A Right to Speak

Supporting Individuals who use Augmentative and Alternative Communication

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A Right to Speak

Supporting Individuals who use Augmentative and Alternative Communication

The Scottish Government, Edinburgh, 2012

Disclaimer

This document contains several case studies that make reference to specific items of equipment which can be recognised by their brand names. The Scottish Government does not wish to endorse any specific brand of equipment. However, it was felt that use of generic names would not demonstrate the variation in need that people who use AAC require during their lifetime, and for this reason equipment has been identified. The Scottish Government recognises that there are many manufacturers and suppliers of AAC equipment both within and outwith the UK. For those who wish to explore the range of equipment available we direct you to the following website: **http://www.communicationmatters.co.uk**.

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Introduction

Augmentative and Alternative Communication (AAC) is 'any method of communicating that supplements the ordinary methods of speech and handwriting, where these are impaired[1] (for a detailed definition of AAC refer to Appendix 1). This document sets out our vision for a Scotland where people who use AAC are fully included in our society. It describes what needs to be achieved through the delivery of four strategic aims. Eight recommendations with specific action points describe what we have to do to meet those aims. Finally, it also contains a set of principles, outlining the shared values that underpin this policy and support our actions.
In 2007, a campaign led by the Royal College of Speech and Language Therapists (RCSLT), with support from Capability Scotland and Augmentative Communication in Practice: Scotland, highlighted a range of difficulties encountered by individuals with communication needs who require to use AAC. The RCSLT also surveyed AAC provision and demonstrated that this was limited in many Scottish regions. In response, the then Minister for Public Health and Sport set up a Short Life Working Group, an outcome of which was a recommendation to produce national multi-agency guidance.

This is issued under the Equality Act 2010 and incorporates the work of the Short Life Working Group which comprised:

- production of quality indicators for AAC;
- consideration of the outcomes of a national AAC provider survey; and
- evidence gathered from focus groups and questionnaires for people who use AAC.

Additional stakeholder engagement with individuals and groups of people who use AAC as well as representatives from statutory and non- statutory agencies also contributed to the production of this report.

Who is the guidance for?

This document should be read by:

- People who use AAC,[*†] their families and carers.
- Strategic and operational heads within Health Boards, local authority Social Work and Education Departments, and the voluntary sector.
- Speech and language therapists, social workers, teachers, learning support teachers, educational psychologists, and staff in further and higher education.

For the purposes of this document AAC does not include:

- Individuals who use assistive technologies to support communication difficulties as a consequence of sensory impairment.
- Individuals for whom English is not their first language and where there is no communication difficulty in their first language.

[*] Individuals who use AAC wish to be described as such and not as 'AAC users'. As this document is referring to both adults and children who may also be described as patients and/or pupils or students, the generic term 'clients' is therefore also used here to refer to all age groups.

[†] The term AAC is used throughout this document and may refer to any of the aspects of AAC provision, AAC support, and to an AAC system or be used as a collective term to refer to all three.

Funding

To support implementation of the recommendations within this report, the Scottish Government will make £4m available over 3 years.

Summary of Recommendations

Key recommendations for NHS Boards, local authorities and other AAC service providers are summarised in the table below:

No.	Recommendation	Action (s)	By Whom	Delivered by
1	AAC services to demonstrate the effectiveness of AAC interventions by promoting the implementation of AAC research on specific, targeted and universal AAC interventions.	Develop a National AAC Research Strategy .	National services with input from Regional Networks/Centres	September 2012
		Evaluation of AAC related data from individual and population based intervention programmes	All AAC services	March 2015
2	National statistics on AAC to be gathered by relevant agencies to support future gathering of cost effectiveness data on AAC to ensure that AAC funding is sustained in the longer term.	Implement use of nationally agreed data sets for AAC	All NHS based AAC services	April 2014
		Implement use of appropriate outcome measures for all people who use AAC	All AAC service providers	December 2014
3	All AAC service providers should develop and implement a population based approach to the provision of support for people who require to use AAC equipment and services, ensuring that needs are recognised and responded to appropriately within the wider community.	Development of national strategy to promote universal support for people who use AAC	Lead by National AAC services(SCTCI* & CALL**) with input from Regional and local services	Commence June 2012, conclude December 2012
		Implementation of national strategies to promote universal support for people who use AAC.	National, Regional and local services	April 2013-April 2015

4	To ensure that people who are required to use AAC have access to appropriate levels of high quality specialist assessment and support delivered as locally as possible, Health Boards and local authorities should work in Partnership with each other and with National AAC services.	National services to design a planned programme of activity to develop capacity and competencies of regional and local services.	National Services	April 2013
		Establish multi agency regional AAC networks or centres providing support to local services and that are supported by National services.	Local Partnerships (NHS & Local Authority and, where applicable, 3rd sector agencies)	April 2013
		National services to implement a programme to develop capacity and competencies of regional and local services.	National Services, Regional Centres/Networks and local services	April 2014
5	The Scottish Government to explore the feasibility of NHS-based National AAC services transferring to National Services Division, within NHS National Services Scotland, to support the monitoring of quality and effectiveness of AAC provision as well as to protect this valuable resource.	Scottish Government will conduct an impact analysis on the transfer of National AAC services to the National Services Division	Scottish Government	April 2013
6	To ensure equitable, efficient and safe provision of AAC equipment for people who are required to use it, Health Boards and local authorities should work in Partnership with each other.	Regional AAC centres/networks to have representation on local Community Equipment Management Groups.	Regional AAC Networks/Centres	June 2012 for existing regional centres/services June 2013 for newly established networks
		Build on existing Partnerships to agree priorities, policies and processes for AAC equipment provision.	Local Partnership^ fundholders	April 2014

7	National AAC services to provide strategic advice to appropriate agencies on AAC equipment to support planning, procurement and provision of AAC.	Establish strategic links with Scottish Government Joint Improvement Team Workstreams for: (i) Equipment & Adaptations (ii) Telecare	National AAC services	Sep 2012
8	All AAC service providers to implement the use of Local AAC care pathways to ensure equitable and timeous provision of equipment and support for people who require to use AAC.	Local AAC care pathways to be agreed with regional and national services	Local AAC partnerships in collaboration with National services	September 2013
		Local quality indicators to be developed and monitored.	National Services And Local Partnerships Scottish Government	December 2013

The Background

Language is at the heart of all human existence. It establishes relationships, conveys information and is the medium through which most of human activity is performed[2]. The ability to communicate is key to the individual's ability to be autonomous, and to be able to make choices and decisions without interference from others.[3]

Communication has an important role in contributing to a person's psychological health.[4] People with motor neurone disease report loss of speech to be the worst aspect of the disease[5]. Loss of intimacy as a consequence of communication difficulties has been recognised as a contributory factor in carer-strain where a carer is caring for a person with communication difficulties.[4,6] For young children, the ability to produce spoken language is an important skill in the acquisition of literacy.[7]

Communication principally occurs through the spoken and written medium. In today's world the use of the written medium via short messaging service (SMS or texting), social networking, email and the world wide web is increasing. The written medium is often the communication of choice where previously spoken communication would have been used. For the individual with communication and/or physical difficulties, written communication can sometimes be the most practical mode of communication.

AAC refers to methods that augment or replace usual methods where an individual has no reliable means of communication. These methods are typically used by individuals with impaired communication. People who use AAC may include, for example, individuals who have communication difficulties from birth as a consequence of cerebral palsy, learning disabilities, autism and other difficulties, or people who have an acquired communication difficulty following stroke, dementia, motor neurone disease and other neurological conditions. AAC systems may also be used by people with temporary loss of communication – for example, within intensive care wards. AAC systems vary from high-tech dedicated computer equipment to adapted mainstream technology with specialist software or simple low-tech picture communication books. AAC has the potential to enhance the lives of many individuals with communication impairments.

Prevalence

In the United Kingdom, there is no specific prevalence data for people of all ages with communication difficulties who use AAC. RCSLT[8] estimates that between 0.3% and 1.4% of the total population require the use of AAC systems although this is reported to be a conservative estimate.

Specific figures for children with AAC needs are not available either, although there is a range of recorded data that gives a flavour of what demand might be. Setting the Scene[9] suggests there are nearly 45,000 young people with additional support needs in Scotland, while some 28,190 children between the ages of 5 and 17 receive Disability Living Allowance.

Additionally, the Support Needs System, administered by the Information Services Division: Scotland, records all children with health needs. National data is

extrapolated from information provided by individual health boards but the system is not consistently applied. For example while there are an estimated 7,200 children with complex needs in Scotland, only 3321 are registered on the Support Needs System. The system collates data for children from 0 to 19 years. Figures for 2009 suggest that approximately 20,000 children in Scotland have communication needs, of which 4,000 have severe communication needs. Meanwhile the number of children with complex needs and severe disability is increasing because of increased survival of pre-term babies and increased survival after severe trauma or illness.[10]

Further guidance on estimated prevalence of AAC use in Scotland can be explored by examining prevalence data for conditions associated with AAC use. One Scottish study[11] exploring AAC training provided by speech and language therapists reports the most common conditions associated with AAC use in Scotland as cerebral palsy, motor neurone disease, stroke and multiple sclerosis. Prevalence rates for these specific conditions, and others associated with AAC use, are summarised in Appendix 2.

The use of a national register for people who use AAC has been considered and, while there would be benefits in such an entity, there are many methodological barriers to overcome ranging from the complex and individual nature of AAC to whether registration is voluntary or mandatory. Meanwhile a current UK study that includes examining prevalence of AAC is in progress and will be a key data source for future AAC commissioning (http//: www.communicationmatters.org.uk).

Demand

Increasing demand is anticipated as a consequence of changing demographics, with an increase in survival of children with disabilities; improving mortality for adults with disabilities; and increasing numbers of people living with acquired long term conditions. In addition, developments in mainstream and specialist technology, and a greater awareness and acceptance of technology, also raise expectations.

Costs

Individual equipment ranges in cost from £30 to £18,000 (minimum and maximum cost of available technology at 2011 prices) and usually has a life span of around 5 years, requiring repair and replacement over the course of an individual's life (from pre-school to adult). AAC equipment is highly specialist, low volume and requires skilled support to be used effectively. While low-tech AAC equipment is generally low cost in terms of initial production costs it can be associated with higher costs over time as these systems are tailored to individual needs and require continual revision and reissue.

Current Service Provision

In some areas of Scotland, joint interagency budgets provide efficient access to AAC equipment. In other areas, services have used a targeted approach to develop the skills of the wider AAC workforce. However, evidence from service providers suggests that provision across Scotland is inconsistent and does not always meet the needs of people with communication difficulties, particularly those requiring high-tech devices. Examples include:

- school children facing long delays before equipment is available;
- school leavers having equipment breaking down and facing a year in work, at college or university unable to communicate before replacement equipment is purchased; and
- people with progressive illnesses dying before the equipment becomes available.

Some services regard assistive technology simply as referring to telecare. This has been described as 'remote or enhanced delivery of care services to people in their own home or in a community setting by means of telecommunications and computerised AAC systems'. In some cases an AAC device can be regarded as functioning as a telecare device – for example, where provision of an AAC device enables a person to reliably contact carers and thus reduce the input required via direct care services. AAC is generally not regarded as telecare but can be a useful tool in the provision of telecare.

Consequences

The cost of not providing adequate AAC services is high, particularly if education and employment opportunities are denied.

An individual who is quadriplegic can control his environment, make text or voice calls, engage in face-to-face conversations and get support from a carer, as well as shop or bank and communicate via the internet using available technology.
The potential cost savings in such a case, for an individual living alone at home, are demonstrated in the box below:

AAC provision/living at home
Total cost of AAC equipment £18,000*
Weekly Care costs 49 hours @ £14.20/hr £ 695.80
Total annual care costs: £ 39,181.60

No AAC provision/living at home
AAC Equipment costs £0
Weekly care costs 7x24 hours @ £14.20/hr £ 2385.60
Total annual care costs £ 124,046

Total Annual Saving with AAC provision £ 84,864.40

*maximum cost based on available technology today; the average lifespan of technology is 5 years so this could be a recurring cost every 5 years. Cost of AAC support not included.

The example above demonstrates a significant increase in care costs if AAC needs are not provided for.

Anecdotally, individuals who are unable to communicate basic needs and emotions are more likely to be admitted to hospital inappropriately and, when admitted, their stay is likely to be longer.

To be unable to communicate is to be excluded from many aspects of everyday life. For a child in school this may mean being unable to actively participate in many aspects of the curriculum. G*etting It Right for Every Child*[13] (GIRFEC) is a national programme aimed at improving outcomes for all children in Scotland. GIRFEC has identified eight well-being indicators, as follows: nurtured; active; respected; responsible; included; safe; healthy; achieving. Where a service is unable to identify AAC needs for a child with communication difficulties or to support and make provision for these needs, it is failing to meet these quality indicators and consequently failing the child. It is difficult to see how any of the above indicators can be met if a child is unable to communicate.

The example below demonstrates how AAC has been used to support an individual to express views and integrate into a wider community.

Case 1

Jack is 53 and had a stroke 10 years ago which left him with a right- sided weakness and severe expressive aphasia. As a result he has no useful speech and is unable to read or write. Jack has been known to SLT services since his stroke and communicated using gesture, vocalisation a communication book and, most recently, a specialist voice output communication aid. He attended his local day centre until about two years ago when he became depressed and sometimes had violent outbursts. At this point, he was re-referred to the multidisciplinary team for input from Psychology, Nursing and SLT.

The team worked with Jack to find out why he no longer wished to attend the day centre. Using Talking Mats, Jack indicated that he did not wish to be defined by his disability, and he was unhappy attending a 'day centre'. Other options to help Jack engage in activities in the community were therefore explored. During this time, the SLT working with Jack obtained a portable media device with a specialist application for Jack to try.

Jack took to this mainstream technology and is now managing well and is integrating into the community.

Failing to meet the needs of people who use AAC results in widening inequalities because of the difficulties accessing justice, healthcare and education. For a child with severe communication difficulties, the potential impact of lack of speech on development, learning and literacy is significant. Early intervention regarding AAC provision and support is crucial to reduce inequalities for the individual who needs to use AAC. Similarly, for adults who use AAC, the cost of being unable to maintain employment, train for employment or participate in education due to lack of adequate provision is widening inequality.

In summary, the costs of not providing AAC are far reaching, widely acknowledged but poorly described. The costs to individuals include restricted educational attainment and employment opportunities, increasing anxiety levels, increasing carer strain, and reduced quality of life. The costs to services include higher care costs, longer and more frequent hospital admissions and barriers to a good quality of life.

The Future

Vision

Individuals who use augmentative and alternative communication (AAC) are included, free from discrimination, and live in an environment that recognises their needs and adapts accordingly.

Consultation with people who use AAC highlighted that, whilst provision of equipment and skilled support are identified areas of need, what is crucially important is that their needs are recognised by the wider community. This requires the wider community to have the skills to recognise the needs of people who use AAC and the ability to adapt to meet those needs. This latter aspiration resonates with equality legislation that requires public authorities to promote equity of opportunity in relation to age, disability, gender reassignment, pregnancy and maternity, race, religion and belief, sex and sexual orientation. It requires public authorities to have due regard to the need to eliminate unlawful discrimination, promote equality of opportunity and foster good relations.

Achieving the vision will mean a co-ordinated approach to ensuring equitable access to AAC equipment and services. In addition, there needs to be development of a population approach to AAC to ensure wider knowledge, understanding and communication skills.

Amongst the individuals who completed questionnaires, participated in a focus group and were interviewed individually were children, adults and carers across Scotland with mixed experiences of AAC. Key themes emerged from the consultation that are embedded into the strategic aims.

Strategic Aims

Strategic Aim

1. The communication needs of people who require to use AAC are universally recognised.

Individuals expressed a desire to live in a community where their needs are recognised and understood, a community that is familiar with AAC and understands how to interact with a person using AAC.

Strategic Aim

2. Individuals who require to use AAC have equal access to quality AAC services at a level commensurate with their needs at any point in their lives.

People who use AAC described a requirement to have timely access to specialist assessment by skilled staff who understand their needs and are knowledgeable about AAC. They described frustration at long delays and some confusion over which services they should be accessing. Specialist regional and national services are highly valued. However, there is no equity of access to these services as they are not always available to all individuals. People who use AAC also highlighted a requirement to have lifelong local access to specialist staff who are skilled in supporting their needs. Frustrations accessing AAC support from staff skilled in AAC were repeatedly highlighted. This was a particular issue during periods of transition – for example, from school to post-school where difficulties identifying appropriate adult services were described.

Strategic Aim

3. Individuals who require to use AAC are supplied with appropriate equipment in a timely manner.

A requirement is to have any equipment needs including provision, repair and replacement met without undue delay. This theme was repeatedly illustrated by reports from people who are life-long users of AAC but who currently have no reliable communication system. This is because their equipment is no longer repairable and they are relying on others to navigate several agencies and services in order to source a replacement device. The impact of this for one individual was being unable to communicate with parents via the telephone, while for another college studies could not be completed.

Strategic Aim

4. Services supporting people who use AAC contribute to developing a robust evidence base for the effectiveness and cost-effectiveness of AAC

In the current financial climate, more than ever, the field of AAC must be able to robustly demonstrate its effectiveness using summary measures and cost-effectiveness ratios. The availability of cost-effectiveness ratios would provide the necessary data to support the provision of AAC as an alternative to competing interventions for clients.

What needs to be done?

As summarised on pages 3 to 5, this document makes eight separate recommendations, with specific action points, to support achieving our ambitions for people who use AAC. These are described in further detail here.

Recommendation 1

AAC services to demonstrate the effectiveness of AAC interventions by promoting the implementation of AAC research on specific, targeted and universal AAC interventions.

Actions

1. National Services will lead on development of a National AAC Research Strategy with input from Regional Centres/Networks.

2. All AAC services will evaluate AAC related data from individual and population based intervention programmes.

AAC has the potential to enhance the lives of many individuals with severe communication impairments. There are numerous case studies, case series studies and personal stories reported in the literature that demonstrate the benefits of AAC to individuals. For example, one study[14] reports on the experiences of eight adults, most with graduate degrees, two with Masters degrees and one with a doctorate, all of whom were in employment and using AAC. All participants in the study identified the importance of technology and AAC in supporting their continued employment. It is acknowledged that publication of cases where AAC is abandoned are less likely to be reported in the literature while in some studies an element of responder bias may over-report AAC use.

An evaluation of recent AAC studies examining the effectiveness of high-tech AAC is presented in the AAC Synthesis.[15] In summary this paper cautiously concludes that there is evidence to support the benefits of AAC to different client groups. It also recognises that more rigorous methodological approaches are required in future studies.

This report identified a total of nine systematic reviews,[16-24] including a Cochrane review, via the Database of Abstracts for Reviews of Effects (Centre for Reviews and Dissemination, University of York, http://www.york.ac.uk/inst/crd/) as relevant to AAC. These are summarised in Appendix 3. In four of the reviews a range of speech and language therapy interventions that included AAC interventions were evaluated, while the remaining five reviews were more specifically evaluating aspects of AAC. The general trend from the reviews is that there is insufficient evidence to support interventions mainly due to poor study design, poor study description and limited sample size (many studies were single case studies). Evaluation of the reviews demonstrated wide inclusion criteria for many of the reviews resulting in heterogeneity between studies. Collectively, review conclusions tend to be suggestive rather than definitive.

One review[16] suggests limited evidence of general carryover of AAC use. This may reflect the lack of understanding of AAC at a population level, where abandonment of AAC results from the levels of communication competency of the wider community experienced by the person who uses AAC. This is acknowledged within the report as an area of need highlighted by people who use AAC. It is also worth noting that measures of effectiveness of AAC tend to be dominated by direct or indirect observations on frequency of use or by rates of abandonment.[25] It is suggested that if effectiveness of AAC technology is based on observed frequency of use then this is likely to under-estimate the effectiveness and prevalence of AAC use.[25] This is because AAC tends to be used for communication repair where communication breakdown has occurred[26] and that it is the preference of unfamiliar listeners[27] while reporting of AAC use tends to be from familiar listeners such as carers and speech and language therapists. Despite the limitations of the evidence demonstrating the effectiveness of AAC and AAC interventions, the personal accounts within the literature provide powerful and compelling evidence to support the efficacy of AAC. Three single Scottish cases are presented below:

Case 2

Maggie is a 42-year-old woman with Motor Neurone Disease, diagnosed 2 years ago. She lives at home with her husband and two teenage children. Maggie's speech deteriorated rapidly following diagnosis and she was provided with a Lightwriter® communication aid and an alphabet chart. For some time she was able to use these as her main methods of communication but as she deteriorated physically she could no longer access the keyboard of the Lightwriter®. Maggie wanted to be able to continue to communicate with her friends. She also wanted to be able to read without relying on others to turn the pages for her. Maggie was provided with a Future Pad communication aid with The Grid 2 software. She is able to operate this with a single switch and use it as her main means of communication as well as to read e-books using kindle software, which is accessed through The Grid 2.

Lightwriter® a text based voice output communication aid
Futurepad, a portable tablet personal computer
The Grid2, specialist communication and computer access software

Forth Valley Health Board

Maggie's story demonstrates how, even with a deteriorating condition, AAC supports the individual to maintain autonomy and independence.

The following personal account by Barry demonstrates how he is able to have a degree of independence that would otherwise be difficult to achieve if he were not able to gain access to his current AAC system.

Case 3 Personal account by person who uses AAC

'I am a person who uses AAC because I have Cerebral Palsy which makes my speech hard to understand. I have been using different types of AAC for most of my life.

I used a low –tech AAC system called Bliss when I attended school. However after I left school I moved back home to Ayrshire and met my Speech and Language Therapist. Following an assessment, we agreed that a Lightwriter SL35 would be the most suitable communication aid for me. I liked it because it was small. Shortly after I got my Lightwriter, I started my course at Motherwell College. It felt good using the Lightwriter – it made a difference to me that people weren't standing over me reading what I was saying which is what happens when you use a low tech system. I used this SL35 Lightwriter for years and loved it.

In my early twenties my goal was to get my own home. Eventually I achieved my goal and moved into my own home – there were problems along the way over adaptations to the house and my mum had to stay with me for 3 months until all of that was sorted out. I also had some problems with local youths. This was not a nice time for me, my first experience of living alone. However, again, technology came to my aid and I was able to get help with my alert button and, most importantly, tell family and the police about what had happened using my Lightwriter®.

I gave a presentation about my life using my Lightwriter® SL35 at a conference. Attending the conference was a fantastic experience for me. It also was my first chance to see the new model of Lightwriter® – the SL40. I got the chance to try it for a few hours and what I loved about it was that I could send a text message for the very first time in my life to my mum. As well as being able to text, I thought it looked quite cool. I also realized that the improved word prediction system was really going to speed up my communication – this is obviously very important to me. The speech was also better as were a number of other features. I was in two minds about handing it back after I had a shot of the SL 40 and thought I might just run away with it I liked it so much!

I told my Speech & Language Therapist about the new Lightwriter®. Things went quiet for a while, but in February 2009 she came to visit me with a surprise package. She had applied for funding for the Lightwriter® SL40 and the funding request was successful. Here was my new Lightwriter® – the first thing I did was send my mum another text message! Mum was so happy because a couple of years ago after I had moved in to my new house she wanted to buy me a mobile phone but we realized I couldn't hold it. Mum feels it has given her peace of mind that I can now text to make contact with someone if I have a problem when I am out and about. This new Lightwriter® has really taken my independence and confidence up a level. Once when I was out alone in my power chair, I toppled over. I had no way of getting help – now with my Lightwriter® SL40 I could text someone to get me help.'

Barry Smith, Ayrshire

Lightwriter® a text based voice output communication aid

The case presented below is described from the perspective of Education staff:

Case 4

Ahmed is 17 years old. He is quadriplegic with severe limb deformities and no controllable movement in any of his limbs. He has no speech but can use eye pointing to communicate his needs which he does in a very determined fashion. When he started school he attended a special school. Further assessment showed that Ahmed was a cognitively able child with a significant physical impairment. He moved to another primary school where his physical needs could be catered for, and then continued his learning journey into Secondary School.

With significant dedicated input from the AAC Specialist, support staff, and support from Speech and Language Therapist services and SCTCI* he was given the opportunity to trial a number of AAC devices to determine the most suitable equipment – a Vanguard II. Ahmed accesses this machine with a reflective tracker placed on his forehead and reciprocal software in the device.

Ahmed is a very skilled AAC user. The Vanguard allows him to communicate with his family and his peers. It is programmed with his individual preferences and vocabulary which help him link home, his community and school with little difficulty. It has a range of additional functions such as texting, phone calls and environmental controls. Within school, the machine can access curricular programmes. However, the skills he has developed are transferable and he is able to access a desk top PC with the appropriate interface (head mouse) which allows full access to all curricular materials. He has achieved a great deal in course work and is completing Access 2 in English and Maths, Access 3 in Modern Studies and various units at Access 3 level in Digital Literacy.

Life without his device would be very different for Ahmed as his disability is a real barrier to initiating communication with others. He will require ongoing personal care and assistance. However the Vanguard allows him to initiate and lead in conversation, it provides a degree of independence where he can make choices, request help and take control of his life in a meaningful way.

** SCTCI: Scottish Centre for Technology for Communication Impaired, a national AAC assessment centre*

Vangaurd™ II voice output communication aid

Glasgow City Education Authority

This case demonstrates quite clearly the positive outcomes achieved with the use of AAC equipment and support. Access to the curriculum would not be possible without it. The AAC equipment has supported Ahmed to achieve many of the well-being outcome indicators identified within GIRFEC,[13] for example, 'developing a level of autonomy, appropriate to age and stage', 'meeting or exceeding appropriate levels of educational attainment' and 'receives additional support to overcome any disadvantages that may contribute to social exclusion' are but a few of the positive outcomes described above.

While positive outcomes following provision of AAC are clearly evident in the accounts presented above, what is not evident is the quantity and quality of AAC support from professional staff, support staff, carers and family, required to achieve these outcomes. It is also apparent that use of AAC is a personal preference and not always an identified goal for individuals. For a person whose route to AAC use has been a long circuitous one it is difficult to separate what elements of input have had a cumulative effect from those that are a consequence of appropriate intervention at the right time.

Demonstrating effectiveness is part of the Quality Strategy for Health.[28] Evidence for effectiveness of AAC and AAC interventions is limited and there is a need to strengthen the evidence base. There is therefore an urgent need for further well-designed research in the field of AAC.

Recommendation 2

National statistics on AAC to be gathered by relevant agencies to support future gathering of cost effectiveness data on AAC to ensure that AAC funding is sustained in the longer term.

Actions

1. All NHS based services to implement the use of nationally agreed data sets for AAC

2. All AAC services providers to implement the use of appropriate outcome measures for all clients who use AAC.

AAC services are competing with other health care technologies, education and social care services for scarce resources. Limited cost-effectiveness data is available regarding the provision of AAC and AAC interventions**.** Outcome measures can be used in combination with costs to develop summary measures such as cost-effectiveness ratios. The availability of such summary measures could support commissioners to direct resources towards AAC provision. Two economic evaluations related to AAC have been identified[29-30] and are evaluated in Appendix 4.

The use of standardised data collection within routine practice as well as the regular use of goal setting and outcome measures will support gathering further information on the effectiveness of AAC and AAC interventions. Focusing on outcome measures is integral to the quality strand of the Curriculum for Excellence.[31] This requirement is echoed in the literature where AAC professionals have been urged to move towards 'documenting the efficacy of AAC services in terms of customer satisfaction, value, quality and cost'.[32] Routine standardised data on AAC and AAC interventions as well as data from local outcome measures is not routinely available at present.

The Chief Health Professions Officer funded a project to develop a national Allied Health Professional minimum dataset and this work is underway. A minimum data set, that includes data such as referral source, demand and activity level has been compiled by the Information and Statistics Division in collaboration with the Allied Health Directors in Scotland under the direction of the National Implementation Group. This was followed by a further project which is a waiting times census which was completed in February 2012. The results of the project are due to be released in May 2012. In addition, the NHSScotland Data Recording Advisory Service supports and provides advice on data recording, using a nationally agreed Data Dictionary.

The Data Dictionary includes descriptive definitions useful for AAC. Local implementation of these data sets within data collection systems would facilitate the growth of a data source that nationally would be able to provide valuable information to support planning, provision and evaluation of outcomes for people who use AAC. Implementation of standardised data in combination with routine outcome measures would facilitate future AAC research and importantly enable services to be evaluated in terms of quality and cost.

Recommendation 3

All AAC service providers should develop and implement a population based approach to the provision of support for people who require to use AAC equipment and services, ensuring that needs are recognised and responded to appropriately within the wider community.

Action
1. National AAC services to lead on development of a national strategy to promote universal support for people who use AAC.

2. All AAC services to implement national strategies to promote universal support for people who use AAC.

As stated previously, intervention at the level of the individual only partly addresses the communication needs of people who use AAC. In addition to identifying individual need, people who use AAC identified that the wider community need to be aware of and able to adapt to their communicative requirements. Effective intervention for people who use AAC supports them to achieve their goals and is required to be both focussed on the individual and to be universal.

The Scottish Government has begun work on developing required competencies of the children's workforce by consulting on the Common Core of Skills, Knowledge & Understanding and Values.[33] This work has provided an opportunity to ensure that communication skills, including the ability to interact appropriately with people who use AAC, are recognised. Additionally, the Scottish Government, Equality Unit funds a project on inclusive communication. This project aims to remove barriers to active citizenship for people with communication support needs, including people who use AAC.

There is scope for more work in this area, particularly to support implementation of the Patient's Rights Act (2011).[34] This Act requires hospitals and healthcare services to improve communication with all patients. Local implementation of measures to meet the provisions of this legislation will encourage hospitals and other healthcare services to introduce appropriate training and access to resources for all of the healthcare workforce on communication skills, including communication support. Communication support refers to the strategies, techniques and equipment used to support people with communication difficulties, including AAC strategies, to facilitate successful communication. This might include training on strategies such as the use

of Talking Mats®[35] or Communication Passports[36] and the development of a symbolised environment. An example of this is detailed in the box below:

Good Practice Example

'Talking Mats have been commissioned by Talking Points, Alzheimer's Scotland and Scotland's Colleges to train staff in the use of Talking Mats to support people with complex communication support needs.'

www.talkingmats.com
a Scottish Social Enterprise

Furthermore, there is scope for generic AAC strategies to become embedded within the training and skills of staff within social work and social care particularly to support the accurate assessment of needs through community care assessments and to access Self Directed Support.[37]

An example of the application of a universal approach to supporting the needs of people who have communication difficulties and require to use AAC within an education setting is the Symbolised Schools Programme in Fife in the box below:

Fife Assessment Centre for Communication through Technology (FACCT)

This is a regional AAC centre that is funded by Health, Education and Social Services, staffed by a team from education and health, and provides services to adults and children. The service provides specialist assessment, support, training and a loan bank of equipment. To support building capacity within education staff the team developed the Symbolised Schools Project. This has been developed over five years and to date has implemented change in 110 schools. An award scheme for schools to support their transition towards a symbolised whole school environment has been implemented. To date, three schools have achieved a Gold award while 14 and 35 have achieved silver and bronze respectively.

A Bronze award indicates that a school has symbolised its environment in terms of routines, reminders and visual timetables in both classroom and public areas.

A Silver award includes curricular supports, e.g. supporting access to literacy and numeracy activities; self registration; and restorative practices.

A Gold award is for a school which implements all of the above; mentors other schools as a Centre of Excellence; and develops more specific symbol resources, e.g. symbolised Personal Learning Plans and joint marking scheme along with feeder secondary schools.

Participating schools have access to a data bank of shared resources available on the Fife Education Intranet service.

'We would not have achieved the transitions evident in the schools if we didn't have joint working across education and health within our service'

Principal Teacher/AAC Specialist
Fife Education Authority, NHS Fife and Fife Social Services

This good practice example demonstrates how inter-agency working has provided the capacity to support implementing a population approach to AAC. In Fife, the Symbolised Schools project has made a significant contribution to promoting a universal understanding of AAC across the children's workforce.

Meeting the needs of people who use AAC requires services to adopt the strategic aims set out previously in this guidance. This involves all agencies working collaboratively to ensure that specialist assessment, appropriate equipment and ongoing support is accessible locally and is appropriate to individual's needs.

It is therefore recommended that a strategic plan to support this recommendation is devised, led by national services with implementation at all levels across AAC services.

How should AAC services be delivered?

Recommendation 4
To ensure that people who are required to use AAC have access to appropriate levels of high quality specialist assessment and support delivered as locally as possible, Health Boards and local authorities should work in Partnership with each other and with National AAC services.

Action
1. National services to design a planned programme of activity to develop capacity and competencies of regional and local services.

2. Local partnerships to establish multi-agency regional networks or centres providing support to local services and supported by National services.

3. National services to implement a programme to develop capacity and competencies of regional and local services.

Provision of AAC addresses five key areas of need within the International Classification of Function.[38] These areas fall within the remit of provisions made by different statutory agencies. Provision of AAC supports access to the curriculum, education and employment, maintenance of safety, health and well-being, and the achievement of independent living.

Therefore, for all clients, AAC provision falls under the remit of more than one agency because the need of any client will undoubtedly be across more than one category. This supports the principle of joint provision of AAC.

Addressing the needs of people who use AAC contributes to several National Outcomes.[39] By supporting individuals to communicate we are improving life chances for children, young people and families for those at risk, providing equity of opportunity through children having the best start, supporting young people as successful learners, promoting the population have healthier lives and tackling inequalities.

The evidence provided by people who currently use AAC and by some of the service providers suggests that we need to make some improvements around AAC provision of equipment and services. By implementing measures to improve how AAC is provided, we can ensure that public services are high quality, efficient and responsive to the needs of local people.

Provision of AAC services falls within the remit of several public agencies, with staff from education, health and social services involved in the assessment, training and support of people who use AAC. As illustrated below, each agency has a defined quality framework to support delivery of their respective services. The frameworks have a high degree of consistency and are summarised below:

QUALITY		
Health‡	**Social Care§**	**Education****
Person-centred	Dignity, privacy, choice	Personal achievement Respect & positive ethos
Effective	Realising potential	Outcome focused
Safe	Safety	Integrated

It is proposed here that a coordinated, multi-agency approach to the provision of AAC equipment and services will increase capacity within those services and contribute to improvements in quality.

Delivering for Health[40] is concerned with delivering local, accessible and timely healthcare services with a shift in the balance of care from hospital to community care and partnership working. A further key aspect of this policy is the shift of emphasis onto preventative care and on tackling inequalities. Within education, The Early Years Framework 2008[41] is focused on developing the strengths of universal services to deliver prevention and early intervention, simplifying and streamlining delivery of services and building more effective collaborations. Similarly, within social work, Changing Lives[42] places an emphasis on delivering 'joined up…. accessible, responsive services of the highest quality and promoting wellbeing'.

‡ Better Health, Better Care
§ National Care Standards
** Curriculum for Excellence

The consensus across all agencies is for high quality local provision that is resourced by appropriately skilled staff working collaboratively to deliver the best outcomes for individuals, families and communities. However, it is also acknowledged that regional, and in some instances national, planning is required to support the delivery of care in local settings[10] particularly with regard to provision for children with complex needs.

At present, the level of AAC service provision varies across Scotland. In some regions a person with communication difficulties can expect to have input from AAC specialists at both regional and national level while in other areas there is no specialist provision. Access to national services is restricted in some areas. For the purposes of this document a national service comprises a multi-disciplinary team and provides input across several geographical boundaries across local authorities and health boards. A regional service is similarly multi-disciplinary in nature but provides services within a restricted geographical boundary, usually a single health board. In Scotland there are two regional services that fit this criteria: FAACT (Fife Assessment Centre for Communication Technology) and KEYCOMM (Lothian Communication Technology Service). There are currently two national AAC services in Scotland: the SCTCI (Scottish Centre of Technology for the Communication Impaired) and CALL (Call: Scotland). SCTCI provides services to the whole population, adults and children, within ten health board regions while CALL provides a national service for children in Scotland.

In other areas specialist services provide limited specialist AAC services. For example, in Ayrshire and Arran, one speech and language therapist provides specialist AAC services for the entire population, while in Grampian (TASSCC: Technological Assessment and Support Services for Children and the Curriculum), a multi-disciplinary service supports children with AAC needs principally within Aberdeen City and Aberdeenshire Community Health Partnership areas with limited services across the wider region. A description of these services is summarised in Appendix 5.

Several areas in Scotland have no designated specialist AAC service, although they have many staff with an interest and specialist skills within the field of AAC across different agencies and staff groups.

Effective implementation of AAC into an individual's communicative repertoire requires specialist assessment, appropriate provision, skilled support and universal recognition in the wider community. It is crucial that all AAC systems are reliable and that all systems, whether high-tech or low-tech, have up-to-date, age appropriate and relevant vocabulary. For a person who uses AAC, intervention is usually episodic but sustained throughout their life. These episodes may be related to initial introduction of a system, maintenance of a system, and education of family, carers and staff groups on how to support the individual to optimise their communicative effectiveness through use of the system. Episodes of care may be triggered by developing educational needs or by transitions, such as from school to college, hospital admission, relocation, or change of carers.

In education settings, generic AAC systems may be used to support learning and acquisition of literacy. It is here that a variety of resources can be utilised to augment an individual's personal AAC system. This requires skilled staff with dedicated time to amend, adapt and programme equipment to keep generic resources in step with the evolving curriculum. Joint funding and integration provide opportunities to develop capacity at a local level.

The Kaiser-Permanente Pyramid of Care[43] has been adopted, in Scotland, as a model for care of people with long-term conditions[44] and for the provision of specialist wheelchair services.[45] This model appears to provide a structured approach for delivery of services that fits with the aim of delivering accessible, inter-agency AAC services. The model, applied to delivery of AAC services, is presented below.

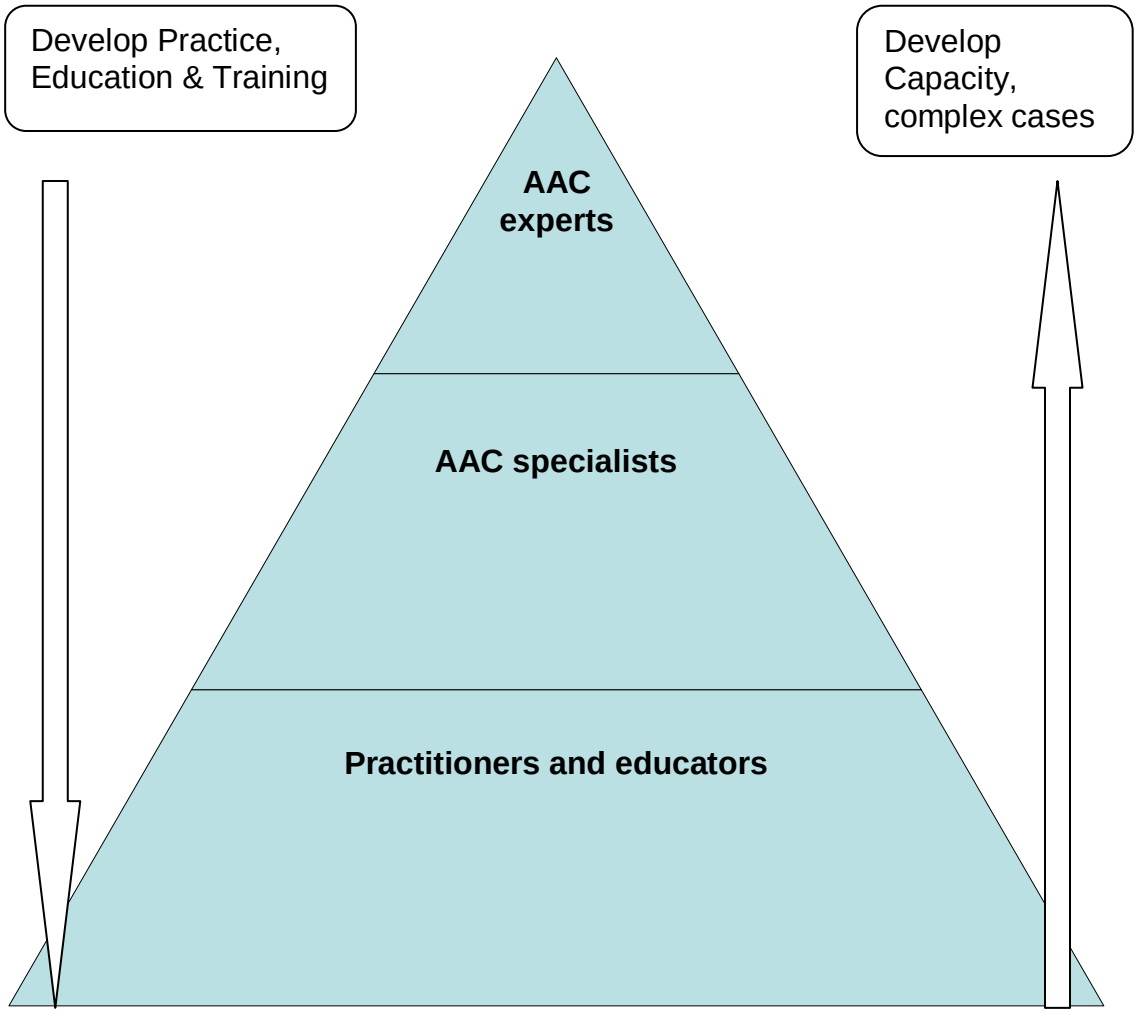
This model encourages the development of regional, multi-agency and multi disciplinary AAC networks or centres that have equal access to national AAC services. These specialist AAC regional services may take the form of a specialist AAC centre or become virtual centres with a network of identified MDT teams of AAC specialists within a geographical boundary. These regional centres or networks support local services within their region. It would be anticipated that boundaries would include several local authorities and one health board region and that local authorities could elect to be part of one or more networks where their boundaries cross health board areas. Small Health Board areas may elect to become part of an AAC network with an adjoining Health Board.

Barriers to effective service provision identified by those working in the field include a lack of full access to the relevant range of specialists, particularly staff with a technical background. Networks or centres should be comprised of core staff across agencies, including AAC specialist speech and language therapists, AAC specialist teachers and medical technologists/bio-engineers. A medical technologist/bio-engineer is typically skilled in the use, maintenance and development of electronic assistive technologies.

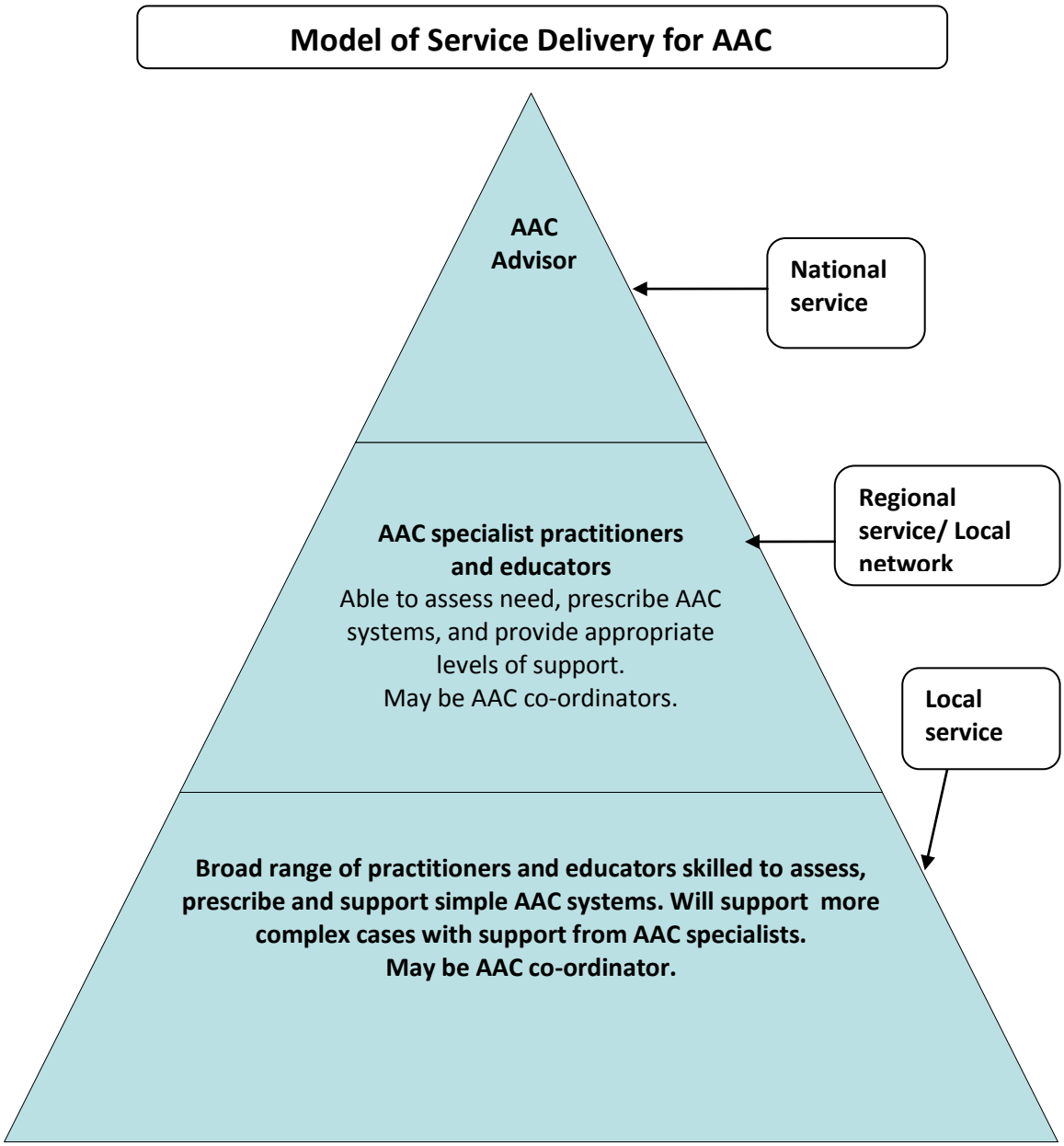
Within this model it is anticipated that the AAC advisors will develop the competencies and practice of the specialist and generalist AAC workforce. The national centres would lead and support the development of regional centres or networks. They would be required to operate at a strategic level with Education, Health and Social Work partners and operationally in the delivery of education and training to regional networks and the wider community as appropriate. It is anticipated that they would be key to the development of inclusive communication and accessible information at a strategic level and would, for example, devise implementation plans taking a population approach to these areas. Some aspects of this model are already in place. For example, the Scottish Centre of Technology for the Communication Impaired runs a Link Therapy network of speech and language therapists across Scotland who receive regular updates on equipment and other developments within the field of AAC.

This model supports the development of an increase in capacity, hence providing an opportunity to improve quality for AAC services and should be achievable by providing local access to specialist support, universal access to National services and a reduction in waiting times to access all services.

Kaiser-Permanate Model



The model recognises that local solutions to providing AAC services may include a designated regional centre of specialist AAC staff or an identified network of multi-agency AAC specialist staff who are appropriately trained and have access to AAC assessment resources.



AAC advisor: role of national centres to develop capacity and practice in tiers below. Responsible for setting and monitoring of standards, planning education and training and an advisory role with complex cases.

AAC specialist: A practitioner or educator who is a specialist in ACC. The specialist works as part of a multi-disciplinary team and supports local staff when required. The specialist refers to the AAC advisor as required.

AAC co-ordinator: this role involves co-ordinating input from the multi-disciplinary team; ensuring that equipment is provided within local timescales; planning a programme of enhanced support; co-ordinating ongoing review of client needs and, where applicable, maintenance of equipment. Within children's services this may be the designated lead professional while within the adult services this may be the local SLT.

It is therefore recommended that AAC services are delivered by local partnerships that are aligned with Regional and National services within each Scottish region. These partnerships may take the form of regional centres or networks.

A set of principles to support the work of AAC services at national, regional and local levels has been agreed through consensus from service providers. These principles are consistent with the vision and strategic aims for AAC provision and are presented in Appendix 6.

Recommendation 5

The Scottish Government to explore the feasibility of NHS- based National AAC services transferring to NHS National Services to support the monitoring of quality and effectiveness of AAC provision as well as to protect this valuable resource.

Action
The Scottish Government will conduct an impact analysis on the transfer of NHS-based National AAC services to the National Services Division.

Throughout this document National AAC service providers are recognised as including both Call: Scotland (CALL) and the Scottish Centre of Technology for the Communication Impaired (SCTCI). While both are recognised as national services for AAC they have different funding mechanisms and provide slightly different services.

The SCTCI is funded by ten of the fourteen health boards across Scotland to provide AAC assessments, training and support for adults and children. CALL is funded centrally through education and provides services for children only across all of Scotland. The remit of CALL includes providing assessment and support for the communication, learning and literacy needs of children in education through the use of technology (including AAC) within the curriculum, and developing national resources for the classroom assessment. Recent work by CALL has included development of 'Books for All' and 'The Scottish Voice' (www.callscotland.org.uk).

Due to the nature of the services and funding mechanisms for CALL, recommendation 5 applies only to the SCTCI. National Commissioning is reserved for highly specialist services and provides support to services, ensuring equity and sustainability. SCTCI is currently hosted by a single health board. However, it is recommended that the mechanisms in place to support the SCTCI in the delivery of its services should be reviewed.

How will AAC equipment be provided?

As has been described, people who use AAC often experience difficulty and delay in receiving equipment. While some areas have designated budgets for this type of equipment, these are often inadequate, particularly given the increasing costs of new developments within the field. Other areas often rely on 'end of year monies' and cannot therefore respond in a timely manner to client need. Service providers report frustration at being unable to meet current levels of identified need and recognise that significant resource is frequently directed towards sourcing funding for equipment. Furthermore, it has been highlighted that lack of funding can sometimes result in poor clinical outcomes where service providers do not fully appraise clients of the best technology available to meet their needs. Services should at all times be identifying need even if needs cannot be met within existing resources.

Developments in technology are offering clients with severe physical disabilities alternative access methods to technology – for example, eye-gaze access to AAC systems as well as voice banking which enables people with deteriorating conditions to create a synthetic speech that sounds like their own voice. New technology requires robust evaluation by AAC advisors and specialists.

Recommendation 6

To ensure equitable, efficient and safe provision of AAC equipment for people who are required to use it, Health Boards and local authorities should work in Partnership with each other.

Action
1. Regional AAC centres/networks to have representation on local Community Equipment Management Groups.

2. Local Partnerships to build on existing Partnerships to agree priorities, policies and processes for AAC equipment provision.

Clear guidelines govern public sector procurement in Scotland[46] where the underlying principle of best value is at the core of public spending. AAC equipment is currently purchased locally by different agencies, and on occasion, through joint funding. In many cases AAC provision is significantly delayed while agencies reach agreement on funding. This impacts significantly on people who use AAC. As highlighted previously, the strategic aim of AAC provision is to ensure that equipment is provided as soon as a specified need is identified.

AAC equipment has clearly been identified within the Aids and Adaptations Guidance[47] and as such should be part of any local partnership arrangement around provision of equipment across Health and Local Authorities. At present these generally involve health and social care but in some areas education equipment is now transferring into partnership provision. Partnership arrangements contain finance arrangements, agreed locally, but they may extend to joint funding or pooled budgets.

Quality standards demand that healthcare is safe and efficient. There are local issues around compliance with management of medical devices. Equipment is generally not traceable or routinely maintained. With increasing pressure on budgets, all services are required to adopt best value routes for provision of equipment.

Good Practice Example
'Equipment to the value of £2.3 million was reissued last year (10/11) at a cost to Partners of £278,000. These savings are significant and are visible across both standard provision of equipment as well as more specialist equipment e.g. a growing area of more effective recycling is within children's services where specialist provision has been standardised and staff are more able to select from items being returned to the store rather than having to buy new.

The other area where savings are made is in procurement where our recent re-tender has provided savings of 18% on core stock equipment and 6% on specialist equipment. Standardising more specialist provision and the ability to liaise with suppliers to negotiate better prices for specialist stock is something that would help drive down cost.'

Service Manager EQUIPU, Glasgow

There are concerns regarding the inclusion of AAC equipment within existing partnership arrangements. In the areas where dedicated joint budgets have been identified – for example, Dumfries and Galloway, and Fife – these arrangements work well. In these arrangements, budgets are administered by local, inter-agency management groups.

In some areas partnership arrangements include the use of joint stores. These resources support area-wide access to joint stores for trained staff to arrange provision of prescribed equipment from a central store within a partnership arrangement. At present AAC equipment is generally not part of this provision. There have been concerns regarding the proliferation of AAC equipment and provision of inappropriate equipment to individuals. The advantage of using these mechanisms is that some of the above issues around quality and efficiency are addressed. To enable AAC equipment to become part of a joint store arrangement would require restricted access for agreed core equipment, with additional specialist equipment only available via designated specialist assessment.

Achieving the transition to partnership provision for AAC equipment requires local service managers to work within the arrangements that exist locally, and agree what equipment is being prescribed and by whom. Local procurement and safety protocols should be adopted. Partnerships would be required to engage with one another to identify why equipment is provided, to identify the local need and to map total provision across all agencies.

Recommendation 7

National AAC services to provide strategic advice to appropriate agencies on AAC equipment to support planning, procurement and provision of AAC.

Action

National AAC services to establish strategic links with Scottish Government Joint Improvement Team workstreams for (i) Equipment and Adaptations and (ii) Telecare.

With the increasing adaptability of mainstream technology and the ongoing advancements in specialist technology, combined with the need for smarter procurement processes and improved access to equipment, it is crucial that national services are able directly to influence the strategic direction of future AAC provision. There is still much work to be done at national and local level to ensure best value for AAC procurement as well as developing solutions regarding handling data and information technology security for AAC equipment. National AAC services will therefore take the lead role in this process by establishing formal strategic links within the Scottish Government and additionally will support regional and local services to implement the appropriate policies and procedures locally.

Recommendation 8

All AAC service providers to implement the use of Local AAC care pathways to ensure equitable and timeous provision of equipment and support for people who require to use AAC.

Action

1. Local AAC Partnerships to agree and implement local AAC care pathways in collaboration with National services.

2. Local quality indicators to be developed by Local Partnerships and National services and to be monitored by appropriate agencies including the Scottish Government.

Future plans for AAC include the introduction of maximum whole journey waiting times. However this is not being recommended here, as there is currently insufficient data available to identify what resources would be required to deliver on such a target. It is proposed that local services develop a local pathway, with indicator timescales, for provision of AAC services and equipment.

A sample AAC care pathway is provided in Appendix 7. This pathway has been developed from quality indicators identified by the AAC Short Life Working Group. The pathway shows the potential journey for each client and attempts to encompass all AAC clients regardless of outcome (high-tech, low-tech or no AAC). The pathway incorporates service provision at all levels from local services to regional and national services. Clearly any locally developed pathway would be done in collaboration with the wider AAC network. It could be anticipated that a client, particularly a child, may make several journeys through the AAC pathway as their needs change.

Implementation and evaluation

A timetable for implementation of the recommendations contained within this report is provided**.** Further guidance on access to funding will be available from the Scottish Government. Mechanisms to evaluate the implementation of these recommendations will be monitored by the Scottish Government.

Appendix 1 Definition and Description of AAC

AAC refers to methods that augment or replace usual methods where an individual has no reliable means of communication. AAC is used to optimise communicative competence for people with communication difficulties. AAC may be aided – for example, by using symbol book or voice output communication aids – or it may be unaided – for example, using gestures or listener scanning. Furthermore, aided AAC is usually catergorised as either low-tech – for example, a picture symbol book – or high-tech – for example, using adapted mainstream technology such as personal computers with specialist software or dedicated voice output communication aids. It is a collective term that refers to methods of communication that supplement or replace traditional methods. A widely accepted definition[48] of AAC's presented in the box below:

Definition of AAC

'An integrated group of components, including the symbols, aids, strategies and techniques used by an individual to enhance communication'

Beukleman & Miranda (1998) adapted from definition by American Speech-Language-Hearing Association

The definition above encompasses all types of AAC, aided and unaided, high-tech and low tech. Crucially it is concerned with optimising communicative competence regardless of mode of delivery, i.e. spoken or written.

An individual may use more than one type of AAC device for different purposes or may have a low-tech system in place to back up a high-tech system when there is a technical failure. So for any one individual AAC can be a global term that refers to a multi-modal system.

An illustrated example of a multi-modal AAC system is presented below. Here an individual describes their AAC system. Ward[49] describes a mixture of high-tech and low-tech AAC aids, each used for different situational and communicative functions. The high-tech system is used at work with a preference for low-tech systems at home. Ward also demonstrates that AAC systems evolve as needs change. He describes how he is no longer able to access his laptop due to decreasing functional use of his knee and that he is exploring alternative high-tech systems for use at home.

Description of an AAC system

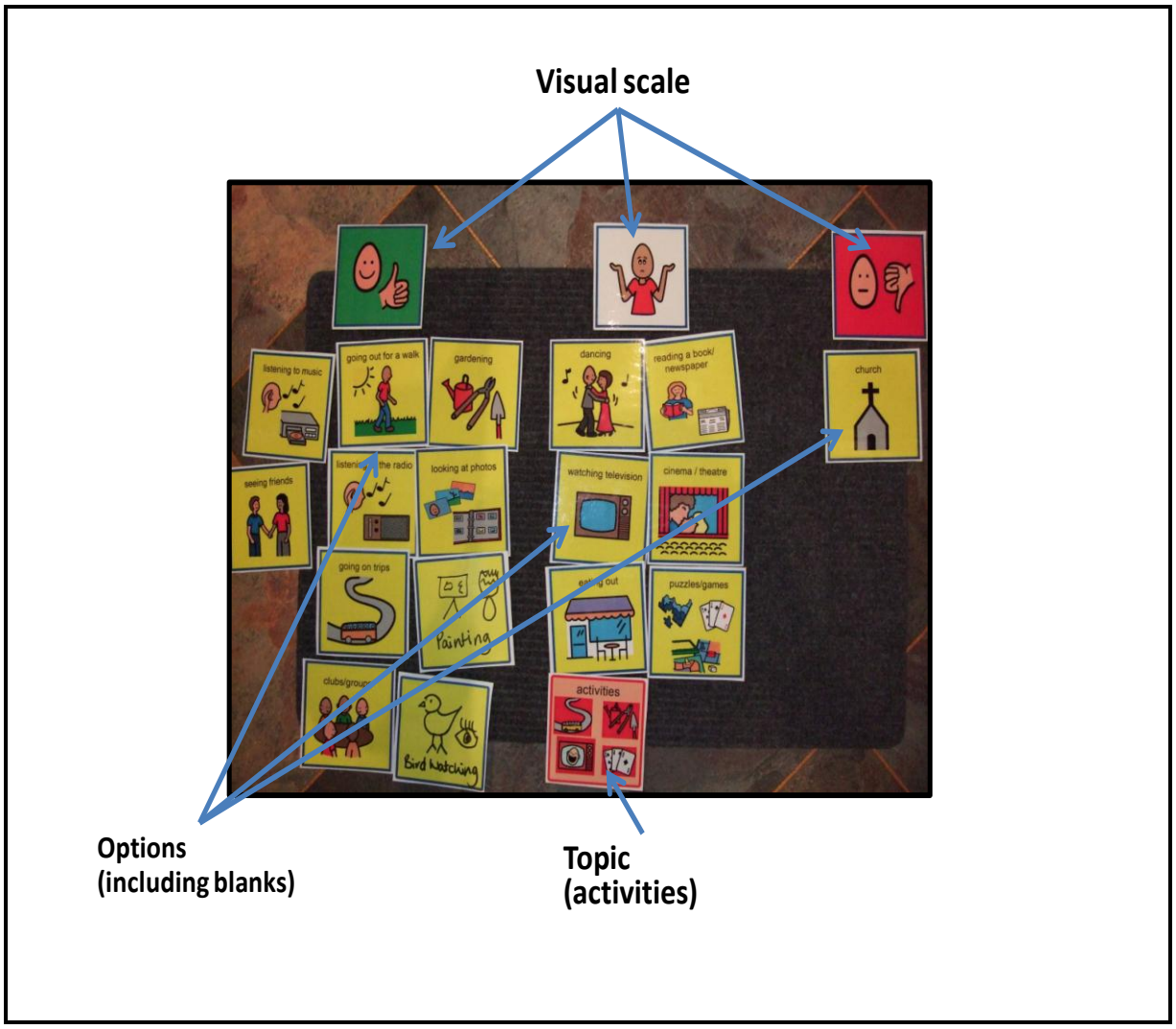
'I really like the Eyegaze system…. I have my Dectalk voice on it and people come in my office and chat with me.
Away from work I communicate with a letter board. I still have my laptop computer but my leg is so weak now I cannot reliably use it. I have an eye blink system I could use but I find the letter board suffices. There are now portable Eyegaze systems available and I'm starting to look at them'

***Mike Ward**, person with MND*
Source: Fried-Oken & Bersani (2000)

Here a person with no understandable speech and physical disabilities can continue to communicate. Ward's use of the letter board described is heavily dependent on the listener taking a very active role in facilitating the communication and on having a skilled listener. The high-tech system allows the speaker to generate messages independently.

Low-tech AAC systems are generally developed for an individual and tailored to suit their specific needs. For example, a low-tech communication book for an individual with a learning disability and unintelligible speech may be topic based and include several sets of pictures specific to different settings, interests and everyday experiences. These low-tech systems are usually produced in the classroom, hospital or clinic by teachers and speech and language therapists using specialist computer software, a colour printer and a laminator. Symbols have to be taught and the number of symbols presented varies depending on levels of understanding, visual acuity and other factors.

Low-tech AAC systems need not always be person specific or be used for daily communication. Some, more generic, AAC frameworks can be utilised to support people with communication difficulties to express their views about specific topics or situations. An example of such an approach is the Talking Mats®[50] framework. Talking Mats has been developed in Scotland by research speech and language therapists at Stirling University (www.talkingmats.com) and has been validated as an approach to support communication for people with dementia, aphasia and learning disability amongst others.[51,52, 53,54] An example of Talking Mats in action is provided below where a person is expressing views about activities in his life that he enjoys and does not enjoy. His completed mat can be photographed and provides a record for the individual and the listener. It can be used as a discussion point around feelings, expectations and needs, as well as to support intervention planning and outcome measurement. In this example he has used blanks to add that he enjoys painting and bird watching. Further sub mats can be done on the areas he wishes to explore in more detail.



Talking Mat ® in action

High-tech AAC systems are sometimes quite simple devices and, for example, may take the form of a device that records real speech and uses interchangeable screens so that messages can be continually updated to reflect the needs of the individual using them. For example, they can be particularly useful with young children who are developing listening and language skills. It would be usual to see such devices used in pre-school nursery where they can be programmed to enable the child to participate in particular aspects of the curriculum.

Some high-tech AAC devices are computer based voice output communication devices that produce digitised speech. These devices are often multi-functional in that as well as providing speech output they can be used as a computer interface device (for environmental controls and to send text messages). Accessing these devices can be via direct access by pressing a keyboard or screen, by direct access using head pointing or eye-gaze technology or by using indirect methods such a scanning via a switch. Increasingly mainstream technology offers solutions to meet an individual's high-tech AAC needs.

Appendix 2 Prevalence for conditions associated with use of AAC

Autistic Spectrum Disorder

The Scottish Government consultation document 'Towards an Autism Strategy for Scotland'[55] presented a detailed analysis of the prevalence data for autistic spectrum disorder in Scotland. Current estimates suggest an incidence rate for autistic spectrum disorder of 42 children per 10,000 as the most accurate figure. For adults, a rate of 5.1 per 100,000 is considered the most accurate estimate.

Cerebral Palsy

The incidence of cerebral palsy is reported to be around 1 in every 500 births. Data from the United Kingdom collaborative network of Cerebral palsy registers[56] (UK-CP) reported 6900 children with cerebral palsy registered in 2006. This equates to approximately 345 children in Scotland. The database in some regions is voluntary and there is a history of poor maintenance in some areas. Accordingly, it currently provides an indication rather than actual numbers of children with cerebral palsy.

Cerebral palsy is a long-term condition where AAC needs evolve and change throughout early developmental years and into adulthood. A further study[57] reports that the survival rates for cerebral palsy are linked to severity of condition. If a child with cerebral palsy lives to age 18 then they are more likely to live beyond age 40. Adults with cerebral palsy die of the same diseases as the rest of the population – heart disease, stroke and cancer.

A multi-centred European study[58] of 818 children with cerebral palsy identified that 43% of the children in the study had impaired or no speech and therefore may potentially benefit from AAC. In addition, 65% of children participating in the study had difficulty with fine motor skills suggesting that these children may have difficulty with writing and accessing a standard keyboard.

Dementia

Dementia primarily affects cognitive function. The number of people with dementia in Scotland is reported as approximately 71,000 people within the total population.[59] As a consequence of the changing demographics within the Scottish population this number is predicted to double over the next 25 years.[59] Cognitive communication difficulties are a recognised feature of dementia.

Learning Disability
The same as you?[60] report estimates that 20 people per 1,000 have a mild or moderate learning disability in Scotland while 3 to 4 people per 1,000 have a profound or multiple disability. *The same as you?* further reports that the number of people with learning disabilities is predicted to grow by over 1% a year as survival rates improve,

Motor Neurone Disease
Motor neurone disease is a progressive neurological disorder that primarily affects motor function and, for some individuals, cognitive function. Standardised incidence in Scotland is reported as 2.4 per 100,000[61] while the incidence for over 80s is 7.3 per 100,000.[62]

In Scotland incidence rates are higher than reported elsewhere[63,64] and survival rates are lower. [62,63,65,66,67] While this trend may be a consequence of artefact it does represent a possible 30% reduction in survival rate when compared to other countries. The median survival time for motor neurone disease in Scotland is 25 months.[68]

Although a national motor neurone disease register provides data on prevalence and survival rates for MND, the number of people in Scotland with MND who use AAC is unknown. For a life-limiting and rapidly deteriorating illness like motor neurone disease response rates for AAC must be timeous and appropriately supported. In Scotland, people with motor neurone disease are the second largest group with whom speech and language therapists report using AAC.[11]

Multiple Sclerosis
Multiple sclerosis is a neurological disease that affects motor and cognitive function. The course of the disease varies and can be rapidly or slowly progressing. The number of people with multiple sclerosis in Scotland is estimated at 10,000, with caveats. Information Services Division: Scotland report incident cases numbering 623 in 2008/9 (based on projected mid year population). Further data for 2008/9 reports a total of 5,600 individuals with MS consulting their primary care team. (These figures have a wide confidence interval as they are based on only a limited number of practice figures.) Reported incidence of dysarthria and communication difficulties for people with multiple sclerosis ranges from 23% to 51%.[68]

Parkinson's Disease
Parkinson's Disease is a progressive neurological condition that affects both motor and cognitive function. In Scotland, there are between 120 and 230 people with Parkinson's disease per 100,000 population. It is reported that the age related incidence of Parkinson's disease means that the number of cases will increase by 25% to 30% over the next 25 years if the population of Scotland remains stable.[69]

Stroke

Stroke is the main cause of disability in Scotland. Of the 80% of people who survive stroke at least half of these individuals will remain dependent after six months and consequently strokes result in life-long disability. There are reports that around 8,500 first-ever-in-a-lifetime strokes occur per annum in Scotland.[70] What is unknown is how many of these individuals use AAC as a consequence of a resulting dysarthria or aphasia.

Dysarthria, a motor speech impairment more readily associated with AAC use, reportedly occurs following 20% to 30% of strokes. Prevalence rates for aphasia, an impairment of language, following a stroke have been reported as ranging from 20% to 38% of individuals[70] to 15% of stroke survivors at 6 months morbidity.[71] Unlike dysarthria, where language functions remain intact and literacy is unaffected, aphasia results in loss of language with varying severity and can affect all communication modalities. For a person with aphasia, AAC may offer solutions to impairment of both spoken and written communication.

Several other neurological conditions including Huntington's Disease, Ataxia, and Progressive Supranuclear Palsy are low-incidence conditions where communication difficulties are common and AAC may offer potential solutions.

Appendix 3 A Summary of Systematic Reviews

Ref No.	Year	Title	Author(s)	No of studies reviewed	Review conclusions	Appraisal of review
24	2003	Speech and language therapy to improve the communication skills of children with cerebral palsy (Cochrane Review)	Pennington, Golbart & Marshall	11	SLT for children with cerebral palsy might improve their communication skills but more research is needed.	
23	2004	Speech supplementation techniques for dysarthria	Hanson, Yorkston & Beukleman	19	Speech supplementation techniques may help speakers with any type of severe or profound dysarthria and any underlying medical condition however more research is needed.	Quality of studies not described Review methods not reported
22	2004	Interaction training for conversational partners of children with cerebral palsy	Pennington, Goldbart & Marshall	4	Limited evidence of positive trends in communication changes resulting from interaction training but good quality research required.	Single reviewer identifying studies for inclusion into review
21	2007	Social/communicative interventions and transition outcomes for youth with disabilities	Alwell & Cobb	30	Review supports the efficacy of social skill training intervention for youth with disability	Wide inclusion criteria Limited reporting of review process Limitations within statistical analysis
17	2006	The impact of augmentative and alternative communication on the speech production of individuals with developmental disabilities	Millar, Light & Schlosser	23	AAC interventions should continue to be introduced to children with developmental disabilities and speech inadequate for communication needs. There should be no concern if gains in speech	Single reviewer for 80% of studies Limited reporting of review process

					production. do not occur immediately following the introduction of AAC interventions. However more research is needed.	Double counting of participants included in more than one study
16	2000	Promoting generalisation and maintenance in augmentative and alternative communication	Schlosser & Lee	50	AAC interventions are effective in terms of behaviour change, but poor in terms of generalisation and maintenance.	Wide inclusion criteria Studies not described in detail
18	2008	Effects of augmentative and alternative communication intervention on speech production in children with autism	Schlosser & Wendt	11	AAC interventions do not hinder speech production and for some children with autism or ASD they may result in increased speech production. More research required.	Wide inclusion criteria, definition of AAC: includes signing
19	2007	Augmentative and alternative communication practice in the pursuit of family quality of life	Saito & Turnbull	13	AAC practice should take family perspectives into consideration & address problems in the joint contexts of child, family, school and community.	Limited reporting of review process and validity assessment. Wide inclusion criteria
20	2010	Literacy Interventions for students with physical and developmental disabilities who use aided AAC devices	Machalicek, Sanford, Lang, Rispoli, Molfenter & Mbeseha	18	Systematic instruction that included scaffolding, direct instruction and least to most prompting with time delay may be the most effective strategies to teach literacy skills to students with significant physical and developmental disabilities.	Number of reviewers conducting validity assessment not described

Appendix 4 An Appraisal of two Economic Evaluation studies related to AAC

Hass, U., Andersson, A., Brodin, H., Persson, J.(1997) *Assessment of Computer – aided assistive technology: Analysis of Outcomes and Costs*, Augmentative and Alternative Communication, **13**, 125-135

Tolley, K., Leese, B., Wright, K., Hennessy, S., Rowley, C., Stowe, J., Chamberlain, A. (1995), *Communication aids for the speech impaired: cost and quality of life outcomes of assessment programs provided by specialist communication aid centers in the United Kingdom*, International Journal of Technology Assessment in Health Care, **11:2,** 196-213

In the Hass et al (1997) study a cost and outcome analysis of computer-aided assistive technology was explored. Crucially the study included people with sensory impairment who had difficulties only with written communication as well as individuals with speech difficulties. In addition, participants in the study were provided with standard PC based systems. There was no provision of dedicated voice output communication aids for people with speech difficulties reported. The results of the study indicate reasonable marginal costs but limited utility rating, particularly for people with speech impairment. Only direct costs such as costs of assessment and training were included but not indirect costs such as carer support, travel costs, etc. No summary benefit measure was used and outcome measures were analysed. Costs for 'selection process' that included assessment, trials and training were reported as 30% of the total first year costs.

The UK study by Tolley et al (1995) compared the costs and outcomes of AAC assessment programmes by specialist communication aids centres for the speech impaired with areas where there are no specialist centres. It is a significant study relating to this guidance and is discussed in detail. The study included 6 regional communication aid centres and 4 districts with no regional communication aid centres in England. The comparator sites with no communication aid centres had recognised AAC specialist staff. Four of the communication aid centres had mixed adult and child caseloads while the remaining two had exclusively children and adult caseloads respectively. The child only centre was located within a special health authority that provided a service to children nationally. Both direct and indirect costs were used including costs such as trial and review costs and time spent on travel and attendance at assessment.

The low numbers of participants in the comparator group possibly indicated that non-specialist speech and language therapists were managing AAC needs within their respective districts rather than transferring clients to a colleague with a special interest in AAC, or that a level of unmet need was not being identified within non-communication aid centre district. Analysis of the clients referred to the communication aids centres and to the 4 non-communication aid districts included in the study demonstrated that just 25% of referrals were under 18 years. The evidence that most referrals, 75%, to communication aid centres were adults may also suggest that the AAC needs of children are poorly recognised or that these needs are catered for within existing non-specialist services.

Two outcome measures were used in the study. Neither of them validated a modified standard quality of life measure and a self-assessed perception rating scale. The outcome measures were not felt to be suitable for use with children therefore; final analysis did not include children. The total number of clients completing both measures was 148. No sensitivity rating or detailed statistical analysis is reported.

The outcome of the study demonstrated increased costs where a communication aid centre provided the assessment. These costs were modest. For clients receiving input from communication aid centres, modest gain in outcomes is reported. These reduced where loan equipment provided and input was protracted. In non-communication aid centre districts improvement in outcomes were lower than in communication aid centres. These outcomes are reported within the limitations of the study, described above, and should be interpreted cautiously.

The lack of summary measures in the above studies does not support the calculation of cost-effectiveness ratios.

Appendix 5 Descriptive Summary of Existing Specialist AAC Services

	SCTCI	CALL	KEY COMM	FACCT	AAC Resource	TASSCC
Population	Adults & Children	Children	Adults &Children	Adults & Children	Adults & Children	Children
Type of service	National	National	Regional	Regional	Specialist	Specialist
Area covered	Scotland 10/14 HB's	Scotland	All LA'S Within Lothian HB	Fife LA and HB	All LA's within Ayrshire and Arran HB	Aberdeen City & Aberdeenshire CHP &NHS Grampian
Access to SCTCI	~	~	No	No	Yes	Yes
Multi-disciplinary team	SLT Clinical Technologist	SLT Teacher Engineer Psychologist Specialist support staff	SLT Teacher Assistant	SLT Teacher Technician Assistant	SLT	SLT Teacher Assistant
Training Provided	Yes	Yes	Yes	Yes	Yes	Yes
Assessment	Yes	Yes	Yes	Yes	Yes	Yes
Trial Equipment	Yes	Yes	Yes	Yes	Yes	Yes
Equipment Provision	No	No	Yes	Yes	Yes	Yes-limited to Aberdeen City &Aberdeenshire CHP

Appendix 6 Joint Principles for AAC Provision

1. Services supporting people who use AAC provide a range of interventions including those that are universal, targeted and specific.

2. All children, young people and adults with communication difficulties are potential users of AAC.

3. All individuals with communication difficulties have an opportunity to access specialist AAC assessment.

4. National services are available to all potential AAC users if the need has been identified.

5. All individuals with communication difficulties have information on, and access to, a local quality pathway for AAC.

6. Local AAC pathways incorporate assessment, provision and support for AAC.

7. Local pathways are consistent with local waiting times and, where applicable, national guidance on maximum waiting times.

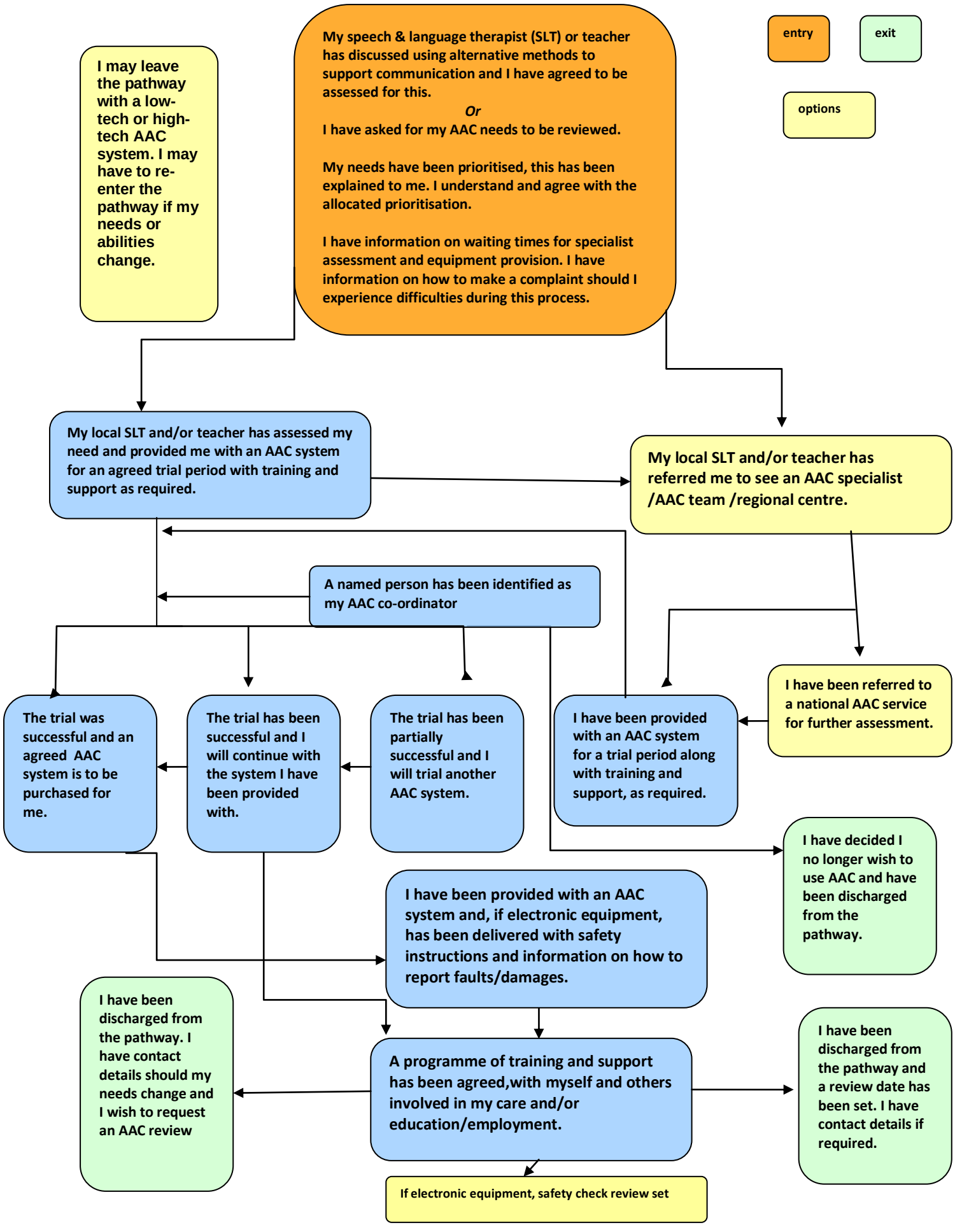
8. Individuals within the local AAC care pathway have a named AAC coordinator.

9. Individuals who use AAC can expect services to be centred on their needs and to be outcome focused.

10. Individuals who use AAC can expect services to be delivered by appropriate staff from an integrated, multi-agency team.

11. Services supporting people who require to use AAC use a range of national and local quality indicators to evaluate their service.

Appendix 7 Augmentative & Alternative Communication Client Pathway



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