

Specialised AAC provision Commissioning national services: a model service specification

Office of the Communication Champion and Council October 2011



This model service specification 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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Schedule 2 Part 1: Service Specifications

[Mandatory headings, but detail for local determination and agreement]

Service	AAC Specialised hub service for regional area: [example: North]
Commissioner Lead	
Provider Lead	
Period	

1. Purpose

1.1 Aims

In recognition that there were problems in access to all types of support for children and young people with speech, language and communication needs (SLCN) John Bercow MP was asked to carry out a review¹ 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.

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 2010² found some good practice in AAC provision, 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,³ 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 services and develop AAC quality standards.⁴

The government's Special Educational Needs (SEN) Green Paper *Support and aspiration: a new approach to special educational needs and disability*,⁵ 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

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

¹ The Bercow Report, July 2008. Available from the DfE website: <u>http://www.education.gov.uk/publications/standard/publicationdetail/page1/DCSF-00632-2008</u>

² The Office of the Communication Champion (OCC) report, September 2010. http://www.thecommunicationcouncil.org/council/communication-council-papers/meeting-on-16september-2010/

³ Specialised Services National Definition Set (SSNDS) 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>

⁴ Quality standard for AAC services, Communication Matters, 2010:

http://www.communicationmatters.org.uk/page/resources/national-standards-aac-services

⁵ Support and aspiration: a new approach to special educational needs and disability, Department for Education, March 2011. https://www.education.gov.uk/aukliastiong/standerd/aukliastion_Datail/Dage1/CM9/ 208037

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.'

This specification embeds the Communication Champion's recommendations for the commissioning of specialised AAC services⁶ as regional hubs supporting local services, and enables commissioners to meet the commitments in the SEN Green Paper. It is based on the Specialised Services National Definitions Set No. 5. and is informed by a Quality standard for AAC services which has been developed by the AAC sector. Using this specification to commission specialised NHS services across England will establish a more uniform, standardised and equitable approach.

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.

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

AAC Specialised Services - A service model, The Office of the Communication Champion, November 2011

 ⁷ 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).

⁸ 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

⁹ Blackstone, S. (1990) Populations and Practices in AAC Augmentative Communication News Vol. 3 No.4

The Office of the Communication Champion (OCC) report, September 2010. <u>http://www.thecommunicationcouncil.org/council/communication-council-papers/meeting-on-16-september-2010/</u>
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¹¹ Population figures are based on mid-2007 census: latest available SHA cluster population figures which are used in later analysis

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>

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 specification 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 specification 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.

The specification outlines a model of care that aims to cost-effectively exploit available and emerging technologies to maximum benefit.

1.2 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 Matters and undertaken by the University of Sheffield School of Health and Related Research (ScHARR).⁷

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 small number of 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.

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".⁸

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.

1.3 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.⁹ These figures indicate the broad group that would benefit from low and high technology AAC equipment and strategies.
- For the purposes of this specification 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 Report¹⁰ 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 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.
- The activity plan and budget in this specification is based on an assumption of a prevalence figure of 10% of the AAC population as 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 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, this specification proposes 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.

This specification assumes that 90% of adults and children requiring AAC will be dealt with effectively at a local level, and that 10% of the AAC population will require a referral to specialised AAC services for a high tech or specialist AAC intervention.

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

			AAC Pop Est. 0.5% a whole popu need a (low and h	verage of lation who AAC	needs: es AAC po	ch AAC st. 90% of p would tech AAC	High tech AAC needs: est. 10% of AAC pop would need high tech AAC		
	Total pop. ¹¹	Children (0-15)	Adults (16-90+)	Children (0-15) (approx. 0.33%)	Adults (16-90+) (approx. 0.54%)	Children (0-15)	Adults (16-90+)	Children	Adults (16-90+)
	51,092,100	9,655,800	41,436,400	31,864	223,599	28,678	201,381	3,186	22,360

1.4 Objectives

Objectives of 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;

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

1.5 Expected Outcomes

Outcomes will relate to the objectives noted above. It is currently difficult to identify the best approach to measuring the goal of supporting clients to attain their personal communication goals through the intervention 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 Matters¹² AAC Outcome Measures working group.

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. Specialised AAC hub services will measure indicators of activity to meet the quality standards noted in the sector's Quality Standard for AAC services.

2. Service Scope

In line with the recommendations from the Communication Champion regional services will provide specialised AAC interventions, including the provision of high tech AAC, to people of all ages across England. In line with government policy^{13 14 15} 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.

2.1 Service Description

Using the basis of good practice and the approach indicated in the Specialised Services National Definition Set (SSNDS)¹⁶ 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.

2.2 Accessibility/acceptability

In line with the SSNDS 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

¹³ 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_118218
The Principles and Rules for Cooperation and Competition, Department of Health, July 2010. Available

from: <u>http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_118221</u> ¹⁵ 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_124324</u>

¹⁶ Specialised Services National Definition Set (SSNDS) 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-physicaldisability-all-ages</u>

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."¹⁷

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. 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 shaped¹⁸ by the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF)¹⁹ 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.

As noted in the AAC quality standard 17, 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 Quality Standard for AAC Services also indicates that it is not acceptable²⁰ for the assessment or trial of equipment to be restricted by the assessor's access to stocks of equipment, confidence, habits or preferences, unless the restriction in interventions and systems trialled are demonstrably in the best interest of the client.

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 is for specialised AAC hub services to implement best practice as an organisation and to develop a common approach over time, based on evidence.

The issues that are likely²¹ 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.

2.3 Whole System Relationships

With allied services: the sector's Quality Standard for AAC services notes a requirement

¹⁷ Royal College of Speech and Language Therapy (RCSLT) Standards for AAC (submitted for publication at October 2011)

- ¹⁹ World Health Organisation (WHO) International Classification of Functioning, Disability and Health: http://www.who.int/classifications/icf/en/
- Quality standard for AAC services, Communication Matters, 2010: <u>http://www.communicationmatters.org.uk/page/resources/national-standards-aac-services</u> (AAC quality standard no. 13).
- ²¹ 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.

²² Specialised Services National Definition Set (SSNDS) No. 05: Assessment and provision of equipment for people with complex physical disability (all ages), Edition 3, 2010. http://www.specialisedservices.nhs.uk/doc/assessment-provision-equipment-people-with-complex-physical-disability-all-ages

¹⁸ This approach was unanimously supported by the AAC specialised services consulted during the drafting of this report.

for continuity of AAC services between children 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 expected that specialised services demonstrate how they intend to work collaboratively with NHS electronic AT (eAT) services and to provide electronic assistive technology services in an integrated way.

2.4 Interdependencies

Between local and specialised services: The care pathway outlined in this specification indicates the close interdependence required between 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 specification for specialised AAC hub services is based on the assumption 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, 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.

2.5 Relevant networks and screening programmes

As with all other specialised services, as noted in the SSNDS,²² 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.

Supporting the development of this level of knowledge, skills and competence within the local team is activity to be undertaken by the specialised AAC hub teams as it 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.

3. Service Delivery

3.1 Service model

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, 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 SSNDS²³, the report from the Communication Champion²⁴ and AAC Synthesis for Commissioners from the RCSLT,²⁵ 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 informatics²⁶, 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.²⁷

²³ 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).

²⁴ 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.

²⁵ AAC Synthesis for Commissioners, RCSLT, 2011. Section 7.

²⁶ Health informatics further information: http://www.nhscareers.nhs.uk/details/Default.aspx?ld=767

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

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 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 Strategic Health Authority (SHA) cluster regional boundaries.²⁸

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 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

²⁸ Developing the NHS Commissioning Board, DH, 2011. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_12811

²⁹ Quality standard for AAC services, Communication Matters, 2010: <u>http://www.communicationmatters.org.uk/page/resources/national-standards-aac-services</u> (AAC quality standard no. 13).

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.

¹¹ The equivalent review and replacement cycles are 2 years in France and 5 years (for children) in the US.

assessment is proposed as constituting an average of 5 days work by the multi-disciplinary team and will include the following activities:

- Review of 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 document 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.'

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 in the sector's Quality Standards document²⁹ 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 document, AAC services are required 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 specification 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. The systems or elements of systems used for trial can be relatively generic as long as they provide a sufficiently close approximation to the intended final system to enable evaluation, for example 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:** For the purposes of assessment and short term trial (approx. and averaged as eight weeks), the regional centres will 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 can be held in closely located equipment stores but the requirement is for a wide range of equipment to be readily available at the point of assessment/ consultation.

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 will 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

- **Product lifetime**: The assumption is that all AAC high tech equipment has a 5 year maximum product lifetime³⁰ (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.³¹ 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 will have to demonstrate how they will put in place an effective approach to maintenance and repair. It is expected that services will be in a position to negotiate cost-effective and timely maintenance and repair arrangements with manufacturers if that is their chosen approach.
- **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.
- **Management**: The cost-efficient management by specialised AAC hub teams of stocks of equipment for assessment and short term trial will need to be supported by administrative, financial and technical staff resources.

Procurement

Specialised AAC hub services will have to demonstrate an approach to procurement which:

- Provides value for money through the exploitation of bulk buying advantage;
- Supports access to innovative and specialist AAC systems and elements of systems in the short and longer term;
- Supports interoperability between system elements (e.g. hardware and software or vocabulary, with mounting and positioning systems) with related electronic assistive technology systems (e.g. environmental controls and wheelchairs), with mainstream electronic systems (e.g. TVs, PCs, etc.).
- Complies with procurement legislation and the requirements of NHS commissioning guidance;
- Creates strong contract arrangements with suppliers which creates added value in relation to long term support for AAC system implementation.

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, specialised AAC hub services are required to:

- 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

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."

Regional co-ordination of care planning, service standard development, quality assurance and 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, specialised services will establish a database to enable the collection and analysis this data, which will be 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.

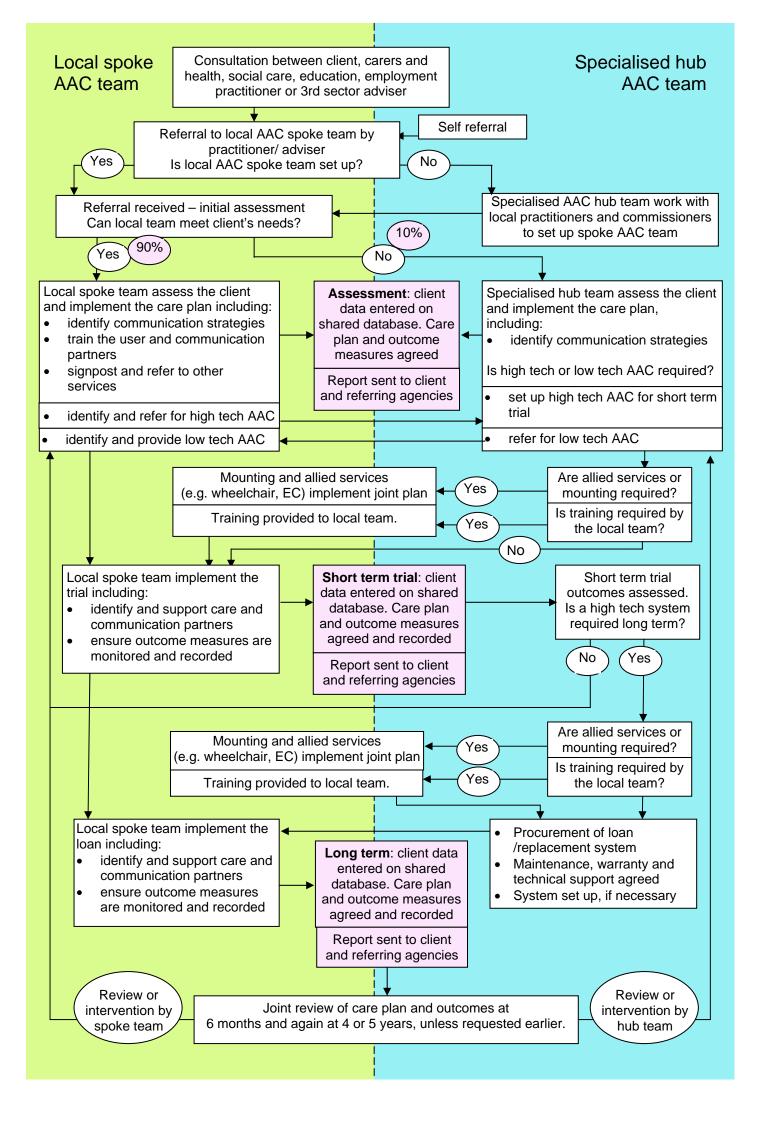
Specialised services are required to co-ordinate the regional development of detailed care pathway processes, including outcome measures and setting evaluation points, and to analyse and present this information for a range of stakeholders regionally and nationally. This information is to be used for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

The Quality Standard for AAC Services⁴ 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. Given the reorganisation of local spoke and regional hub AAC services and the use of standardised care pathways, care record management systems and care communication protocols should demonstrably reduce or negate the need for allocation of an AAC specific key worker.

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 care pathway set out in this specification is based on the service model and 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 will collaboratively evolve standardised referral documentation that would allow greater flexibility to reflect the local situations and needs while maintaining a high level uniform and standardised processes across England.



4. Referral, Access and Acceptance Criteria

The detailed referral, access and acceptance criteria for specialised hub AAC services will be set out for local AAC teams in the care pathway documentation but will ultimately be dependent on their competence and decision making skills. For this reason, referral patterns should be closely monitored by each specialised AAC hub team to ensure they can identify gaps in local non-specialised spoke teams' knowledge, competence and confidence and can provide training to enable local teams to manage and refer clients appropriately.

4.1 Geographic coverage/boundaries

Specialised AAC specialised hub services will be commissioned within a regional boundary aligned with the SHA cluster area. 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 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.

	nd for region ervices in SH			AAC Pop Est. 0.5% a whole popu need (low and h (not annu	verage of lation who AAC igh tech)	Specialise needs: est AAC p (not annu	Total				
	Total population ³²	Children (0-15)	Adults (16-90+)	Children (0-15) (0.35%)	Adults (16-90+) (0.55%)	Children (0-15)	Adults (16-90+)				
Total	51,092,100	9,655,800	41,436,400	26,170	227,900	3,380	22,790	26,170			
North	14,605,900	2,746,800	11,859,100	9,064	63,994	906	6,399	7,306			

4.2 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.

See OCC report on Specialised AAC service provision for proposed advantages for delivery of specialised AAC hub assessments in the community, in the environments and with the communication partners relevant to each individual and, conversely, the rationale for delivery of specialised AAC hub assessments in a centralised facility.

The proposed location for undertaking the assessment/ consultation element of the service should be addressed by specialised AAC hub services on a case-by-case basis,

³² Population figures are based on mid-2007 census: latest available SHA cluster population figures

demonstrating creative thinking 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.

4.3 Days/Hours of operation

- Given the presumption of a comprehensive coverage of local teams, there should be no requirement for an emergency response required from specialised AAC hub services, even for challenging situations such as provision within ICU settings as this should be addressed in the first instance by the local spoke AAC service.
- Specialised AAC hub services may need to offer times of appointments to accommodate fluctuations in performance or capability if the individual is affected by fatigue/ concentration problems or pain, e.g. early in the morning.
- Otherwise a weekday, 9am-5pm service by the specialised AAC hub service should be adequate to meet needs.

4.4 Referral criteria, sources & route

- Referrals will only come in to the specialised AAC hub teams via the hub's local AAC spoke teams. These referrals may originate from a broad range of practitioners and referral agents including speech and language therapy (SLT) and occupational therapy (OT) teams in local and acute health teams, primary care teams, social care and residential care services, schools/ academies, local authorities, further education and employment support teams, prisons, residential homes and for looked after children in care. As the responsibility for provision of AAC support and long-term implementation of AAC will remain with the local teams it is vital that the local AAC team hold responsibility for referral, although care of those individuals requiring high tech AAC and specialised assessment will be co-ordinated with AAC specialised hub teams.
- Self referral into the system will also be via the individual's local team who will refer to the specialised AAC hub service according to the care pathway process.
- Referral criteria from the local AAC spoke team into the specialised AAC service are to be detailed in care pathway documentation, as noted above, primarily in relation to the knowledge, skills and competences of the local spoke team, with the aim that the local, non-specialised spoke teams have sole management of approximately 90% of people requiring AAC and specialised hub services are actively engaged in joint management with local spoke teams of the remaining 10% of the population group requiring AAC.
- In those situations where someone is not resident for significant periods of time in their 'originating' area, for example when a child is resident for much of the year in a special school away from their family home, then the choice of the local team should reflect this. The local AAC spoke team for the special school at which the child was resident would receive the referral and make an onward referral to their specialised AAC hub service. The local AAC spoke team would then be responsible for implementing the long term AAC plan for the child and would pass on responsibility for the child to the relevant local

³³ OCC report (footnote reference 2) (page 22)

AAC spoke team when the child moves from the school.

4.5 Exclusion criteria

There are no exclusion criteria considered to be relevant to the AAC specialised hub service, given the care pathway process outlined above.

4.6 Response time and detail and prioritisation

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

- Referrals, appointments and report delivery: the sector's AAC Quality Standard 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 immediately available 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 notes³³ 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 provided 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.
- The prioritisation of the AAC case load should be managed through the review process

as required in the specification and care pathway, with regular 4 and 5 year reviews for the entire children and adult AAC population respectively, and intermediate review triggered by the local team when required. Outside of this process, if prioritisation is required, it should be at the discretion of the local AAC spoke team and AAC hub specialised team working collaboratively. These teams are likely to give priority, in no order of precedence, to those adults and children in the following categories:

- with a rapidly progressive degenerating condition, such as MND;
- those adults and children receiving end-of-life care;
- those people who are receiving multi-disciplinary support where timely AAC service response maximises the benefit to the individual and minimises costs to health and care services, such as people receiving ICU and in-patient care, those undergoing intensive rehabilitation, etc.;
- those adults and children with no current means of communication;
- those adults and children whose lack of communication is resulting in demonstrable risk of physical or psychological harm;
- those children whose learning and development is being significantly delayed by lack of communication;
- those adults and children who are at a point of transition and whose requirement for AAC intervention is delaying successful transition, for example between school, college and work settings.

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 needs to demonstrate that they have the 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 demonstrate how they can 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 demonstrate how a specialised AAC hub service providing a service over a large geographical area with a potentially widely dispersed, outreach workforce will 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.

5. 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 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 will 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.³⁴

6. Self-Care and Patient and Carer Information

The context for specialised AAC practitioners' support to individuals to self care is set by national guidance such as the Common Core Principles to Support Self-Care. ³⁵ Principle 5 - Support and enable individuals to use technology to support self care. This document notes that: "The worker ensures appropriate equipment and devices are discussed and when appropriate puts individuals in touch with the relevant agency from where they can procure the item(s), and where possible provides the relevant tools and devices. The worker also engages with individuals to support and enable the use of technology."

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_1 19445 and:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH 1 19449

³⁴ 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 including disabled children....':

³⁵ Common Core Principles to Support Self-Care, Skills for Care and Skills for Health: http://www.skillsforcare.org.uk/selfcare/

The AAC services quality standard also sets out the principles on which service users can expect AAC teams to base their services:

- 1. I can expect to have the right to equal access to an AAC service regardless of:
 - age or time of onset
 - severity of disorder
 - geographical location
 - economic status
 - linguistic or cultural background
- 2. I can expect to be involved in an assessment process that is demonstrably impartial independent and objective.
- 3. I can expect to receive a high quality, fair and personal service from AAC Services.
- 4. I can expect the professionals working with me to share information, knowledge and skills.
- 5. I can expect all members of the AAC service to have the required skills, knowledge and competences.
- 6. I can expect my knowledge, skills and experience to be valued and acknowledged.
- 7. I can expect to be involved as an active participant throughout the whole decision making process.
- 8. I can expect that, if my needs for AAC cannot be addressed by my current team, a referral will be made to a team with the appropriate knowledge, skills and experience.
- 9. I can expect the professionals working with me to communicate effectively with each other to my best interests.

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

7. Quality Requirements

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

Standards which should be adhered to are:

 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',³⁶ 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,

³⁶ Care Quality Commission Essential Standards: http://www.cqc.org.uk/usingcareservices/essentialstandardsofqualityandsafety.cfm

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'.
- The Quality Standard for AAC Services⁴ developed by a Communication Council Special Interest Group (set out in Appendix 1).

Documents that may provide contextual guidance:

- An AAC competence framework is under development by Communication Council³⁷ AAC Workforce Special Interest Group (SIG) and this should be available by 2012.
- BSRM (2000) 'Electronic assistive technology'³⁸
- 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)'³⁹
- 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'⁴⁰

The specialised hub AAC services will need to meet national quality standards and governance requirements and any other quality requirements that may from time to time be specified by commissioners.

8.	Activity
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8.1

Activity Performance	Threshold	Method of measurement Consequer				
Indicators	Thround		breach			
Support clients to attain their personal communication goals	Guidance on appropriate outcome measures should be available in 2012 as a result of activity by a Communication Matters AAC Outcome Measures working group.	Appropriate outcome measurement approach such as PIADS, TOMS, or Goal Attainment Scaling to be used.				
Provide timely access across England for the estimated population that require specialised AAC services	Within 2 years of service initiation.	Identify levels of need within regional area, working collaboratively with local AAC spoke services. Develop and use care pathway documentation to identify and monitor				

³⁷ Communication Council website: http://www.thecommunicationcouncil.org/

³⁸ British Society of Rehabilitation Medicine (BSRM): www.bsrm.co.uk

³⁹ Department for Children, Schools and Families: www.dcsf.gov.uk

⁴⁰ Department for Children, Schools and Families: www.dcsf.gov.uk

Increase adoption and use of appropriate high tech AAC interventions and minimise abandonment of these AAC systems	Within two years of service initiation.	response and action times.Document adoption and continued effective use of high tech AAC through input of outcome measures by local AAC spoke teams to regional database.
Support the development of effective local AAC teams and care pathway procedures by which to manage referrals to specialised AAC services	From initiation of service to end of year 2.	Establish, working with local commissioners, a comprehensive network of local spoke AAC teams across the region. Provide training and capacity building to ensure they can manage 90% of AAC population needs. Establish and monitor implementation of care pathway actions and processes including use of regional database and input of outcome measurement information by local AAC spoke teams.

8.2 Activity Plan

	Year C	Dne	Year	Тwo	Year Three		
	Children Adults		Children	Adults	Children	Adults	
	(0-15)	(16-90+)	(0-15)	(16-90+)	(0-15)	(16-90+)	
SHA cluster area:		(numbers	(numbers	(numbers			
North	(numbers	annually)	annually)	annually)	(numbers	(numbers	
Years 1-3 : phased	annually)	5 year	4 year	5 year	annually)	annually)	
capacity increase to	4 year	product	product	product	4 year	5 year	
100% capacity in	product	lifetime	lifetime	lifetime	product	product	
year 3 (based on 4 &	lifetime and	and	and	and	lifetime	lifetime	
5 year review cycle)	review ^{41 42}	review	review	review	and review	and review	
Capacity							
management	60%	30%	80%	60%	100%	100%	
Referral levels	136	384	181	768	227	1,280	
	Total <u>520</u>		Total	949	Total	1,506	

8.3 Capacity Review

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% 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

⁴¹ The OCC report (footnote reference 2) 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.

⁴² The replacement/ review cycle for children is 5 years in the US is 5 years and 2 years in France.

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.

9. Prices & Costs

The mandatory tariffs for outpatient attendances do not appear to include any TFCs directly relevant to AAC services.⁴³ 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.⁴⁴

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.

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

⁴³ PbR tariffs for 2011/12: <u>http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_125398.xl</u> <u>s</u>

 ⁴⁴ Further guidance on PbR tariffs for 2011/12: <u>http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_1</u> <u>24356</u>

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 a few hundred pounds for some PC based 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 costeffective service. For this reason specialised AAC services are recommended to implement procurement on a regional basis.

£4,000 per high tech AAC system is the figure on which the budget is 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 for children and adults respectively), 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, delivery and storage facilities) and related workforce costs for staff responsible for equipment maintenance, cleaning, transport and procurement.

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.

	Children	Adults	Child	ren	Adult		Total			
	ar	umbers nnually)							Infrastructure investment and local	Regional totals Years 1-3
SHA cluster area:	4 year (cl								service	
North		(adult)	Total	Total	Total	Total	Total	Total	development	
Years 1-3 : activity	product and rev		device	service	device	service	device	service	(per 1,000	
and budget		iew	cost	cost	cost	cost	cost	cost	AAC pop.)	
Per person Year 1:			£4,000	£2,500	£4,000	£2,500	£4,000	£2,500		
(60% children, 30%										
adult capacity)	136	384	£543,866	£39.917	£1,535,858	£959,911	£2,079,724	£1.299.828	£547,721	£3,927,273
£75 per 1,000 AAC			2010,000	200,011	21,000,000	2000,011		21,200,020	20,	20,021,210
population										
Year 2:										
(80% children, 60%										
adult capacity)	181	768	£725,155	£453,222	£3,071,716	£1,919,822	£3,796,871	£2,373,044	£365,148	£6,535,063
£50 per 1,000 AAC										
population Year 3:										
(100% capacity for										
children and adults)	227	1,280	£906,444	£566 528	£5,119,526	£3 199 704	£6,025,970	£3 766 231	£219,089	£10,011,290
£30 per 1,000 AAC	'	.,200	2000, 111	2000,020	20,110,020	20,100,101	20,020,010	20,100,201	~210,000	2.0,01.1,200
population										

⁴⁵ The OCC report (footnote reference 2) 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. The replacement/ review cycle for children is 5 years in the US and 2 years in France.

⁴⁶