in mind the higher levels of wear and tear implied by multiple use and transportation, set up, etc.
- **Maintenance and repair**: Specialised AAC hub services need to consider the most effective approach to maintenance and repair. It is likely that services can negotiate cost-effective and timely maintenance and repair arrangements with manufacturers given their strong procurement position.

³⁷ The OCC Report (p26) proposed an average three-year period before an aid needs to be replaced because of changes in the user's needs, or new technological developments.

³⁸ The equivalent review and replacement cycles are 2 years in France and 5 years (for children) in the US.

- **Recycling:** Specialised teams will need to have the appropriate facilities to meet quality standards for cleaning and infection control, and for repair and testing if recycling is to be undertaken for systems that become available well within the product lifetime. The cleaning and recycling of each set of equipment and each stage of the recycling process must be costed up and undertaken only if significant benefits accrue from recycling the equipment. While there are benefits to maximising value through recycling,³⁹ there are disadvantages in relation to direct costs of establishing effective recycling processes and a negative impact on innovation from holding large stocks of equipment for which interoperability becomes a greater issue than innovation.
- **Management**: The cost-efficient management by specialised AAC hub teams of stocks of equipment for assessment and short term trial needs to be supported by administrative, financial and technical staff resources.

Procurement

- There is currently an NHS national framework agreement for electronic Assistive Technology⁴⁰ that includes AAC high tech equipment that features nine suppliers. The history of the development of this framework agreement for electronic assistive technology is that from the mid-1990s the framework focused on environmental control (EC) devices which were supplied by two companies, who provided relatively well differentiated product ranges. These contracts tended to be for fixed periods (3-5 years) for the supply of a technology support service, including on-site technical input to case conferences from the manufacturers' team, product set up and delivery and on-site maintenance, repair, etc. The majority of NHS regional areas purchase EC services through the framework agreement.
- As these EC products developed through technical innovation to enable speech output, the scope of the framework widened to include other dedicated or specialised speech output device ranges, but this was an ad hoc process, with several AAC companies choosing not to sell through the framework agreement. Unlike the EC services, the AAC services listed on the framework were for the device alone, sometimes offered with a 3 year extended warranty, usually with return to company to repair faults, no on-site support, nor inclusion of the manufacturer's team in the case planning process. As many of the current AAC suppliers are micro businesses, providing small numbers of devices in a highly contested and not particularly profitable field, it was not possible for them to provide a national on-site advice and support service.
- There was no obligation or practice for specialised AAC service providers to buy AAC devices through the framework agreement as this is only mandatory for large value contracts in order to comply with European Union tendering rules. OJEU⁴¹ tender constraints apply to statutory organisations purchasing over €100,000 (or GDP equivalent) per National Contract period (2 years). The alternative is for specialised services to have arranged their own local EAT contract. It does not appear that there are any such local contracts for AAC.
- There is also currently little incentive for customers to use the National Contract and Framework Agreement as, without some guarantees on bulk purchase, suppliers could not offer a bulk purchase discount through the framework. In return for listing on the framework, NHS Supply Chain, the organisation running the framework agreement required total transparency on sales data from supplier companies, even though there

³⁹ The OCC report estimates (p26) that the proposed cost of establishing service for children could include and assumed 10% equipment being recycled for use by another child or young person.
⁴⁰ NHCL existing application application application of the proposed cost of establishing service for children could include

⁴⁰ NHS Logistics electronic assistive technology framework agreement: https://my.supplychain.nhs.uk/catalogue/contracts?eclassid=gsb

⁴¹ OJEU - Official Journal of the European Union in which such tenders must be advertised.

was not necessarily a correlation with the sales achieved through being listed on the framework. This was a disincentive to joining the list and some companies originally on the framework agreement chose not to apply for subsequent rounds of listing.

- There is also an issue that AAC devices span the range of specialised, dedicated devices (including specialised software and vocabulary) through to mainstream devices (such as the iPad which can run some AAC software and vocabulary). This tends not to be the case for EC devices/ systems, which can also be delivered through more mainstream systems, but the procurement of which currently focuses on specialised products. It is unlikely that mainstream device manufacturers will enter NHS framework agreements for the volumes that may be purchased by AAC or EC specialised hub services.
- The framework agreement is well suited to the bulk purchase of large numbers of standardised equipment, for example, walking frames, but is not well suited to sale of such a diverse set of services provided by a wide range of small and medium-sized enterprises (SMEs).
- As the electronic AT framework agreement currently stands, there does not appear to be any advantage to the companies or to customers to buying through the framework agreement. It does appear likely however that, in order to comply with OJEU tendering regulations, if consortia providing specialised AAC hub services are led by NHS or local authority organisations, they will need to put in place the required local contracts to cover the procurement of high tech AAC systems. There will in any case be a requirement for robust contract arrangements to be put in place to maximise cost benefits from bulk purchase and service benefits to individual AAC system users.

Procurement opportunities

- If specialised AAC hub services were in a position to identify a level of purchase they were able to guarantee over a year and had the buying position to represent the bulk of the buyers, they would be in a strong position to negotiate contract terms with manufacturers and suppliers relating to cost, to some terms of sale and potentially, in the longer term, to design. For example, under the Communication Aid Project⁴² (CAP) programme there was a mandatory 2 year minimum warranty required from all participating companies; the companies then priced their devices through the CAP scheme accordingly. Similarly, it may be possible to require companies to provide as part of the warranty agreement other benefits to clients, such as to provide replacement equipment while a client's device is with the company for repair. As this would depend on the level of stock held by the company, which is a cost that would have to be borne and passed on to the customer, it is unlikely that this could be mandatory (even with performance targets providing some flexibility) until the market conditions under any changed commissioning situation become clearer. There may also be the potential of using the regional hub's bulk buying position to require greater collaboration between manufacturers and a move towards more interoperable solutions that will lead to efficiencies for service providers and a greater choice for clients.
- It is recommended that regional specialised AAC services will, alone or together, use the power of their bulk purchasing position to set terms and conditions for companies to respond to, including requiring a percentage discount for quantity purchase. Current indications are that sales of high tech devices are approximately 50% of the level that would be anticipated if a four-year (for children) and five year (for adults) obsolescence period for devices is assumed and if there is a target to meet all eligible needs. As the

⁴² CAP was a national government-funded initiative to provide communication technology for children with complex needs which ran between 2002 and 2006. Evaluation of the CAP project: <u>https://www.education.gov.uk/publications/RSG/publicationDetail/Page1/RR580</u>

market situation would be initially unclear and there is a longer term benefit to having a vibrant, diverse and innovative SME base, this will need to be a process negotiated with industry over the next 2-4 years.

- The potential benefits in relation to cost, technical and service innovation, and growth within the sector have been foreseen by the OCC. The OCC report notes (p23): 'Organisations commissioned to provide the regional hubs would be able to enter into agreements with preferred suppliers, at lower cost than if local commissioners purchased equipment. They would be able to shape the market, insist on warranties, and hold suppliers to account for poor services. ... Coherent and consistent procurement would in turn ensure a vibrant, innovative and sustainable supplier base working within an efficient and responsive market.'
- It is proposed that appropriate product lifetime/ obsolescence periods are assumed for equipment and that recovery and recycling of equipment, if no longer needed by a user within these product lifetime periods, could be considered by manufacturers and designed into the business model. Recycling and recovery rental or lease models offered as an option by the manufacturer, are likely to be relevant to younger AAC users whose needs change rapidly. Rental or lease models might also be suitable for clients whose needs will change rapidly due to neurodegenerative conditions, such as MND, or those whose needs may reduce with rehabilitation, such as survivors of stroke. This would be a substantial change of business model and would require some market research before suppliers are likely to feel confident to cost up such a sales model.
- Another possible procurement model might be similar to that for mobile phones: based on the hub taking out a monthly subscription to a service which includes the device, set-up, installation, equipment training for local staff and users, remote support, on-site support, maintenance and replacement on breakdown, etc. with, after the 'contract period', the option of replacement system. There would need to be considerable market development, supply-side and client-side, before such a model would be viable however.

Training and local service development of spoke AAC teams

Due to the lack of coverage of local spoke AAC teams and the interdependence of regional specialised AAC hub services with local spoke AAC teams, a requirement of specialised AAC hub services is that they:

- establish working relationships with all local spoke AAC teams and the relevant commissioning bodies for local AAC services within their regional boundary or the agreed sub-regional area which they cover;
- identify gaps in coverage by local AAC spoke teams and, working with local commissioners, support local SLT teams to develop AAC competence sufficient to manage local AAC needs or, alternatively, support neighbouring spoke AAC teams to extend services to fill the gap;
- support the training needs of local SLT/ AAC teams to raise their awareness of new technologies and new interventions and to build their competence in assessment skills and practice;
- build the capacity of the local team to: deliver an AAC service for the 90% of the local AAC population who will not require specialised assessment or high tech AAC; make appropriate referrals to the AAC specialised hub team; measure outcomes; record data; provide training to individual AAC system users, their care teams and communication partners.

The requirement to train and support local teams is supported by the SSNDS document: "A hub and spoke model is an effective service delivery model for specialised equipment services with the hub playing a key co-ordinating and educating role whilst supporting the spokes to ensure high standards are maintained even when dealing with less complex cases."⁵

Regional co-ordination of care planning, service standard development, quality assurance and improvement

The hub role makes possible the regional collection of data from specialised services and through collating data from local spoke services, to enable analysis, forecasting of need and to recommend measures for quality improvement. The specialised AAC hub services will be responsible for the development of regional databases for care planning and co-ordination, for input of care records for their own clients and for supporting local AAC spoke services to input care records for all clients, whether care is shared or not. Given the close interworking between local and specialised teams and the need to collate data on local populations, on outcomes and on activity, it would appear necessary to ensure the establishment of a database shared between regional and local AAC services. It would be cost effective to have the same database approach across regional areas or, at a minimum, to ensure these are interoperable.

Related to this is the requirement for specialised services to co-ordinate the regional development of detailed care pathway processes, including outcome measures and evaluation points, and to analyse and present this information for a range of stakeholders regionally and nationally. This information is essential for quality assurance of local AAC spoke teams and of the specialised regional AAC hub teams and for service improvement.

The sector's Quality Standard for AAC Services⁷ notes a requirement for key worker(s) allocation (standard 9) in order to ensure effective communication between the local and specialised services and between AAC and allied services while keeping the client and their care network fully informed. Key worker allocation is a relatively cumbersome 'work around' measure to address structural complexity or failure of the care process. Quality standard 9 was prompted by clients' experience of complex, undocumented and variable care pathways. Given the potential reorganisation of local spoke and regional hub AAC services and the proposed use of standardised care pathways, there is the opportunity to institute care record management systems and care communication protocols that would reduce or negate the need for allocation of an AAC-specific key worker – although for children there would still be a role for a generic key worker whose role is to liaise with the family and help coordinate the range of education, health and social care provision required by their child.

The development of a regional database to collate and share care planning information, with the required permissions settings under the consent of the AAC system user, or their guardian if relevant, is technically relatively straightforward. This database should also link appropriately to the NHS IT spine, where feasible, to allow key information about a client's AAC use to be available on their core dataset. The challenge of data sharing into NHS IT systems is an issue that is being addressed by related eAT services such as those in assisted living (telecare and telehealth).

Care pathway

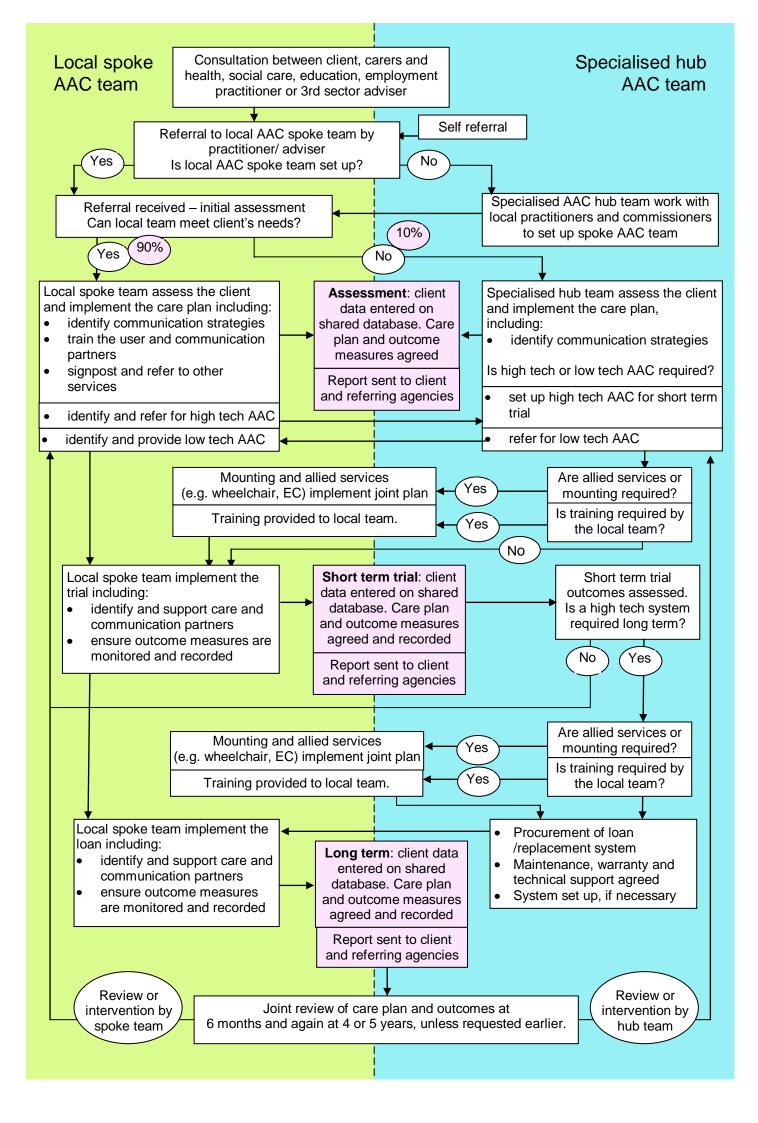
The proposed care pathway is based on the service model as set out in this report. The pathway is informed by the sector's Quality Standard for AAC Services. The pathway sets out a high level process and it would be expected that, in time, specialised AAC hub services would collaboratively evolve standardised referral documentation that would allow greater flexibility to reflect the local situations and needs.

For AAC specialised services response times and detail in relation to:

- Referrals, appointments and report delivery: the sector's Quality Standard for AAC Services notes a requirement for response times to be published in care pathway documentation and for these response times to be brought to the attention of service users. Until the standard care pathways are implemented it will not be possible to require specific timed responses at points in the care pathway. The service level agreements that relate to the care pathway must define both the timing and the nature of the response.
- Equipment provision: as noted above, the response times relating to the flexible and overlapping phases of equipment provision, which are noted in this report as assessment, trial and provision, will vary depending on the complexity of the system and whether non-standard elements are required. In broad principle, a comprehensive range of equipment must be available to hand for the purposes of pre-arranged assessment appointments. For the purposes of the trial phase of assessment, the system should be available at a maximum of five days, for standard systems, and 20 days, for systems requiring a level of customisation, following conclusion of the consultation/assessment phase. For the purposes of the long term provision of the system, properly set up for the individual and including any customised elements, the maximum delay in providing the system should be no more than six weeks following conclusion of the assessment/ trial phase, if there is sufficient justification for such a delay.
- Equipment breakage and breakdown: the Communication Champion in her recent report notes⁴³ the requirement for same-day response to users in case of equipment malfunction. A response to the service user to state how the breakage/ breakdown will be resolved and when should be entirely possible within this timescale, given the opportunity for specialised AAC hubs to have in place comprehensive stock management approaches and well documented service level and warranty agreements with suppliers. There should in addition exist, for each system out on loan, a back-up plan for when the high tech AAC system breaks down (this is almost inevitable at some point). This back up plan is required as part of the care plan and may include the use of a back-up system in the form of low tech systems or systems that have been replaced but are still functional. The response time and detail for replacement or repair of high tech systems or elements of systems should be governed by the warranty and service level agreements which are negotiated through the procurement process by the specialised AAC hub service, if this is the approach chosen. If AAC systems are used as environmental control systems and are therefore critical to safety (for control of the home services or for calling for help) then a risk assessment will be in place that identifies the 'fall-back' system to be used in the case of system breakdown.

⁴³

OCC report (footnote reference 1) (page 22)



Geographical coverage/ boundaries

Given the emerging arrangements for commissioning of specialised services⁴⁴ the proposal is to commission specialised AAC specialised hub services within a regional boundary aligned with the four SHA cluster areas. A map of the four SHA cluster areas is shown in Appendix 3. The minimum size of population to be served by a specialised service is noted as 1 million in the SSNDS Definition 5 paper. Given the prevalence of need, and the 4 and 5 year review cycle for children and adults, it is likely that a maximum of three sub-regional services would be viable in the larger SHA cluster regions, each of which may be made up of a number of organisations, centres of activity and sub-contracted team members in order to give regional coverage.

Demand for regional spec Cluster area	AAC Population: Est. 0.5% average of whole population who need AAC (low and high tech) (not annualised)		Specialised AAC needs: est. 10% of AAC pop. (not annualised)		Total need for specialised AAC hub services (not annualised)			
	Total population ⁴⁵	Children (0-15)	Adults (16-90+)	Children (0-15) (approx. 0.33%)	Adults (16-90+) (approx. 0.54%)	Children (0-15)	Adults (16-90+)	
Total SHA cluster areas and population base North	51,092,100	9,655,800	41,436,400	31,864	223,757	3,186	22,360	25,546
= N East, N West & Yorks & Humber Midlands and East	14,605,900	2,746,800	11,859,100	9,064	63,994	906	6,399	7,306
= E Mids, W Mids & E of England	15,442,600	2,947,400	12,495,100	9,726	67,426	973	6,743	7,715
London = London South	7,556,900	1,455,600	6,101,200	4,803	32,923	480	3,292	3,773
= S Central, SE Coast & S West	13,486,700	2,506,200	10,980,700	8,270	59,254	827	5,925	6,752

⁴⁴ According to 'Developing the NHS Commissioning Board' four "commissioning sectors" based on the 4 SHA clusters will carry out specialised commissioning and 'a more uniform approach to this work across the country would also be developed'.

⁴⁵ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128118

⁴⁵ Population figures are based on mid-2007 census: latest available SHA cluster population figures

Demand for local, non-spe services by SHA Cluster a	AAC Population: Est. 0.5% average of whole population who need AAC (low and high tech) (not annualised)		Non-specialised AAC needs: est. 90% of AAC population (not annualised)		Total need for non- specialised AAC spoke services (not annualised)			
	Total population ⁴⁶	Children (0-15)	Adults (16-90+)	Children (0-15) (approx. 0.33%)	Adults (16-90+) (approx 0.54%)	Children (0-15)	Adults (16-90+)	
Total SHA cluster areas and population base North	51,092,100	9,655,800	41,436,400	31,864	223,757	28,678	201,239	229,917
= N East, N West & Yorks & Humber Midlands and East	14,605,900	2,746,800	11,859,100	9,064	63,994	8,158	57,635	65,753
= E Mids, W Mids & E of England	15,442,600	2,947,400	12,495,100	9,726	67,426	8,754	60,726	69,437
London = London South	7,556,900	1,455,600	6,101,200	4,803	32,923	4,323	29,652	33,954
= S Central, SE Coast & S West	13,486,700	2,506,200	10,980,700	8,270	59,254	7,443	53,366	60,772

⁴⁶ Population figures are based on mid-2007 census: latest available SHA cluster population figures

Location(s) of service delivery

There is currently no consensus on whether specialised AAC assessments are best undertaken in the individual's home and community locations or at a centralised facility. Specialised AAC services have identified advantages and disadvantages to each approach and the logistical and cost burden shifts between the specialised service and the extended communication network, depending on the approach taken.

The advantages of delivery of specialised AAC hub assessments in the community, in the environments and with the communication partners relevant to each individual are described in a number of publications:

- The RCSLT recommend²³ as good practice that speech and language therapy assessments take place in the person's own communication environment, as this "helps to identify different communication environments and the communication systems, strategies and equipment used in each. Understanding the communication environments helps to optimise and maximise communication.' The environmental factors are noted as including the range of familiar and less familiar communication partners.
- While the literature review undertaken by Sharr¹³ does not identify any research that explicitly supports this recommendation, the findings of a range of studies are that decision making by the individual and close care network, and training and support of the individual and close care network, influences the effective delivery of AAC services.
- The Communication Champion's report¹ notes a requirement for assessment in the client's home or school setting, taking equipment and staff to the child
- Assessment/ consultation in the client's home may be required to reduce the impact of travel for the client and their care network. This may be particularly relevant for clients with a learning difficulty, such as ASD, or people with physical disability which makes extended travel difficult or impossible.

The advantages of delivery of specialised AAC hub assessments in a centralised facility is based on:

- The availability of a large range of equipment on site, and engineering resources when required.
- The logistics of transporting a range of equipment, particularly mounting equipment to inhome/ community assessments.
- Travel costs for the assessment team (usually a minimum of two team members) and the time spent on travelling.

In conclusion, the optimal location for undertaking the assessment/ consultation element of the service has to be addressed by specialised AAC hub services on a case-by-case basis, with creative thinking required to reduce the logistical and cost burden for the team and the client and their care network. Examples of this might include:

- Use of videoconferencing for observation, liaison with the care network, training, assessment/ consultation.
- Use of observation (possibly by outreach workers) in the client's home or education and work environments to gain detailed information prior to the assessment.

Facilities required

The provision of office space for the management of the service and to deliver training will vary depending on the service model and how 'virtual' it is proposed that the AAC specialised hub service can feasibly be.

Given the requirements for equipment management as stated above, a specialised AAC hub service will require facilities to manage the set up, programming, mounting, integration, testing, recycling, repair and customisation, of systems or elements of systems. If these activities are outsourced to contracted services, for example within local NHS electronic assistive technology services, or to manufacturers and suppliers, there is still a requirement for the specialised AAC hub service to ensure these activities are undertaken safely, in compliance with relevant regulation, and that the activities can be undertaken in a timely fashion. There is also a requirement to consider how a specialised AAC hub service providing a service over a large geographical area with a potentially widely dispersed, outreach workforce would make available these activities/ facilities, if it is proposed that they are provided in a centralised way.

These activities are likely to include (in no order of precedence):

- Cleaning and decontamination;
- PAT and LOLER testing;
- Stock management, secure storage;
- For day-to-day maintenance: changing batteries, repairing and attaching strapping, minor adaptations, etc.;
- For mounting, integration with other systems and customisation services: grinding/ foam shaping/ welding, drilling/ bolting, etc.

Transfer of and discharge from care obligations

The assumption is that the majority of adults and children with communication impairment will have a lifelong requirement for support and intervention, and primary responsibility for on-going support for all clients will sit with their local spoke AAC team. The recommendation is that a specialised AAC hub service, working collaboratively with a local spoke AAC service, will plan care on the basis of review by specialised AAC hub service at 6 month post-intervention and then every 4 years post-intervention (for children) and 5 years (for adults). In the meantime local services should be reviewing more regularly, ideally 6 months for children and annually for adults, as a minimum. This should allow for a review by specialised AAC hub services to be triggered by the local team if the individual's circumstances change and they consider that a specialised AAC assessment is required. The use of a shared database and care planning system should make the triggering of referrals and management of the review schedule for the AAC population more straightforward.

The regular 4 and 5 year cycle of review for children and adults by the specialised AAC hub service has been proposed to coincide with the requirement for a replacement system, unless reassessment has been triggered earlier. Such a re-assessment of need is likely to require face to face (or equivalent) assessment by the specialised AAC hub service. Even with a situation where the individual's situation appears relatively stable and the technological solution appears satisfactory, there may be new circumstances, new knowledge on interventions or technological developments which should be considered.

- Transfer of care to local team will be formalised at the 6-month post-assessment review.
- Whether synchronised with the 4 and 5 year review cycle or not, any transitions between school or college settings and work settings, for example, are likely to trigger review.⁴⁷

⁴⁷ The NHS operating framework for 2011/12 also includes services for disabled children as an element in service quality requirements: 'Both the report by Sir Ian Kennedy, [*Getting it Right for Children and Young People]*, commissioned by Sir David Nicholson, and *Achieving Equity and Excellence for Children*, which sets out how the NHS White Paper relates to children and young people, highlight the need for the NHS to pay greater attention to the needs of children, young people and families in commissioning and delivering services. NHS organisations should consider the issues they raise, particularly in the management of transition throughout 2011/12 and, as identified, pay particular attention to groups with specific needs

Quality requirements

There are a number of quality standards that have been developed for the AAC sector specifically and some which relate to the wider scope of SLT services which may provide contextual guidance.

Standards that are AAC specific:

- The most directly relevant quality standard is the Quality Standard for AAC Services⁷ developed by a Communication Council Special Interest Group which was developed in wide consultation with the AAC and SLT sector. The Quality Standard for AAC Services is set out in Appendix 1.
- An AAC competence framework is under development by Communication Council⁴⁸ AAC Workforce Special Interest Group (SIG) and this should be available by 2012.

Standards relating to assistive technology provision more generally:

- Care Quality Commission: All providers of health and social care in England have by law to be registered with the Care Quality Commission, initially by meeting its 'Essential Standards of Quality and Safety',⁴⁹ and then by continuing to meet these as evidenced by inspections and assessment. All NHS hospitals and community services, adult social care and independent healthcare providers in England, including AT and AAC services, must be registered. The Standards are based on statutory regulations. Standard 3 covers safety, including infection control and use of equipment, in all settings including the home.
- Department of Health's publication: 'The Code of Practice for health and adult social care on the prevention and control of infections and related guidance'.
- BSRM (2000) 'Electronic assistive technology'⁵⁰

Standards relating to speech and language therapy (SLT) services:

- Department for Education and Science (2000) 'Report of the working group on the provision of speech and language therapy services to children with special educational needs (England)⁵¹
- Department for Children, Schools and Families (2008) 'Better communication: An action plan to improve services for children and young people with speech, language and communication needs'⁵²

Activity

NHS standard contracts include an activity plan that sets down the amount of work to be done, based on a standard currency and the price to be paid, based on the national tariff where applicable. Activity levels for the numbers of people to be seen by specialised AAC hub services are set out on pages 43-45.

As specialised AAC services are currently providing services at a level estimated at approximately 60% for children and 30% for adults, a phased approach to building the capacity to delivery services is proposed, with a planned service in year 1 and 2 for 60%

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_11944

including disabled children....':

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_11944 5 and:

⁴⁸ Communication Council website: http://www.thecommunicationcouncil.org/

⁴⁹ Care Quality Commission Essential Standards:

http://www.cqc.org.uk/usingcareservices/essentialstandardsofqualityandsafety.cfm

⁵⁰ British Society of Rehabilitation Medicine (BSRM): www.bsrm.co.uk

⁵¹ Department for Children, Schools and Families: www.dcsf.gov.uk

⁵² Department for Children, Schools and Families: www.dcsf.gov.uk

then 80% capacity service for children, and 30% then 60% capacity service for adults. In year 3, specialised AAC hub services should be aiming to be provide a100% capacity service for both children and adults. A 100% capacity service is based on a planned review cycle of 4 years for children and 5 years for adults. This means that within 4 and 5 years of full capacity service, all children and adults respectively, who require high tech AAC, would be seen.

Prices and costs

The SSNDS notes the following information in relation to costs:

Identifying and costing equipment for people with complex physical disabilities 5.1 Existing currencies

- out-patient attendances
- non face to face out-patient appointments cost per case
- annual fee for maintenance of equipment.

5.2 Classification systems

SSNDS Definition No.5 Assessment and Provision of Equipment for People with Complex Physical Disabilities (all ages) (3rd Edition) Currently there are no classification systems for specialised equipment service activity.

5.3 Costing activity

Please refer to the latest Department of Health Guidance on Payment by Results for up to date information on national tariffs and activity included/excluded from tariff. Please note that not all the Payment by Results inclusions and exclusions listed below are specialised activity, but they are included here for completeness.

(i) Is in scope of 2010/2011 Payment by Results and has a national tariff:

- out-patient attendances see PbR list of inclusions for first/follow-up and single/multi-professional:
- multi-disciplinary out-patients attendances mandatory tariff
- non face-to-face out-patient attendances (for TFCs that have a mandatory tariff for face-to-face out-patient attendances) non-mandatory tariff.

(ii) Is excluded from 2010/2011 Payment by Results and therefore requires a locally negotiated tariff:

• services -

•

- · community health services
- rehabilitation services
- spinal cord injury services undertaken at spinal cord injury centres
- out-patient attendances
 - rehabilitation out-patient attendances (Treatment Function Code: 314)
- admitted patient care see list of specific exclusions
- drugs see list of specific exclusions.

5.4 Outstanding issues raised regarding currencies and classification systems For all specialised equipment services appropriate currencies and costing mechanisms need to be developed with particular regard to equipment maintenance including service repairs and replacements. In light of the above, Payment by Results (PbR) guidance⁵³ was reviewed to establish what information might apply in 2011/12 to the communication aids services supplied under SSNDS Definition No.5, to give some information about tariffs of analogous services to complement real-world data.

PbR currently covers the majority of acute healthcare in hospitals, with mandatory national tariffs for most admitted patient care, outpatient attendances, accident and emergency (A&E), and some outpatient procedures. Some non-mandatory tariffs have been developed for procedures excluded from national PbR.

In 2011-12 there are 56 treatment function codes⁵⁴ (TFCs) which have a mandatory outpatient attendance tariff, representing the vast majority of outpatient activity. An outpatient attendance tariff is payable for a pre-booked appointment at a consultant led clinic (the consultant may not be physically present but they remain clinically responsible). As with the admitted patient care tariff, the aim is to provide the right incentives by publishing separate tariffs for:

- (a) first attendances that include some of the costs of follow up attendances to disincentivise unnecessary follow ups
- (b) single-professional and multi-professional or multi-disciplinary attendances that recognise the benefit to the patient in seeing two or more healthcare professionals at the same time.

The mandatory tariffs for outpatient attendances do not appear to include any TFCs directly relevant to AAC services.⁵⁵ They specifically exclude prosthetics, orthotics, rehabilitation, neurology, spinal injuries, most non-consultant-led attendances, physiotherapy, occupational therapy, and speech and language therapy. Note in relation to local AAC services that community services are also excluded. The list of excluded devices mentions certain prostheses but does not mention communication aids.

Tariffs for the acute phase of rehabilitation do not appear relevant as they presumably include inpatient care. Top-up payments applicable to certain specified specialised services also appear irrelevant.⁵⁶

In conclusion, the mandatory tariffs for outpatient attendances do not appear to include any treatment function codes (TFCs) directly relevant to AAC services. They exclude prosthetics, orthotics, rehabilitation, neurology, spinal injuries, most non-consultant-led attendances, physiotherapy, occupational therapy, and speech and language therapy. However, tariffs for some analogous services may provide information to complement real-world data on costings.

⁵³ The Simple Guide to Payment by Results: <u>http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_12886</u>

 ⁵⁴ 2 Classification – systems used to code particular interventions. Currencies - the unit of healthcare for which a payment is made e.g. an outpatient attendance Tariffs - the set prices paid for each currency. Healthcare resource group (HRG) - currency for admitted patient care, outpatient procedures and A&E. Treatment function codes (TFCs) - currency for outpatient attendances.
 ⁵⁵ PbR tariffs for 2011/12:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_125398.xls
 Further guidance on PbR tariffs for 2011/12: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_12435

<u>6</u>

Costs for specialised assessment of high tech AAC needs;

In order to estimate a tariff for specialised assessment/trial activity it has therefore been necessary to describe 'averaged' activities relevant across client groups and over time. The time required for activities previously noted as likely to constitute the assessment/ trial phase has been estimated as follows:

- Review the referral information, seek further information including, potentially, observation (multi-disciplinary team 1 day total)
- Consultation/ assessment (can include several consultations over trial period, but total staff time allowed) (multi-disciplinary team 1 day ea. total 2 days)
- Report writing, referrals, outcomes setting, documentation (0.5 day)
- Post-trial (approx. 6 week) follow up (review / conclusion of trial, face to face with local team to assess training needs and discuss outcomes measurement) (0.5 day)
- 6 month review with local team including report writing (0.5 day)
- Possible mid-cycle review allowance (0.5 day)

Given the multidisciplinary nature of these assessments, the requirement to build in management, administrative and estates costs, plus travel costs (at 40% of direct costs) the cost per day has been estimated at £500.

• 5 days x £500 = £2,500

This averaged activity includes time to undertake reviews that are triggered for an estimated quarter of clients at interim points between the 4 or 5 year cycle of full reviews (for children and adults respectively). The assumption is that these would take an average of 2 days to complete, given that much of the required information should be available on the database either from the previous review or from outcome and care planning information logged by the local AAC spoke team onto the shared database.

Costs for regional management, including procurement, of high tech AAC systems The variety in direct procurement costs for different high tech AAC systems is significant, with eye gaze systems costing around £10,000-15,000 compared to around £1,000 and occasionally as low as £500 for some PC based AAC systems which do not require access or control methods or mounting supports. It is necessary for the purposes of establishing a budget for devices that is based on an 'averaged' cost relevant across a large client group. In this way variation in cost can be managed while providing a cost-effective service. This is one reason for proposing procurement on a regional basis.

The OCC report proposes⁵⁷ an average cost of £3,500 per aid. This figure is derived from the average cost of equipment provided during the CAP project. Although this figure was relevant 3-5 years ago and prices have gone up for some systems or elements of systems, such eye gaze and mounting equipment, other systems have reduced in price as the cost of computerised systems have fallen.

Based on updated information from service providers and device suppliers, £4,000 for total procurement costs per high tech AAC system is the figure on which the proposed budgets in this report are based. This figure includes costs relating to the procurement and set up of all elements of the system, including those possibly provided from allied services such as mounting and posture support, as described above and also includes the costs for outsourcing some service elements to external contractors. This system price is inclusive of VAT and factors in warranty costs over the product lifetime (4 or 5 years), or equivalent activity, to cover maintenance, repair, etc. It also factors in the AAC system set up, delivery and maintenance costs associated with specialised AAC hub service facility provision (e.g. work bench/shop, cleaning and storage facilities) and related workforce costs for staff responsible for equipment maintenance, cleaning, transport and procurement.

⁵⁷ The OCC Report (footnote reference 1) p26.

An additional issue that was considered to derive this average device cost was that some current costs for the more expensive high tech AAC systems are likely to include time spent by manufacturing and supplier staff on providing support for assessment and demonstration, which under the proposed system is likely to be provided by specialised AAC hub team and can be discounted within this element of costs.

In order to set up the initial stocks for assessment and short term loan, it has been suggested that manufacturers would be willing to provide 2 sets of their systems and elements of systems, including mounting and positioning elements, in order to ensure their range was available for consideration from the start. This would be in addition to the loan stocks already held by specialised services.

Costs for training and service development of local spoke AAC teams and for regional co-ordination of care planning, service standard development, quality assurance and improvement of local AAC teams

The proposal is that within the first two-three years the specialised AAC hub services focus much of their activity on working with local commissioners to establish a comprehensive coverage of local spoke AAC services across their region. This activity requires specialised hub services to provide training to local teams to ensure they are confident to provide low tech AAC and have the capability to refer appropriately for, and to provide support for, high tech AAC. It will also cover training to ensure teams are confident to use the shared database and to participate in the data gathering and quality assurance programmes that will be run on a regional basis. This training work will be an on-going need, at a reduced level, in year three and beyond. This budget will cover the costs for development and on-going maintenance of the regional database. Included in this budget are the costs relating to quality assurance, standards development and any costs relating to development of the care pathway process.

The budget for on-going costs will include staff costs for training, facilities for training and a share of video-conferencing facilities if used for training purposes, plus travel costs related to training and capacity building.

The phased budget for this activity has been established on a per head of AAC population basis, at £75 in year one, £50 in year two and £30 in years three and beyond.

Specialised AAC hub services - proposed budget requirement

Year 1: assumption that specialised AAC hub services are working at 60% capacity for children and 30% capacity for adults (on 4 & 5 year review cycle)

SHA cluster areas and population	Children (0-15) (numbers annually) 4 year product lifetime and review ^{58 59}	Adults (16-90+) (numbers annually) 5 year product lifetime and	Children Total	Children Total	Adult Total	Adult Total service	Adult and Children Total	Adult and Children Total	Infrastructure investment and local service development (per 1,000
base Capacity	leview	review	device cost	service cost	device cost	cost	device cost	service cost	AAC pop.)
management	60%	30%							
Per person			£4,000	£2,500	£4,000	£2,500	£4,000	£2,500	£ 75.00
Total no. seen	478	1,342							
North Midlands and	136	384	£ 543,866	£ 339,917	£ 1,535,858	£ 959,911	£ 2,079,724	£ 1,299,828	£ 547,721
East	146	405	£ 583,585	£ 364,741	£ 1,618,225	£ 1,011,391	£ 2,201,811	£ 1,376,132	£ 579,098
London	72	198	£ 288,209	£ 180,131	£ 790,159	£ 493,849	£ 1,078,368	£ 673,980	£ 283,384
South	124	356	£ 496,228	£ 310,142	£ 1,422,097	£ 888,811	£ 1,918,325	£ 1,198,953	£ 505,751
			£ 1,911,888	£ 1,194,930	£ 5,366,340	£ 3,353,962	£ 7,278,228	£ 4,548,892	£ 1,915,954
* includes warranty or similar arrangements for repair, maintenance, etc)			Children total service & device cost	£ 3,106,818	Adult total service & device cost	£ 8,720,302	Adult and children total service & device cost	£ 11,827,120	£ 13,743,074

⁵⁹ The replacement/ review cycle for children is 5 years in the US is 5 years and 2 years in France.

⁵⁸ The OCC report (footnote reference 1) p26: An average three-year period before an aid needs to be replaced because of changes in the user's needs, or new technological developments.

Year 2: assumption that specialised AAC hub services are working at 80% capacity for children and 60% capacity for adults (on 4 & 5 year review cycle)

SHA cluster areas and population base	Children (0-15) (numbers annually) 4 year product lifetime and review	Adults (16-90+) (numbers annually) 5 year product lifetime and review	Children Total device cost	Children Total service cost	Adult Total device cost	Adult Total service cost	Adult and Children Total device cost	Adult and Children Total service cost	Infrastructure investment and local service development (per 1,000 AAC pop.)
Capacity management	80%	60%							
Per person			£4,000	£2,500	£4,000	£2,500	£4,000	£2,500	£ 50.00
Total no. seen	637	2,683							
North Midlands and	181	768	£ 725,155	£ 453,222	£ 3,071,716	£ 1,919,822	£ 3,796,871	£ 2,373,044	£ 365,148
East	195	809	£ 778,114	£ 486,321	£ 3,236,451	£ 2,022,782	£ 4,014,564	£ 2,509,103	£ 386,065
London	96	395	£ 384,278	£ 240,174	£ 1,580,318	£ 987,699	£ 1,964,597	£ 1,227,873	£ 188,923
South	165	711	£ 661,637	£ 413,523	£ 2,844,195	£ 1,777,622	£ 3,505,831	£ 2,191,145	£ 337,168
			£ 2,549,184	£ 1,593,240	£ 10,732,679	£ 6,707,924	£ 13,281,863	£ 8,301,164	£ 1,277,303
			Children total service & device cost	£ 4,142,424	Adult total service & device cost	£ 17,440,604	Adult and children total service & device cost	£ 21,583,028	£ 22,860,330

Year 3: assumption that specialised AAC hub services are working at 100% capacity (on 4 & 5 year review cycle) - steady state

•									
	Children (0-15) (numbers annually)	Adults (16-90+) (numbers annually)	Children	Children	Adult	Adult	Adult and Children	Adult and Children	Infrastructure investment and local
SHA cluster	4 year	5 year							service
areas and	product	product							development
population	lifetime and	lifetime and	Total	Total	Total	Total	Total	Total	(per 1,000
base	review	review	device cost	service cost	device cost	service cost	device cost	service cost	AAC pop.)
	100%	100%							
Per person			£4,000	£2,500	£4,000	£2,500	£4,000	£2,500	£ 30.00
Total no. seen	797	4,472							
North Midlands and	227	1,280	£ 906,444	£ 566,528	£ 5,119,526	£ 3,199,704	£ 6,025,970	£ 3,766,231	£ 219,089
East	243	1,349	£ 972,642	£ 607,901	£ 5,394,085	£ 3,371,303	£ 6,366,727	£ 3,979,204	£ 231,639
London	120	658	£ 480,348	£ 300,218	£ 2,633,864	£ 1,646,165	£ 3,114,212	£ 1,946,382	£ 113,354
South	207	1,185	£ 827,046	£ 516,904	£ 4,740,324	£ 2,962,703	£ 5,567,370	£ 3,479,606	£ 202,301
			£ 3,186,480	£ 1,991,550	£ 17,887,799	£ 11,179,874	£ 21,074,279	£ 13,171,424	£ 766,382
			Children total service &	6 5 4 70 0 00	Adult total service &	c 20 0CZ CZ2	Adult and children total service &	6 24 245 702	6 25 042 004
			device cost	£ 5,178,030	device cost	£ 29,067,673	device cost	£ 34,245,703	£ 35,012,084

Indicative staffing levels required to undertake assessment activity at regional specialised AAC hub services by year 3 (steady state running at 100% capacity) See total service cost for adult and children's AAC service, on previous page.

(This staffing level excludes those staff providing AAC system procurement and management activity as well as those undertaking capacity building, care pathway development and training for local spoke AAC services.)

	Assessment (6) & M&A (2) staff days	Referrals pa (children)	Referrals pa (adults)	Per annum	Regional FTE staff for assessment activity	Staff (inc.	on costs)	Estates &	travel @ 40%	Yr 3 (steady state) budget
				working days	total	(pp)	(total)	(pp)	(total)	service
North	8	227	1,280	240	50	£ 45,000	£ 2,259,739	£ 30,000	£ 1,506,493	£ 3,766,231
Midlands										
and East	8	243	1,349	240	53	£ 45,000	£ 2,387,523	£ 30,000	£ 1,591,682	£ 3,979,204
London	8	120	658	240	26	£ 45,000	£ 1,167,829	£ 30,000	£ 778,553	£ 1,946,382
South	8	207	1,185	240	46	£ 45,000	£ 2,087,764	£ 30,000	£ 1,391,843	£ 3,479,606
					176		£ 7,902,854		£ 5,268,570	£ 13,171,424

Local AAC spoke services - proposed budget requirement

This budget requirement estimates an average, total low tech AAC device/ intervention cost of £100 pa for children and £75 pa for adults (on a one year and two year equipment review cycle respectively). This costing for devices is based on a review of the manufacturers' information on the cost of low tech equipment.

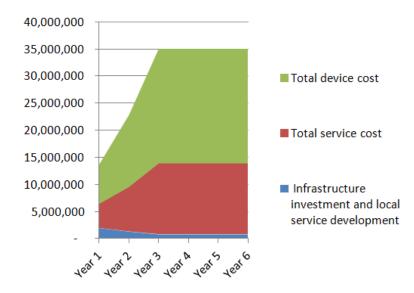
The budget requirement for service delivery has been established using a cost estimate of £300 per day (including all on-costs) for local AAC spoke staff with allocation of 2 days p.a. (4 half days) for a service for children and 1 day p.a. for a service for adults. This service level consists of a half day for review of needs for children every 6 months and annually for adults, with 3 half days for children and 1 half day for adults for further AAC support over each year for the individual and their communication partners.

	Children (0-15)	Adults (16-90+)	Children	Children	Adult	Adult	Adult and Children	Adult and Children
SHA cluster areas and population	(numbers	(numbers	Total	Total	Total	Total	Total	Total
base	annually)	annually)	device cost	service cost	device cost	service cost	device cost	service cost
Per person			£100	£600	£75	£300		
Total	31,864	223,599						
North	8,158	57,635	£ 815,800	£ 4,894,798	£ 4,322,642	£ 17,290,568	£ 5,138,442	£ 22,185,365
Midlands and East	8,754	60,726	£ 875,378	£ 5,252,267	£ 4,554,464	£ 18,217,856	£ 5,429,842	£ 23,470,123
London	4,323	29,652	£ 432,313	£ 2,593,879	£ 2,223,887	£ 8,895,550	£ 2,656,201	£ 11,489,429
South	7,443	59,254	£ 744,341	£ 4,466,048	£ 4,444,054	£ 17,776,216	£ 5,188,395	£ 22,242,264
			£ 2,867,832	£17,206,992	£ 15,545,047	£ 62,180,189	£ 18,412,879	£ 79,387,181
			Children total service & device cost	£ 20,074,824	Adult total service & device cost	£ 77,725,237	Adult and children total service & device cost	£ 97,800,061

Local AAC spoke services

Table and diagram to illustrate the budget requirement for activity areas for specialised AAC hub services, rising to year 3 which represents the steady state (100% capacity) working level.

	Year 1	Year 2	Year 3	Year 4	Year 5	Year 6
	£	£	£	£	£	£
Infrastructure investment and local						
service development	1,915,954	1,277,303	766,382	766,382	766,382	766,382
Total service cost	4,548,892	8,301,164	13,171,424	13,171,424	13,171,424	13,171,424
Total device cost	7,278,228	13,281,863	21,074,279	21,611,484	21,611,484	21,611,484
	13,743,074	22,860,330	35,012,084	35,885,043	35,885,043	35,885,043



Transition from existing AAC service provision arrangements:

Existing arrangements

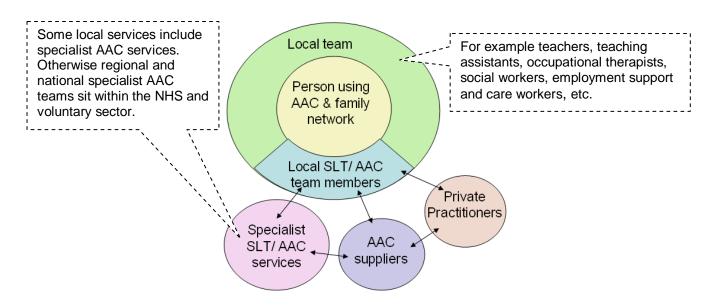
As noted in the Quality Standard for AAC services⁷ a broad range of individuals and organisations currently provide AAC services including statutory, third sector and private practitioners (speech and language therapists (SLT), rehabilitation professionals, educational assistive technology and Access to Work practitioners) as well as equipment suppliers. The models of service are noted as varying widely across the country. The sector's Quality Standard for AAC Service uses a generic service model in order to clarify the roles, responsibilities and referral responsibilities of organisations and individuals making up the whole system.

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 speech and language therapists (SLTs). Some of these local SLTs will have AAC competence, occasionally at a specialised 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.
Specialised SLT/ AAC service ⁶⁰	Specialised AAC services may sit at local, regional or national levels ⁶¹ . Regional and national services are provided by the statutory or voluntary sector from which local teams in health, education and social care commission services. Some specialised AAC services are delivered by teams that do not include speech and language therapists (SLTs) (e.g. rehabilitation engineering teams) and draw on external SLT expertise.
Suppliers	Most teams, whether at local or specialised 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 ⁶² .
Private practitioners	Some gaps are filled by private practitioners, often SLTs with AAC competence, who work with local teams and in liaison with suppliers.

Examples include: ACE Centre North Oldham, Ace Centre Advisory Trust Oxford, PCAS in Bristol, the Wolfson Centre in Great Ormond Street Hospital, the Assistive Communication service in Charing Cross Hospital, the West Midlands regional Access to Communication and Technology Centre.

A map of AAC services is available on the Communication Matters website: <u>www.communicationmatters.org.uk/page/resources/aac-assessment-services</u>

⁶² Suppliers who are members of Communication Matters sign a Code of Conduct that requires them to work to the best interest of clients and act transparently in relation to commercial interests.



The OCC report highlights examples of services that are working collaboratively to deliver integrated specialised and local services, based on a hub and spoke service model. The report also notes examples of a number of organisations, working across the NHS, education and third sectors to deliver services across a regional area.

Future AAC hub and spoke service delivery options

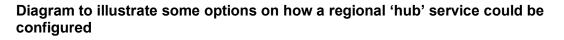
As set out previously in this report, the term 'specialised AAC hub service' indicates the following range of activities to be undertaken rather than a presumption that there must be a centralised hub location or provision of hub services by a single organisation:

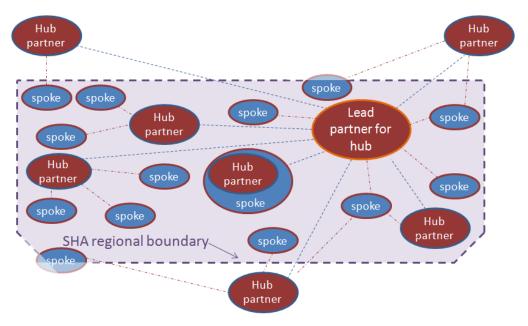
- Specialised assessment of high tech AAC needs;
- Regional management, including procurement, of high tech AAC systems;
- Training and service development of local spoke AAC teams;
- Regional co-ordination of care planning, service standard development, quality assurance and improvement of local AAC teams.

The activity plan set out in this report estimates the numbers of child and adult referrals that are likely to be received in each of the regional areas on an annual basis when the specialised AAC hub services are working to capacity. Indicative staffing levels have been outlined and the range of competence to be held by staff and sub-contractors has been specified. The physical facilities required have also been noted.

Should the proposals in this report be adopted, any contract for specialised AAC hub services would most probably be made with a single organisation that will take responsibility for delivery of the contract and for compliance with legal requirements and statutory and contractual standards for delivery of the AAC specialised hub service. This organisation may choose to act as the lead partner for a consortium of organisations across a region. There may be a case for a regional specialised commissioning group to choose two or three lead organisations within a region, though it is less likely that a business case could be made for contracting with more than three lead organisations. The lead organisation and consortium partners may also choose to employ under contract individuals within other organisations, or who are self employed, to deliver elements of the specialised AAC hub services. How this activity is undertaken, whether by staff employed directly or on sub-contract as part of the hub team or through contracted out services is a decision to be made by the lead organisations and their consortium partners.

The decision on the number of specialised AAC teams to commission within any SHA cluster area will depend on the analysis of cost savings to be achieved through scale of service, the capacity to deliver effective and accessible services across the full reach of each geographical area and capacity of current specialised AAC teams to form consortia to deliver regional services.⁶³





While there is not a requirement for a centralised location or a single organisational structure for delivery of specialised AAC hub services, if the service is provided collaboratively by team members spread across a regional area, there will need to be mechanisms to manage a dispersed specialised services team and to implement standardised processes.

- There will be a requirement that the lead organisation has the administrative, technical and financial capacity and experience to manage complex care planning and communication and procurement and equipment management functions.
- If tendering as part of a consortium, the lead organisation will also have to demonstrate their capacity to manage the contractual and service level agreements between consortium partners and for a distributed workforce or contracted out staff.
- Organisations could participate as consortium partners in two neighbouring regional areas. Organisations could also provide services into a regional area although they are based outside of that region.
- Some local AAC spoke teams currently provide elements of specialised services. Under the proposed model the local service could identify which elements of specialised AAC service they are able to provide as part of a consortium service offering. Elements of service, such as specialised teacher expertise, are currently contracted from organisations such as education authorities and this could be continued under a consortium and sub-contract approach. Within a service that is providing both local and specialised AAC service activities there would need to be a formal distinction between these activities in line with the contract or consortium

⁶³ Recommendation from OCC report (find page ref): The number of hubs should be determined on the basis of population numbers plus geography. Where a region has a large number of children and young people (for example the South East, and London) or covers a wide geographical area (for example the South West, and the East of England), commissioning might be on a sub-regional basis.

agreement. These services could also refer to a specialised regional service for more expert advice or for elements of the specialised service they are unable to provide, for example for mounting of equipment.

- As budgets and activity plans are currently established on an SHA Cluster population basis, referrals from local spoke teams will need to align fairly closely to the SHA cluster boundaries. For local spoke AAC teams that serve populations that significantly extend into different SHA Cluster boundaries, referral relationships may need to be established with regional specialised AAC hub services in two neighbouring regions.
- There are cost savings and quality improvements made possible by having one regional centre for project management, database management, finance, legal, and contracts management. These cost savings would increase the budget available for providing services directly to AAC users and their care networks.
- There are clear advantages to a consortium approach to enable local AAC spoke teams to have specialised hub team members and facilities within easy travelling distance for clients. The disadvantage to providing specialised AAC hub services via a consortium approach is that there is an administrative cost to managing consortium agreements and ensuring contract compliance.

Transition planning

- It is recommended that organisations delivering specialised AAC services consider the steps they need to take to form consortia and to work with partners to reach consensus on the best approach to delivering specialised AAC services, as outlined in this report.
- For those services that have previously found ways to provide a more comprehensive level of AAC service than has been more generally available, the commissioning of specialised AAC systems needs to be implemented in a way that supports and integrates with these existing arrangements. Commissioners of these services, which are often provided as an integrated package either for children's health services or for electronic assistive technology, need to consider the activity plan and budget proposed in this report to ensure they can integrate both commissioning and service delivery approaches.

Appendix 1: Quality Standard for AAC Service	Appendix 1:	Quality Standard	for AAC	Services ⁷
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	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
1.	D	I can expect my local team to identify that I have a need for AAC at the earliest opportunity.	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: local teams and local SLT/AAC team members Support: specialised AAC teams to raise the awareness within local teams of SLT/ AAC indicators of need and possible solutions.	The Bercow ¹ review's recommendation: Early identification and intervention are essential. Doyle & Phillips (2001) ⁶⁴ note the critical nature of timing of intervention for AAC users who have motor neurone disease.
2.	D	I can expect my local team to know how to manage my AAC needs or, if they are not able to, know which specialised AAC service to refer to.	An AAC care pathway process is in place. This should include effective signposting to local and national resources and services.	Compliance: local SLT/ AAC teams Support: specialised AAC teams by negotiating a care pathway process with local teams.	Lund and Light (2007) ⁶⁵ outlined a perception of a lack of availability of local AAC services, and in particular a lack of services for adult users. Difficulties in accessing a specialised evaluation are described by parents and AAC users (McNaughton et al. 2008) ⁶⁶ .

⁶⁴ Doyle, M. & Phillips, B. (2001). Trends in augmentative and alternative communication use by individuals with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication*, 17, 167-178.

⁶⁵ Lund, S. & Light, J. (2007). Long-term outcomes for individuals who use augmentative and alternative communication: Part III -contributing factors. *Augmentative and alternative Communication*, 23, 4, 323-335.

 ⁶⁶ McNaughton, D., Rackensperger, T., Benedek-Wood, E., Krezman, C., Williams, M. & Light, J. (2008). "A child needs to be given a chance to succeed": parents of individuals who use AAC describe the benefits and challenges of learning AAC technologies. *Augmentative & Alternative Communication*, 24, 1, 43-55.

	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
3.	D	Members of the AAC team at local and specialised levels have the range and level of competence in AAC required to undertake their role.	AAC teams have mapped their competences against those required within a local or specialised team ⁶⁷ . The team meet, or have a strategy to meet, the competence requirement. AAC team members have training and CPD opportunities to acquire required competences for current roles and to enable career development.	Compliance: local SLT/ AAC team members, specialised SLT/ AAC teams.	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) ⁶⁸ . Teachers, teaching assistants and parents reported that a lack of training for staff was a significant barrier to successful implementation of systems. Matthews (2001) ⁶⁹ 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. (2001b) ⁷⁰ in an analysis of school records described the amount of official training of other staff by communication specialists as minimal.

⁶⁷ Work to carry out a mapping of required competences is being carried out by a special interest group facilitated by the Communication Council: contact admingroups@communicationmatters.org.uk

⁶⁸ Soto, G., Muller, E., Hunt, P., & Goetz, L. (2001). Critical Issues in the Inclusion of Students Who Use Augmentative and Alternative Communication: An Educational Team Perspective. *Augmentative and Alternative Communication*, 17, 2, 62-72.

⁶⁹ Matthews, R. (2001). A survey to identify therapists' high-tech AAC knowledge, application and training. *International Journal of Language & Communication Disorders,* 36 Suppl, 64-69.

 ⁷⁰ Clarke, M., McConachie, H., Price, K. & Wood, P. (2001). Speech and language therapy provision for children using augmentative and alternative communication systems. *European Journal of Special Needs Education, 16,* 1, 47-54.

	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
4.	C	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.	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: local SLT/ AAC teams Support: specialised AAC teams by negotiating a care pathway process with local teams.	The Bercow ² review's recommendation: Joint working is critical. Parette et al. (2000) ⁷² 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/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
5.	C	I can expect that my consent for referral or interventions will be obtained, recorded and regularly confirmed.	A referral process is in place that documents the consent process.	Compliance: local SLT/ AAC team members, specialised SLT/ AAC teams.	 CQC regulation of health and social care is based on highlevel 'essential standards of quality and safety' ⁷¹ 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)⁷² highlighted the importance of involving families in decisionmaking. In Rackensberger et al. (2005)⁷⁸ adult users described how they benefitted from taking a lead role in decision-making.

⁷¹

Available from: http://www.cqc.org.uk/usingcareservices/essentialstandardsofqualityandsafety.cfm Parette, H., Brotherson, M. & Huer, M. (2000). Giving families a voice in augmentative and alternative communication decision-making. *Education & Training in Mental Retardation & Developmental Disabilities*, 35, 2, 177-190. 72

	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
6.	D	At any 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.	Local services have a process in place by which they collect and maintain stocks of service information for all AAC specialised services to which they refer and ensure this information is given to service users at the point of referral. Specialised services publish information about their services that include service response timescales.	Compliance: local SLT/ AAC teams Support: specialised AAC teams by providing information about their service, including service response timescales to local teams.	Users have requested ⁷³ that AAC services publish and comply with timescales for responding to queries, referrals and requests for assessment appointments.
7.	C	I can expect that AAC services will comply with their stated service response timescales.	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: specialised SLT/AAC teams	The NHS Constitution ⁷⁴ 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.

⁷³ Communication Matters Symposium 2010, user consultation exercise to support the development of the AAC quality standard The NHS Constitution: <u>http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx</u>

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	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
8.	C	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.	Evidence of compliance in terms of timing of report production as well as the quality ⁷⁵ and scope of the information provided, assessed against the process set out in the agreed care pathway documents.	Compliance: local SLT/ AAC team members, specialised SLT/ AAC teams	AAC service users have voiced frustration ⁷³ at the lack of clear, timely communication they have encountered.
9.	D	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 to my AAC care plan.	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: local SLT/ AAC team members, specialised SLT/ AAC teams.	Users have requested ⁷³ key worker support to manage a sometimes complex and confusing AAC care pathway process. Lund and Light (2007) ⁶⁵ outlined limited expertise of local professionals and a lack of collaboration between professionals. The Bercow Report ¹ recommendation: A continuum of services designed around the family is needed.
10.	D	I can expect roles and responsibilities to be made explicit throughout the assessment process, with key contacts identified within each team.	AAC teams have a process in place by which roles are explained to service users and documented and key contacts are identified.	Compliance: local SLT/ AAC team members, specialised SLT/ AAC teams.	As above.

⁷⁵ An example may be compliance with requirements for plain English: http://www.plainenglish.co.uk/files/howto.pdf

	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
11.	C	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.	The plan for the assessment process is drafted and amended on a regular basis and agreed and shared with all involved.	Compliance: local SLT/ AAC team members, specialised SLT/ AAC teams.	Sector consensus.
12.	C	I can expect that the AAC assessment team will apply their knowledge and skills to consider the broad range of AAC options that are available, to meet my requirements.	AAC assessors demonstrate that they have knowledge of an appropriately broad range of AAC options through their CPD and self directed learning plan.	Compliance: local SLT/ AAC team members, specialised SLT/ AAC teams.	McDonald (2008) ⁷⁶ 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.'
13.	С	I can expect that the AAC assessment service can provide me with the opportunity to physically interact with a range of AAC equipment and strategies.	Local and specialised AAC teams can demonstrate how they provide access to an appropriate range of AAC equipment and strategies.	Compliance: local SLT/ AAC team members, specialised SLT/ AAC teams.	Sector consensus.
14.	D	Where possible I can expect to be offered a trial of recommended equipment for a reasonable period of time as part of the assessment process.	Local and specialised AAC teams can demonstrate how they provide access to equipment for trial, including agreements with suppliers, etc.	Compliance: local SLT/ AAC team members, specialised SLT/ AAC teams.	Sector consensus.
15.	С	I can expect that the equipment that I trial, or which is	Local and specialised AAC teams can demonstrate that,	Compliance: local SLT/ AAC team members, specialised SLT/ AAC	The barrier of limited availability of technical support

⁷⁶ McDonald, R., Harris, E., Price, K & Jolleff, N. (2008). Elation or frustration? Outcomes following the provision of equipment during the Communication aids project: Data from one CAP partner centre. *Child: Care, Health and Development*, 34, 2, 223-229.

	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
		recommended for my use, will be provided to me with adaptations and programming in place to meet my needs.	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.	teams.	was outlined by Bailey et al., (2006) ⁷⁷ , Rackensberger et al. (2005) ⁷⁸ , Parette et al. (2000) ⁷² and Soto et al. (2001) ⁶⁸ . 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 ⁷⁷ , Parette et al. 2000) ⁷² .
16.	C	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.	Local and specialised 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 specialised AAC team members have the competence and skills and time available to provide adequate training.	Compliance: local SLT/ AAC team members, specialised 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.	Murphy et al (1996) ⁷⁹ 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) ⁸⁰ paper reported that their own knowledge and skill level was a barrier to usage. Lund and Light (2007) ⁶⁵ , and Parette et al. (2000) ⁷² reported a need for family support.

⁷⁷ Bailey, R. L., Parette, H. P., Stoner, J. B., Angell, M. E., & Carroll, K. (2006). Family Members' Perceptions of Augmentative and Alternative Communication Device Use. Language, Speech, and Hearing Services in Schools, 37, 1, 50-60.

Rackensperger, T., Krezman, C., Mcnaughton, D., Williams, M. & D'Silva, K.(2005). "When I first got it, I wanted to throw it off a cliff": The challenges and benefits of learning AAC technologies as described by adults who use AAC. *Augmentative and Alternative Communication,* 21, 3, 165-186.

⁷⁹ Murphy et al (1996) AAC systems: obstacles to effective use. European Journal of Disorders of Communication. Vol 31, No.1

⁸⁰ Smith, M. & Connolly, I. (2008). Roles of aided communication: perspectives of adults who use AAC. *Disability & Rehabilitation Assistive Technology*, 3, 5, 260-273.

	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
					McNaughton et al. (2008) ⁶⁶ identified the important role of parents in teaching usage of a device.
17.	С	I can expect a clear rationale to be given for the AAC strategies and / or equipment that are trialled and recommended.	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: local SLT/ AAC team members, specialised SLT/AAC teams	Sector consensus.

	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
18.	C	I can expect that, when a decision is made about equipment for long-term provision, a plan of implementation is agreed.	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: local SLT/ AAC team members, specialised SLT/AAC teams	 Evidence from Norway⁸¹ 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)⁸⁰ reported that few users had assistance with programming or maintenance when they were provided with their devices. CQC regulation⁸² of health and social care is based on highlevel 'essential standards of quality and safety' You will be given opportunities, encouragement and support to promote your independence.'

⁸¹ AAC Ministerial Short Life Working Group (2010) AAC Summary Report. Scotland: AAC Short life working group Available from: <u>http://www.cqc.org.uk/usingcareservices/essentialstandardsofqualityandsafety.cfm</u>

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	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
19.	C	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.	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: local SLT/ AAC team members Requested support: the wider local team	International research has indicated that nearly one third of all AAC equipment is abandoned if there is insufficient support available in its use ⁸³ . Teachers in the Soto et al. (2001) ⁶⁸ paper, identified back up services and support being in place as requirements for successful introduction and use of AAC. Hodge (2007) ⁸⁴ found that technical problems were a common cause of frustration, particularly with the more sophisticated devices.
20.	D	I can expect my AAC assessment teams' proactive support when seeking the funding or resources that are required to implement their recommendations.	Local and specialised 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: local SLT/ AAC team members, specialised SLT/AAC teams	Service users have voiced ⁸⁵ their frustration the lack of funding for equipment. Parents in the Golbart and Marshall (2004) ⁸⁶ paper perceived that there were demands on parents to fund AAC resources themselves.

⁸³ Blackstone, S. (1992) Re-thinking the basics. Augmentative Communication News, 5. No.3

 ⁸⁴ Hodge, S. (2007). Why is the potential of augmentative and alternative communication not being realized? Exploring the experiences of people who use communication aids. *Disability & Society*, 22, 5, 457-471.

⁸⁵ 'No voice, no choice' campaign co-ordinated by Scope in 2007. Report available from the Scope website: <u>http://www.scope.org.uk/help-and-information/publications/no-voice-no-choice-final-report</u>

⁸⁶ Goldbart, J. & Marshall, J. (2004). "Pushes and Pulls" on the Parents of Children who use AAC. *Augmentative and Alternative Communication*, 20, 4, 194-208.

	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
21.	D	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.	Local commissioners publish their strategy for commissioning AAC equipment and services that meet the AAC quality standard.	Compliance: commissioners	The Bercow Report ¹ 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.'
22.	C	I can expect to receive periodic review aimed at ensuring the equipment/ support is proving useful and effective.	Local AAC teams have a review process in place for all current clients and their personal support network. Teams demonstrate that they carry out review using a range of methods, with face-to-face (or equivalent) review likely to be required by most clients.	Compliance: local SLT/ AAC team members, specialised SLT/ AAC teams	Murphy et al ⁷⁹
23.	С	I can expect to be able to recommence the assessment process as my needs, circumstances and AAC practice and technologies change.	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: local SLT/ AAC team members, specialised SLT/ AAC teams Support: specialised AAC teams by providing information about innovative AAC practice and technologies	Sector consensus.

	Current/ develop- mental	Quality statement	Measure	Compliance required/ support requested	Rationale for quality statement
24.	D	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.	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: commissioners	Kent-Walsh and Light (2003) ⁸⁷ 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) ⁸⁴ 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) ⁷⁸ 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.

⁸⁷ Kent-Walsh, J. & Light, J. (2003). General Education Teachers' Experiences with Inclusion of Students Who Use Augmentative and Alternative Communication. *Augmentative and Alternative Communication*, 19, 2, 104-124.

Appendix 2: Local and specialised AAC service interface

Source: The Office of the Communication Champion Report¹

Figure 1

The interface between local and tertiary (regional) services

