



For Professionals and Statutory Agents

No Voice, No Choice: Designing the future of AAC Services

No Voice, No Choice is a campaign to ensure all those who need Alternative and Augmentative Communication (AAC) get the equipment and support they need.

In 2008–2009, the **No Voice, No Choice** campaign is looking at the experiences of professionals. We want to hear from those who provide support to people who use AAC, as well as people who are involved in the commissioning of AAC services.

Scope is working in partnership with the BT Better World Campaign which aims to give every young person a voice. Scope and BT believe that communication is a fundamental human right.

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Time to get equal

scope

About cerebral palsy.
For disabled people achieving equality.

This pamphlet has come about as a result of an event held by Scope in April 2008 to discuss and understand the experiences of professionals and statutory agents, in relation to AAC services. Over 45 professionals and statutory agents attended the event from across England and Wales.

A summary of the key points made at the event are presented here. Whilst experiences, opinions and suggestions varied amongst the participants of the event, we have presented here an overview of the general discussions.

Background

Services for the provision and support of Alternative and Augmentative Communication (AAC) have been historically varied and vulnerable. Many professionals and people working for statutory agencies do not have the access to the support and training they need to support disabled people's use of AAC services. Over the past eight years, since 2000, the Government has made attempts to improve the situation on the ground – through creating a range of commissioning, provision and funding opportunities.

Integrating Community Equipment Service (ICES)

In 2001, the Department of Health announced £105 million funding for Integrating Community Equipment Services (ICES) until 2005. Communication aids were on the list of *disability-related community equipment*. The guidance stated that: 'the government's intention is that some of the additional funding for equipment services should be directed to improving provision of communication aids'. However, when surveyed in 2004, a year before central Government funding came to an end, 81% of ICES services had not yet begun work on AAC provision.

This lack of focus on high-tech communication equipment was primarily due to ICES prioritising the provision of low-tech community equipment, such as adjustable toilet seats and grab rails. The focus on low-tech, high-volume, disposable equipment means that this initiative did not deliver for people who require high-tech specialist equipment.

The Communication Aids Project (CAP)

In 2002, the Communication Aids Project (CAP) was established by the then Department for Education and Skills. CAP provided £5 million each year for expert assessment, communication equipment and training for *school-aged* children as a complement to local provision. Equipment was provided to more than 4,100 children, who could not get their needs met locally. Funding for CAP 2005-06 ran out half-way through the year and approximately 180 children on the CAP waiting list were left without provision. While CAP provided ring-fenced funding over the lifetime of the project (resulting in more children getting the equipment they needed) it was always designed as a short-term, education-focused programme and did not address the need for a sustainable model or commissioning incentives of provision and support to deliver AAC on a universal basis.

The ending of the CAP funding highlighted the problems associated with devolving responsibility for funding high-cost equipment for low incidence groups to local authorities and primary care trusts. The low incidence of people of all ages with complex Speech, Language and Communication Needs (SLCN) and the high cost of providing expert assessment, expensive equipment and ongoing support, means that local health and equipment service providers do not prioritise the needs of this group of disabled people.

CAP was meant to build capacity in local authorities to provide and support communication aids, through the funding of unmet local need. Unfortunately, many local authorities did not take this opportunity to create a viable, local or regional model of provision. Consequently, the infrastructure was not in place when CAP closed and little capacity was built-up locally. Considerable expertise, partnerships and infrastructure were built up during CAP and those children who received equipment through CAP have had their expectations and life chances significantly increased¹. Withdrawing CAP funding and not replacing it with a broader all-age initiative undermined the very positive achievements that the project had made.

The Transforming Community Equipment Review

In 2006, the Government launched the *Community Equipment Review*, which considers the current model for providing community equipment and proposes a new model of provision and support. Provision of specialist AAC equipment has not been addressed specifically in the proposed Retail Model. There are concerns that this model will not give users adequate access to the necessary specialist assessment they require and that the model will do nothing to address the current funding shortfall for AAC.

The capacity of the Retail Model to meet the needs of those who require more specialist equipment (including high-tech AAC) needs further attention and if it is concluded that it cannot meet these needs, alternative provision must be made. It should be noted that the Retail Model is solely designed to be a commissioning structure. It will commission equipment (to improve efficiency and value for money) but the equipment will be funded through existing funding streams, i.e. health, social services, integrated technologies and education.

The Bercow Review of Children, Young People and Speech, Language and Communication

In September 2007, the Government announced a new review of the Speech, Language and Communication Needs of Children in England, to be lead by John Bercow MP, supported by the Department of Health and the Department for Children, Schools and Families. The review looked at the speech, language and communication needs of children up to the age of 19 years. Since the launch of the review, Scope (along with partner organisations) has been working closely with those supporting the Review to ensure that Alternative and Augmentative Communication (AAC) provision is meaningfully included in the review and its recommendations.

In December 2007, Scope facilitated a focus group on AAC for the Bercow Review which explored the themes of experiences of the use of AAC, identification and awareness, commissioning, training and support, equipment and models of provision. The focus group was made up of representatives from organisations working in the field of AAC, including people who use AAC and their families, commissioners of services, health and education professionals, assessment centres, speech and language professionals, and manufacturers of communication equipment. The Review's interim report, published in May 2008, contained many key observations around AAC that the No Voice, No Choice Campaign has highlighted through the written submissions to the Review and during the AAC focus group.

In total, to date, Scope and partners of the No Voice, No Choice Campaign have had over 30 meetings and 20 separate written briefings and submissions to the Bercow Review, primarily focusing on AAC, but also considering commissioning, workforce development and children and young people's policy. The final report of the Bercow Review was published on 8th July 2008. The final report can be found at:

<http://www.dfes.gov.uk/bercowreview/docs/7771-DCSF-BERCOW.PDF> .

Although the needs of people who use and support the use of AAC have been addressed in numerous recommendations of the final report of the Bercow Review, the No Voice, No Choice Campaign has been extremely successful in influencing two specific outcomes. The first: that the Bercow Review has recommended that the Department of Health creates a speech, language and communication annex to Standard 8 of the Children's National Service Framework: Disabled Children and Young People and those with Complex Health Needs. This annex would be supported by a set of exemplars and care pathways, including a specific one around AAC. This means that for the first time AAC will be part of mainstream children and young people policy, be in guidance for commissioners of children and young people's services and will act as a lever for policy and campaigning work in the future.

The second, and more significant, outcome is an AAC specific recommendation. This AAC specific recommendation was taken verbatim from the document we sent to John Bercow MP. It recommends that the Government develop a 'hub and spoke' model of regional provision coordinated by a national organisation to meet the needs of children and young people who use AAC. The national organisation should establish and oversee the delivery of standards for AAC services in regional centres, which will in turn be required to support developing AAC expertise in all local areas in England. In the long term, sustainable funding for this model should come through a budget pooling arrangement between education, health and social services.

In the short term, until sustainable funding is agreed, the Review has recommended that there is an immediate injection of capital for purchasing, monitoring and measuring the supply of equipment and services. It has also recommended that there is an immediate short term injection of revenue

needed to avoid the imminent closure of both the ACE Centres (DCSF) and to support the on-going services of NHS centres (DH) to avoid the loss of highly experienced practitioners. This will mean that all regional centres will be expected to develop and support local services whilst a sustainable long-term solution is established. This is a real success for the No Voice, No Choice campaign and the joint working of the AAC community and third sector. The No Voice, No Choice campaign and Scope will be continuing to support the Government in their work to implement the recommendations of the Bercow Review.

Effective Provision and Support

Below is outlined the key suggestions that participants of the event made to ensure that provision and support of AAC is effective.

Effective Assessment

- Effective assessment of AAC need is based on multiple routes of referral.
- Individual needs change over time. Assessment procedures should be designed to reflect this changing need through on-going assessments. This need is particularly acute during transition periods.
- Assessments need to be holistic and engage with a multi-disciplinary team to ensure communication systems will be effective.
- Multi-disciplinary teams should meet the needs of the individual and could comprise of specialist staff including: a speech and language therapists, an occupational therapist, possibly a medical physics or rehab engineer, an educational or clinical psychologists, an AAC technician and a specialist teacher.
- Assessment is most effective when the professionals involved in a multi-disciplinary are not limited by the funding of their roles. A multi-agency approach through pooled budgets ensures that the right people can be in the room.
- Effective assessment takes time and therefore individuals should be given an opportunity to trial equipment for a period of time and then review the effectiveness of the system.
- In order to trial equipment, assessment centres need to have the funding and support to loan equipment to individuals.
- Technology and new communication systems are continually being developed and therefore assessment should not just go for one device for life. People could benefit from different systems at different periods of their life.
- Assessment outreach from specialist services to mainstream settings is effective, but not always sustainable and only has a limited reach.
- Regional centres of expertise are key resources in undertaking an effective assessment of AAC need.
- Effective assessment works on the basis of an evidence-base with the understanding of good practice models and care pathways.

Effective Funding and Commissioning

- In order to fund and commission AAC services effectively there needs to be a clear responsibility for one agency to lead.
- Effective commissioning and funding can be achieved through joint working between different agencies (health, education and social care) through the implementation of pooled budgets.
- In regions where there are existing centres of expertise (for example the ACE Centres), immediate funding is needed to protect the regional capacity that has already been built.
- Effective commissioning needs to be based on robust data, an evidence-base and good practice models.
- In order to ensure AAC services are commissioned effectively, AAC and SLCN need to become a priority with commissioners.
- The preference on the day was for a lifelong and sustainable funding stream that may be wider than purely AAC, but have a specific remit on it.
- Innovative and creative commissioning and funding of AAC services allows for the appropriate level of flexibility needed to effectively provide these types of services.
- When funding is agreed it needs to encapsulate a holistic package of equipment and support.
- There is a real need for the funding and commissioning of loan banks that allow for the training of new AAC technologies.
- In cases where a statement of special educational need is sought for a child, it must include holistic support elements as well as the communication equipment.

Effective Models of Provision

- There is a real need across the UK for lifelong provision models that address, if not transcend, transitions from children to adult services and from one local authority to another.
- Effective models of provision should include outreach from specialist services to mainstream ones that is sustainable in the long-term and linked into local, regional and national networks of expertise.
- The preferred model for AAC service provision is a 'hub and spoke' model of regional provision, coordinated by a national organisation. The hub and spoke model would see the delivery of services through local teams that comprise of multi-disciplinary teams matched to the needs of the individual. These multi-disciplinary teams have responsibility for providing a first line assessment service and ongoing support for all individuals in their locale via appropriate local services. More complex assessments should be referred to one of the regional centres so that their expertise can be called upon.
- Clear policies around AAC underpin effective models of provision. There, policies could sit under a wider framework (either of communication support more generally or assistive technologies), but have a specific remit around AAC.
- There is a need in England and Wales for core standards around AAC that service provision models can adhere to.

Effective Workforce Development

- In order to ensure that the workforce can effectively support the use of AAC speech, language and communication needs, and specifically AAC, needs to be a priority in their professional roles.
- To address the issue of high turnover amongst staff supporting the use of AAC, senior managers should encourage clear pathways of professional development of AAC.
- To ensure that AAC support is not affected by time management within case loads, specific expertise and sufficient time to implement these skills should be written into job descriptions.
- In a world which is ever becoming more technological it is important that professionals are supported to become competent in a range of SLCN technologies that will enable them to support AAC use.
- The workforce is spread across a large number of disciplines and therefore there is a pertinent need for joined-up and multi-agency working.
- In educational settings, there is specific need for frontline staff to have appropriate levels of knowledge about how to access both the communication equipment and the curriculum with a child or young people who uses AAC.
- To ensure that the workforce can support the needs of clients who have SLCN and could benefit from AAC use, there needs to be greater diversity of gender and ethnicity.

Effective Use of Specialist AAC Knowledge

- In order to ensure that the workforce can make effective use of specialist AAC knowledge, professionals should have varying levels of knowledge according to their role and interaction with AAC provision and support.
- Speech and language therapists are key players in the support of AAC, and awareness needs to be raised amongst them (and allied professionals) to ensure they can deliver AAC services and apply specialist AAC knowledge effectively.
- Networks are vital in maintaining the knowledge transfer around specialist AAC knowledge; for example through the opportunities offered by national organisations (such as Communication Matters) and regional centres of expertise (i.e. the ACE Centres)
- There is a need to ensure that the network structures are strengthened and that those located in areas of poor or no provision benefit from these networks of specialist knowledge.
- There is a need to acknowledge the level of skill and specialism of the AAC technician and ensure that they are supported and funded to take on new case loads and work as part of a multi-disciplinary team.
- To ensure the workforce has necessary levels of skills around SLCN and AAC, a framework which encapsulates the workforces' needs and constructs a clear development pathway for the acquisition, retention and implementation of different and appropriate levels of knowledge and skills, is needed.

Effective Support and Training

- In order to achieve effective support and training of the workforces, awareness needs to be raised of existing training opportunities and dissemination of good-practice models; particularly those that include voices and experiences of people who use AAC.
- There needs to be a greater recognition amongst senior managers and people holding the training budgets that training should be an on-going process.
- There needs to be multiple signposting routes to effective training.
- Accreditation is needed for the network of training opportunities that have to be established. This should include an audit of existing skills and a clear training pathway for professionals.
- There must be a commitment to both fund professionals to attend training around AAC issues and to enable staff to have the time to attend training opportunities.
- For support networks to be effective there needs to be 'buy-in' from senior management.

Morning Workshops

During the morning workshop, participants discussed the themes of *assessment procedures, commissioning and funding and models of provision*. They shared their own professional experiences of these issues and discussed in groups what solutions they could offer to resolve current problems in the system. Below is an overview of the key points that were made by all of the groups on the day.

Assessment Procedures

Joined-up Working

Currently, across England and Wales, there is a postcode lottery of assessment with highly variable practices being implemented in different localities. This is partly due to the 'hit and miss' system of assessment in which individuals who could benefit from AAC encounter professionals with varying levels of knowledge and experience and a vast range of disciplinary interests. This variability in practices of assessment actively impacts on whether an individual is identified as having a communication need. To a large extent this variability, particularly amongst the children's workforce, is due to the legacy of the Communication Aids Project (CAP), which was funded by the then Department for Education and Skills (DfES) from 2002-2006. Whilst CAP did help establish local teams in a small number of areas, on the whole little local capacity was built in the system. Even after the demise of CAP in 2006, much of the workforce had lost the skills that had been built up due to a 'CAP can deal with it' culture within management and mainstream provision. CAP was limited to children in England in education and, as such, capacity to assess AAC need was never fully developed in Wales or the adult's workforce.

A key barrier to effective assessment is the challenge of getting all relevant parties into the same room. This was due to the primary responsibility for AAC assessment being seen to be with Speech and Language Therapists (SLTs). Whilst SLTs are in many cases the impetus for referral and assessment, other key professionals should be actively engaged in the assessment process. Thus, needs assessments are best served through the establishment and implementation of multi-disciplinary teams.

Multi-disciplinary teams should be designed to meet the needs of the individual being assessed. As such, they should comprise of specialist staff including: a speech and language therapists; an occupational therapist; possibly a medical physics or rehab engineer; an educational or clinical psychologists; an AAC technician and a specialist teacher. In cases where the communication equipment needs to be mounted, it is vital that wheelchair services be included in the assessment. Without a joined-up and multi-disciplinary approach to assessment, children and adults alike are left with inappropriate communication equipment and unsustainable access to it.

One participant from a school with specialist status in social interaction and communication noted that whilst it had a multi-agency approach to

assessment, it had been useful to incorporate expertise from the regional AAC centres (i.e. ACE Centre North). A number of participants noted that their respective team was built up under the better provision areas of CAP; however the current lack of funding has increased the vulnerability of existing good practice. This postcode lottery means that whilst SLTs in the know refer individuals for AAC assessment services, in most cases getting access to assessment is either due to chance or a highly vocal family member who advocates on behalf of the individual.

A key factor in an individual's need being assessed was the involvement of health service providers in the procedures. This is one of the primary reasons for the low level of early intervention in the area of AAC needs. Without the specialist input that some health professionals can offer, early intervention was seen to be endangered. That said, a number of the professionals working in the education field reported that localised schools with specialist status (in interaction and communication) and regional centres (such as the Ace Centres) offer a real opportunity to increase awareness and referral from the mainstream. This was supported by a professional who highlighted that commercial companies who develop communication equipment are sometimes being used for assessment to replace poor local services. Whilst this offers a route to assessment it is not preferable, as the model of these services has a high level of variance.

Statementing

Referrals for statements of Special Educational Needs (SEN) can be stopped when the Local Education Authority (LEA) approaches their budget limit. Statements of SEN often do not include the necessary equipment they need to communicate. In many areas a child's referral for assessment was driven by statementing, however this still left a question as to what the levers and enforcements for adult needs were. It was argued that once schools, colleges and teachers see the benefit of AAC systems to an individual's curricular activities it can lead to more referrals and a greater level of awareness. In many cases education is the only sector forced to get involved, and unfortunately this can mean that the assessment is disproportionately skewed towards curricular activities.

Transitions

Despite there being pockets of good practice across the country, all participants highlighted that this was not the picture across all of adult services. Once a young person transitions from children's services to adults services the situation becomes bleaker. One of the key associated barriers to an effective assessment post-transition is the balance of case loads. The SLTs we talked to told us that across the board, children are a far greater portion of their case load. Many told us that this situation is becoming more acute with the ineffective funding for SLTs in (adult) neurological and learning difficulty services. That said, a number of organisations reported that they actively worked with young people in transition in order to challenge the barriers that adult services presents. However, on the whole this work could not be continued as clients inevitably fell off their books.

Evidence and Guidance

In some areas, assessment is made without structure or evidence-base, which leads to an ineffective and inefficient assessment procedure. However as it stands there is no universally applied set of guidelines for assessment. This situation is exacerbated by the lack of clear pathways due to assessment and budget allocations. This lack of evidence-base on what works and what does not means that many people are sent out of their local authority for assessment and have a less clear pathway for assessment and support. A clear care pathway, which can be used as a basis for individual need would be the first step towards resolving this.

New Technologies

Another key concern was the introduction of new assistive technologies to the AAC market. Assessment protocols for the newest assistive technologies, including systems such as eye-gaze, are uncharted territory. Furthermore, the introduction of new technologies to the market creates a challenge for professionals. The challenge is whether professionals contact clients using other systems to assess whether the newest systems would be of greater benefit than their current equipment.

Funding and Commissioning

Responsibilities

The funding and commissioning of AAC services is characterised by a postcode lottery. Whilst participants reported that commissioners in their area were willing to fund AAC services, many described a bleaker situation with limited, existing provision becoming ever more vulnerable. Whilst CAP, between 2002 and 2006, had provided much needed funds for children's communication equipment in England, many young people and adults were left without the ongoing funding they needed.

Post CAP the situation has become confused. Responsibility for the funding of AAC services remains elusive, with many agencies citing the other as having the responsibility. A commonly reported situation by professionals is for an agency (education, social services or health) to refer an individual or team to another claiming that the funding responsibility is not theirs. Individuals and teams are sent from pillar to post to find the funding they need to maintain or create an AAC service. This lack of clarity around funding responsibilities leaves established AAC services highly vulnerable to changes in budgets. In the case of CAP, ring-fenced funding sometimes led to equipment being prescribed too soon because of pressure to get funding during a finite period.

The consensus from professionals and statutory agents was that the most effective funding resulted from joint commissioning between different agencies through the use of pooled budgets. This allows for the flexibility in funds that is associated with variability in need and circumstances of the individual who could benefit from the use of an AAC service. As previously noted this form of funding best facilitates joined up working across a multi-

disciplinary team. It also enables local teams to buy in expertise from regional centres. There is, however, a need to ensure that this joint funding / commissioning responsibility (for example through Children's Trusts) is effective and meets the needs at a local level. Participants hoped that joint funding and commissioning would reduce the current over-reliance on charitable funding for services and provision.

Commissioning

Effective commissioning is reliant on a robust evidence-base of local need and comparative models of good practice. Participants felt that these were not widely available and a number of commissioners highlighted that a lack of statistics was a key barrier to designing and commissioning future services. Across the piste, commissioners currently did not have examples of the type of care pathways people should be going through in AAC services, which made it hard to decipher what kind of service should be commissioned.

Coupled with an evidence-base is the need for SLCN and AAC to be a priority for commissioners. Many participants suggested that commissioners needed to be incentivised at different levels to commission services around AAC and SLCN; there was no consensus whether this is financial or by national indicator. It was felt that at the heart of innovative and effective commissioning was the client group of the service. There is a significant benefit in involving people who use AAC, their families and other key professionals working on the ground in the commissioning process.

AAC-Specific Funding

It was noted on the day that AAC-specific funding is not always the most effective method of delivering funding, with CAP being cited as a case in point. The real need is to create a sustainable stream of funding for lifelong support and provision of AAC. Many participants mentioned the large disparity between funding streams in their area. One noted that £100,000 had been ring fenced for AAC, compared to £1.24m for environmental controls in the same locality.

Some participants found that funding streams that linked AAC to allied assistive technologies, such as environmental controls or telecare may offer a more sustainable option. This was illustrated by the integration of AAC into larger and less vulnerable funding streams in participant's localities. That said, a key consideration was to ensure that the larger funding stream could have a specified remit, in some cases ring-fencing, to fund AAC devices.

Innovation and Creativity

In many localities the successful funding and commissioning of AAC services is based on financial innovation and creativity. This need for flexibility at commissioning and senior management levels has become more acute with the need to justify funding AAC-specific streams in the midst of national funding priorities. The preference on the day was for local teams providing services, funded by a centralised budget that transcends one agency: health, social care or education. Innovation and creativity of funding streams has only

been successful in areas where the necessary level of flexibility has been championed at the highest commissioning levels by a strong leader.

In localities where pooled budgets between health, social care and/or education had been introduced, lasting benefits could be seen. Furthermore, it brought the flexibility needed to establish and maintain multi-disciplinary working. That said, many participants reported that local authorities and Primary Care Trusts were hesitant to implement this flexibility. A number of areas have made progress with establishing pooled funds and moving towards the implementation of a lifelong funding stream infrastructure.

Equipment

When commissioning and funding the provision and support of AAC devices, it is important not to limit the usage of the equipment. A number of participant's clients had had their equipment restricted to specific settings (for example the school context) due to funding regulations. The ability to voice one's opinions is a fundamental human right and therefore the individual should have access to the use and support of AAC in any given context. Participants were keen for AAC to be seen as the method of communication as opposed to, for example, a tool by which to access the curriculum. The solution to this would be the pooling of budgets and the establishment of long-term insurance and warranties that are not tied to a particular setting (i.e. the home, school or work). Participants highlighted that the future of self-funding through individual budgets was an unknown on the horizon that may alter the market for equipment.

Long-term, equipment loan services were seen to be important for the effective funding of AAC equipment not least because they allow the individual and the professionals supporting them to ensure the device is effective for their communication needs. Moreover it allows for an appropriate level of flexibility in the system which means that clients and professionals can try communication systems before they buy. There were, however, concerns expressed with loaning, given the current funding climate. A number of participants discussed that loaning and trialling prohibitively expensive equipment (such as the latest eye-gaze technologies) means that individuals', families' and supporting professionals' expectations are raised. These expectations are usually not met when funding is sought for long-term use of the equipment.

Statementing

For some children a statement is the key mechanism by which they get their communication equipment funded. It is important to ensure that if the child has equipment mentioned on their statement, it also includes sufficient time for programming and training and auxiliary support for school and families. Without these aspects mentioned in the statement the funding is limited to the equipment rather than being a holistic support package. Participants reported that statements were not the most effective way of funding equipment as they were over-reliant on budgets that were already stretched. One participant

highlighted that in their authority the equipment budget for statemented children was only £100,000.

Statementing does, therefore, have an impact on the funding of communication equipment and effective support. Overcoming many support barriers is dependent on whether or not the child has a statement. It was further suggested that in localities that are reducing the number of statements they give, less money is filtered through to the services that support the use and development of AAC. A number of participants highlighted that a reduction of statementing in their area has created a reduction in funding for their posts.

Models of Provision

The State of Provision

To date, provision of high-tech assistive technologies has been fragmented and inconsistent across geographical areas and age groups. An effective model and framework for support and provision of AAC is needed to overcome the current challenges faced by disabled people whose access to AAC services is dependent upon their post code. Furthermore there is a disparity between the provisions of AAC services to children or young people and adults. On the whole, and even in areas with good practice, AAC services for children and young people far outstrip provision for adults and older people.

Many participants discussed areas of the country where there is no knowledge, let alone provision, of AAC services or even how to support adults who use AAC. In some areas where there is provision of AAC services for children and young people, adults are left without the support they need to communicate. This means that the communication skills built up in childhood may be lost in adulthood and that disabled people will fail to reach their full potential. Even in areas where models of AAC service provision were available, very few were commissioned to meet life-long needs or provided for adults. Furthermore significant problems remain in transitioning from children's services to adults' services or from one local authority to another.

Outreach was seen as patchy and over-reliant on good practice local specialist services. Whilst it was viewed as a crucial model of supporting AAC use in a mainstream setting, many providers of outreach reported that it was susceptible to cuts in funding. It was generally felt that outreach was extremely important in the provision model of AAC services but a more sustainable approach needs to be adopted.

Participants discussed the previous Government initiatives around the provision of AAC services and the pros and cons of each (as summarized in the background section of this pamphlet). In addition to the well rehearsed debates around previous models of provision, participants focused on one specific model which offers good practice provision. Whilst the implementation

of this 'Hub and Spoke' model varies in different localities and regions, in general it was considered to be the preferable model of provision and support.

The Hub and Spoke

Generally speaking, the participants' preferred model is a 'hub and spoke' model of regional provision, coordinated by a national organisation. It would be the responsibility of this organisation to establish and oversee the delivery of standards for integrated technologies, including high-tech communication technologies, and services in regional centres. In turn these will be required to support developing integrated technologies, including high-tech communication technologies and expertise in all local authorities in England. This is also the model that has been suggested to Government by national organisations including Scope and Communication Matters in their submissions to Government reviews.

The regional centres currently providing AAC services or other assistive technology services do not provide their services to all authorities in England. There are considerable variations in how these centres are funded, staffed and resourced, their geographical coverage, the age range they provide services for and the types of services they offer. Some participants felt that priority should be given to establishing a two-tier assessment and support service with local teams in each cluster of local authorities, with up to 8-10 regional centres of excellence for complex assessments and training in the use of communication technologies.

There was a difference in approach suggested by some of the participants on the day. Whilst a number wanted an AAC-specific model, others opted for a more integrated approach that covered a range of assistive technologies. Whilst both models were seen as feasible, those advocating a more integrated approach said that in the long-term, this would be more sustainable. As part of this debate a range of existing approaches from both sides were discussed, including the model used in the ACE Centres and that of ACT in the West Midlands.

All participants saw the best practice model being delivered through local teams that are comprised of a multi-disciplinary team matched to the needs of the individual; whether they are a child or an adult. These multi-disciplinary teams have responsibility for providing a first line assessment service and ongoing support for all individuals in their locale via appropriate local services. More complex assessments should be referred to one of the regional centres so that their expertise can be called upon.

These regional centres of expertise bring together existing specialist (regional) assistive technology assessment services to provide an integrated one-stop-shop service for those with the most complex needs who could benefit from assistive technology. It was suggested that the services of these regional centres should include a standard tariff of services typically including specialist assessments from a multi-disciplinary team, access to a specialist equipment loan bank, the provision of training for local teams and awareness

raising materials. Together with an ongoing support service either direct to families for complex or new solutions or via supporting professionals working in local services.

AAC Policy

One of the key barriers to effective provision models identified by participants is the lack of clear AAC policies in most areas of the UK. Professionals from those areas that did have AAC policies reported that best practice occurs when AAC policy sits under a wider framework - either of communication support more generally or assistive technologies. Participants claimed that if there is a specific remit in these policies around AAC then they are effective.

It was, however, noted that AAC policies should be underpinned by robust evidence - something that is chronically lacking across the UK especially in terms of adult AAC needs. It was suggested that a consolidated list of authorities who have made provision post-CAP and the dissemination of good practice models will go some way to addressing this barrier. To support this it was felt that there was a need in England and Wales for core standards around AAC that service provision models can adhere to, as is the case in some regions of Scotland.

Afternoon Workshops

During the afternoon workshop participants discussed the themes of *workforce development*, *specialist knowledge* and *support and training*. They shared their own professional experiences of these issues and discussed in groups what solutions they could offer to resolve current problems in the system. Below is an overview of the key points that were made by all of the groups on the day.

Workforce Development

Competing Priorities

One of the key barriers to taking forward a workforce development agenda around AAC is the lack of clarity around what the current state of the workforce is. This lack of data is exacerbated by a high reported turnover in staff, particularly within the professionals working on the ground with people who use AAC. The sheer number of disciplines and workforces who come into contact with individuals who have SLCN, or need to support the use of AAC in both mainstream and specialist settings means that workforce development is a key priority. The number of professionals and teams that the client (or their family) has to deal with means that communication slips off the agenda.

Case Loads

As is the case with many professionals working with low incidence and high need groups, the workforce supporting SLCN and in particular AAC needs has heavy work loads and competing priorities which tend to restrict the amount of time that can be dedicated to creating effective communication systems. This means that the specialist skills needed to support SLCN and AAC are inconsistently maintained in the workforce as they are dependent on professionals' exposure to different demographics of people who use AAC.

In many instances these heavy case loads mean that specific skills become unused and diminish. Ultimately this leaves those who would benefit from SLC intervention disenfranchised and without the support they need. This is particularly true of adult services where a lack of knowledge around SLCN in the workforce results in an over reliance on family members or other informed people. To safeguard against this situation occurring, participants suggested writing expertise into the job descriptions of professionals.

Technophobia

It was reported that in general both the children's and adults' workforce had little understanding of new technologies which impacted on their confidence in using them in their day-to-day professional lives. Those professionals who do have an interest in Information Communication Technologies (ICT) tend to have little support to develop their skills or be supported when necessary. Particularly in a mainstream setting the workforce was characterised as being technophobic and, in many instances, unwilling to engage with technological facilitation.

For teachers and teaching support staff, at least, this situation may change with the introduction of new technologies into the curriculum. There is an increasing need for the whole of the workforce to be comfortable with technology and have a level of competence which enables those they support to participate in any given setting. In light of this there is a growing role for ICT co-ordinators to become integral parts of the children's and adults' workforce.

Demographics of the Workforce

Many of the participants discussed the changing demographics of the SLCN and AAC workforce. Whilst once it had been regarded as the domain of SLT, the workforce had diversified to include a wider range of disciplines. This had been heightened with the introduction of new technological interventions in the field of SLCN and AAC and multi-agency teams delivering SLCN / AAC services in some localities.

One area of concern on the day was the gender and ethnic distribution of the workforces. One group suggested that up to 95% of the workforce involved in the delivery of SLCN and AAC services were female. It was felt that this may have an impact on the SLCN on those clients (particularly male) who wanted to interact and be supported by a professional of the same gender.

A similar concern was raised by another group who discussed the lack of ethnic minority representation in the workforces. This was seen as particularly concerning given that there was a need for the workforce to support those clients from families from ethnic minority cultural backgrounds or where English was not a first language. Examples included the cases of a child with a diagnosis of autism from a Hassidic Jewish community and a teenager from a religious Muslim background, who both at certain times of the week could not use their communication equipment due to religious reasons. In both these cases, and others given on the day, it was seen to be extremely important that the workforce be able to meet the SLCN of the client in their cultural setting.

Specialist Knowledge

Knowledge and Understanding

Both the children's and adults' workforce need a greater level of understanding of SLCN amongst their respective client groups. The consensus on the day was that this awareness should be at varying levels, according to the role of the professional, but it was felt that in general both mainstream and specialist settings would benefit from a greater understanding of SLCN and AAC issues. This would help address the current situation in which every child is used as a learning experience.

In one county, reportedly, there is no one in the local NHS Trust with AAC expertise. This is symptomatic of the picture of specialist knowledge of AAC across the board even in SLCN specific disciplines. Participants reported that whilst doctors and teachers may have a basic level of knowledge of AAC, enough to refer clients to a SLT, the SLT will usually not have the appropriate

level of knowledge to take the referral forward. Although this is not the case in every locality, participants discussed that many SLTs do not understand that their role covers the support of AAC use or that what they are doing on a day-to-day basis is in fact supporting AAC.

To address the first point; participants discussed that many SLTs argue that they 'just don't do AAC' and will attempt to refer their clients on. On the flip side many of the SLTs participants have spoken to did not associate the interventions they were using for a range of clients, as AAC. This was despite the fact that in the main the techniques they were using were low-tech forms of AAC. Scope found in 2007 that most SLTs spent no more than one academic week during their studies on AAC, unless they opted to specialise in the area. This clearly highlights the lack of AAC awareness amongst the SLT workforce and demonstrates the need to raise awareness and understanding of AAC issues. If this could be addressed it was felt that less reliance would be placed on individual, passionate professionals (usually SLTs) having to champion AAC issues within their locality. Rather, it would create a joint understanding across the workforce to ensure all children, young people and adults who could benefit from AAC support, do so.

Networks of Knowledge

AAC involves such a vast range of communication systems and communication equipment it is not possible for any one professional (ordinarily) to know about all of them. This is why for AAC, in particular, networks of expertise are so important. All participants said that they relied on the specialist knowledge of regional centres (for example the ACE Centres) to support their local service. Sometimes it would be in the form of a specialist assessment, at other times advice on the latest technologies available to their client.

Similarly, outreach from specialist local services, such as technology teams at specialist schools and colleges, was seen to be a key method in supporting the networks of specialist AAC knowledge, particularly in mainstream settings. National organisations, including Communication Matters (the UK hub of ISSAC) were seen to be important in facilitating knowledge transfer through their annual symposium and regional road shows. The challenge identified by participants was how to ensure that those areas with little provision or support for AAC were brought into the networks and were actively engaged in their activities.

The Role of the AAC Technician

Currently there is no unified definition of what or who an AAC technician is. Participants reported that where an AAC technician is situated (in what locality) and what type of service they work in, will significantly affect the work they undertake. The AAC technician's job is further underpinned by what is perceived to be the local level of AAC need. In some authorities, an AAC technician will move from mainstream service to service supporting staff on specific work practices. In other localities, an AAC technician will be tied to a

specialist service, giving outreach to other special or mainstream provision when they have time.

Many participants noted that much of the work done in the field of high-tech communication equipment was most effectively done by an AAC technician. This is primarily due to the fact that the maintenance and programming of communication equipment could be achieved more effectively by a professional specialising in the area of technology rather than speech and language therapy (SLT). A number of participants felt that more AAC technicians should be encouraged and funded to take on new cases, as it may provide the most beneficial outcome for the person using the equipment. It was argued that AAC technicians taking on more case loads and work as part of a multi-disciplinary team (including colleagues from SLT and teaching / learning staff) could resolve some of the time and capacity issues that the children's and adults' workforce face.

Qualifications

Qualification was seen to be crucial in addressing the disparity in levels of SLCN and AAC knowledge across the workforces. However the qualification needs to have a standardised level of knowledge and competence around SLCN. Currently there is a hierarchy of qualification in both the children's and adults' workforces, and within them education, health and social care, however the level of qualification usually does not equate to the appropriate level of knowledge around SLCN.

Participants recommended the need for a framework which encapsulated the workforces' needs and constructed a clear development pathway for the acquisition, retention and implementation of different and appropriate levels of knowledge and skills around SLCN and AAC. This standardised level of knowledge would then be incorporated into respective qualifications and courses for each workforce. This was seen as particularly necessary for allied professions to Speech and Language Therapy (SLT) that would be responsible for the support of SLCN and AAC. This standardising of knowledge will allow local teams to call on a more specialist knowledge-base from regional centres of expertise or from local specialist outreach when needed. Participants further suggested that there was a continuing need for open workshops to ensure that support skills around SLCN and AAC were being continually developed.

Support and Training

Training Opportunities

Across the board, professionals working in health, education and social services have very little access to AAC-specific training. This is coupled in most workforces with a lack of commitment to training around SLCN. The need for training is particularly acute for SLTs, who are working with less visible SLCN and need appropriate training to deliver the early intervention of AAC. Whilst some training exists at a regional level and in a small number of specialist local services, training opportunities are scarce. Where opportunities are available they tend to be one-off introductions to the area of AAC. Providers of this form of training who attended the event reported that take-up, in general, was low apart from those localities that already had good practice models in place. Participants reported that the best practice models of training included the voices and experiences of people who use AAC.

Participants felt that this was a real weakness in the system and that there needed to be a greater recognition amongst senior managers and people holding the training budgets that training should be an ongoing process. Furthermore these various training opportunities must be expanded and promoted widely. Many participants reported a lack of multiple signposting routes to effective training and found it hard to distinguish between the effectiveness of different training courses.

Training courses should be moderated and monitored so that professionals can understand their effectiveness. Accredited training and required competencies from this should be essential to the job description of professionals working in the field. Participants highlighted the need for national standards and accreditation around training, across vocational, professional and academic courses. To support this accreditation it was suggested a network of training opportunities needed to be established. This should include an audit of existing skills and a clear training pathway for professionals.

Committing to Training

Accredited training will aid the development of an effective workforce in the field of AAC; however without a commitment from employers for the time to attend training the investment will be futile. At the highest level, and if possible written into job descriptions, should be a commitment to both fund professionals to attend training around AAC issues and to enable staff to have the time to attend training opportunities. Many participants reported that in order to manage their case loads and access the training they needed they had to negotiate study leave with their employers or were forced to take time out of their holiday allocation.

This is an untenable position to be in. If the workforce needs to access training, to deliver effective service then there must be a responsibility on employers to enable the staff to have the funding and time they need to access it. This commitment to funding staff to access training opportunities

may also address the vulnerability that some effective training courses face due to a lack of sustainable funding. In a fast changing field such as AAC, particularly at the high-tech end of the spectrum, there is more of a need than usual to ensure that professionals have the training they require to effectively fulfil their roles in supporting AAC use.

Support Networks

Previously we have covered the knowledge transfer aspect of support networks and similarly support networks in the whole follow the same structure. Participants believed that the regional centres of expertise, where they existed, did offer a holistic support service that enabled local teams to call upon regional expertise in AAC as and when they needed. Similarly, national organisations such as Communication Matters and, to a lesser extent, the Royal College of Speech and Language Therapists (RCSLT), offer forums in which professionals can access the support they need to effectively deliver AAC services.

Support networks are only effective if there is 'buy-in' from senior management. Participants were concerned that in many localities, senior managers did not allow their staff enough flexibility in their roles to respond to or seek support from other professionals working in the area of AAC. This was a concern both in terms of low-tech AAC, which is time intensive, and high-tech AAC, which may need a high level of support from allied professionals to fulfil their role. Professionals working in the field of AAC need stronger connection to professionals working in Information Communication Technology (ICT) who, on the whole, can offer specific support around integrating high-tech systems. They can also offer troubleshooting for staff that require instant ICT support.

Future Opportunities

Whilst the account given above may seem pessimistic, more recent opportunities and initiatives could go some way to resolving the current disparity in provision and support.

The Communication Trust

In June 2007, Scope welcomed the establishment of the Communication Trustⁱ by Lord Adonis, and alongside it the establishment of the Communication Consortium - the third sector reference group for the Trust. The purpose of the Communication Trust is to raise awareness of the importance of speech, language and communication across the children's workforce and to enable practitioners to access the best training and expertise to support the communication needs of all children. The Trust was founded by Afasic, the BT Better World Campaign, Council for Disabled Children and I CAN. This small core group is supported by a number of partners and stakeholders, including over 20 voluntary and community groups who deliver services and support to children with SLCN.

The Communication Trust is working closely with a number of lead bodies in the field of workforce development including the Children's Workforce Development Council (CWDC) and the Training and Development Agency for Schools (TDA). They are also working with professional groups in the field of speech, language and communication including the RCSLT and the National Association of Professionals concerned with Language Impairment in Children (NAPLIC). The Trust's work is supported by the Department for Children, Schools and Families and other funders. The Trust is hosted by I CAN and works to a representative board.

Increasingly there has been a stronger representation of organisations representing AAC issues on the Communication Consortium, including Scope, Communication Matters, ACE Centre North and 1Voice – Communicating Together. Scope, with its partners, is supporting the work of the Communication Trust and the Communication Consortium in its development of resources for workforces. An illustration of the initial work being done in collaboration is the Communication Trust's publication 'Explaining Speech, Language and Communication Needs' authored by Scope, I Can and Treehouseⁱⁱ. This document sets out a definition of SLCN that has been endorsed by the 25 organisations represented on the Communication Consortium and is a real achievement in getting, for the first time, a sector-wide agreed definition.

The Speech, Language and Communication Framework (SLCF)

The Communication Trust is currently working on a pilot Speech, Language and Communication Framework (SLCF)ⁱⁱⁱ. This will identify the skills and knowledge necessary for the children's workforce to support children's communication effectively, support the inclusion of children with SLCN and create the best outcomes for children mapped against the Every Child Matters agenda.

The framework aims to support managers in assessing the skills and knowledge of their staff and to identify staff training and development programmes that help staff develop appropriate skills. The SLCF will be an online audit tool that individuals and institutions can use to consider what areas of speech, language and communication they may need to develop skills and knowledge in.

The framework updates the Joint Professional Development Framework (JPDF), which sets out joint training requirements for education and speech and language therapy colleagues working with children and young people with speech, language and communication needs. Scope, Communication Matters and ACE Centre North have been feeding into the development of this framework and influencing how AAC is conceptualised within the framework-in-progress.

Inclusion Development Programme

In October 2007, the DCSF launched the Inclusion Development Program (IDP)^{iv}, which takes forward the commitments made in the Government strategy for Special Educational Needs (SEN) *Removing Barriers to Achievement*^v. Over four years, the IDP will develop and deliver a programme of Continuing Professional Development (CPD) designed to strengthen the confidence and expertise of mainstream staff in early years settings and in primary and secondary schools in ensuring the progress and achievement of pupils with Special Educational Needs (SEN). The focus of the IDP during the first year is on SLCN and dyslexia. Throughout the remaining three years of the programme, the focus will be on autistic spectrum disorders (ASDs), behavioural, emotional and social difficulties (BESD) and moderate learning difficulties (MLD).

The Communications Forum

The Communications Forum^{vi} is the UK's national information resource network for children and adults with speech, language and communication impairments and people who support them. Representatives from Scope sit on the board of trustees for the forum. The Communication Forum is currently working on a Charter for Communication that services can sign up to, in order to show their commitment to addressing the needs of people with speech, language and communication needs (SLCN). The board is currently working on supporting the Government in the implementation of the Bercow Review recommendations and looking into the current state of provision of services for adults (19+ years) with SLCN.

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No Voice, No Choice

If you would like to know more about the outcomes from the *Designing the Futures of AAC Services* event or about the No Voice, No Choice campaign, please contact us via email at communication_aids@scope.org.uk or by post at No Voice, No Choice, Policy and Government Affairs, Scope, 6 Market Road, London, N7 9PW.

If you would like to speak to someone about the No Voice, No Choice Campaign, please ring us on 020 7619 7254.

ⁱ The Communication Trust (2007) *The Communication Trust: every child understood*, London: The Communication Trust:
http://www.ican.org.uk/upload/communication%20trust/documents/tct%20leaflet_07%20final%205th%20dec.pdf

ⁱⁱ Hartshorne, M., Bush, M. and Daly, S. (2008) *Explaining Speech, Language & Communication Needs*, London: The Communication Trust:
<http://www.ican.org.uk/upload/communication%20trust/explaining%20slcn.pdf>

ⁱⁱⁱ The Communication Trust (2007) *The Speech, Language and Communication Framework (SLCF): a multi-agency framework for professional development in children and young people's communication (a revised and extended JPDF)*., London: The Communication Trust:
<http://www.ican.org.uk/upload/communication%20trust/documents/slcf%20overview%20final.pdf>

^{iv} DCSF (2007) *The Inclusion Development Programme*, London: DCSF:
http://www.standards.dfes.gov.uk/primary/publications/inclusion/idp_flier/pr_sen_idp_flier_00710-07.pdf

^v DfES (2004) *Removing Barriers to Achievement: the government's strategy for SEN*, London: DfES:
<http://www.standards.dcsf.gov.uk/eyfs/resources/downloads/removing-barriers.pdf>

^{vi} <http://www.communicationsforum.org.uk/>

Scope is a national disability organisation whose aim is that disabled people achieve equality. We work with disabled people and their families, policy makers and professionals to advance the human and civil rights of disabled people through our Time to Get Equal campaign. We provide information, support and a range of innovative services to disabled people, particularly those with cerebral palsy, across England and Wales. To find out more, visit: www.scope.org.uk

If you would like to know more about our work on designing the future of AAC services, or about the **No Voice, No Choice** campaign, please contact the Policy and Government Affairs Department at Scope.

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