

Communication Matters awareness-raising and campaigning for improved AAC provision

The following relates primarily to England and Wales only. Other campaigns were run in Scotland (and Northern Ireland) where differing government policy priorities and different education legislation, and NHS structures apply.

- **Dept of Health meetings with AAC stakeholders**. In 1995 Toby Churchill Limited received a letter of congratulation from Gerald Malone, Minister of Health, on their receipt of a *Queen's Award for Export*. As Simon Churchill's MP, Simon took the opportunity to contact him to request a meeting to discuss funding of communication aids. The Minister declined the invitation but arranged for his colleague, Alistair Burt, Minister for the Disabled, to meet and discuss the issues. A team comprising Simon Churchill (representing CASC), Janet Larcher (Chair of CM), Prue Fuller (Director of ACE Centre, Oxford), Liz Panton (head of *Communicate*, CAC Newcastle), Anthony Robertson (who uses AAC) and Mark Williams (head of Charing Cross Hospital CAC) met with the Minister to raise awareness of the need for funding AAC. Subsequent meetings were chaired by Dept of Health representatives with involvement from other key AAC stakeholders at the time. This led to the submission of a paper outlining a proposed model of funding for AAC services and equipment provision. Despite commendation of the report, it did not meet identified health priorities at the time and was rejected as a proposal.
- **Inclusion of communication aids within Community Equipment Services**. In 2000 an Audit Commission report exposed the failures of the Community Equipment Services (CES) that were operating in England and Wales at that time. The Commission's report highlighted the inequality and inefficiency of the service provision and suggested that a lack of clarity and leadership led to disabled people getting poor quality equipment and poor quality outcomes. The following year, the Department of Health announced £105 million funding for Integrating Community Equipment Services (ICES) until 2005. Thirty-two specific communication aids were included in the list of disability-related community equipment, although few services managed to provide and maintain communication aids within their community equipment loan stores.
- **The Communication Aid 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 ran out half way through the year 2005/6 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 need, it was always designed as a short-term, education-focused programme, and did not address the need for a sustainable model of

provision or for commissioning incentives to deliver AAC on a universal basis for children and adults. 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. This led to a significant number of letters being sent to constituency MPs by professionals, families and AAC services to raise awareness of the identified gap in AAC provision that was left when CAP ended.

- **The Bercow Review of services for children and young people (0-19 years) with speech, language and communication needs.** In September 2007 the Government announced a review of services for children and young people with speech, language and communication needs in England following considerable lobbying from a wide range of voluntary sector organisations involved in supporting children and young people with speech, language and communication needs (SLCN). It was recognised that a common theme was the lack of skills and knowledge within the children's workforce. The independent review, commissioned by the Department for Children, Schools and Families (DCSF) and the Department of Health (DH), was led by John Bercow MP (now Speaker of the House of Commons). Scope, along with partner organisations, submitted more than 35 pieces of evidence to the review and in December 2007 was invited by the Bercow Review team to facilitate the focus group on AAC.
- **Communication Matters online survey.** In 2007, the Communication Matters Board of Trustees requested feedback from its members using an online survey to which 94% of respondents expressed a positive wish for Communication Matters to undertake lobbying activity for improved AAC provision and awareness-raising.
- **The Bercow Review AAC Focus Group.** Members of the AAC Focus Group included people who use AAC; their families, 1Voice, Communication Matters, AAC service providers, AAC suppliers, and researchers. Communication Matters led on a consultation process with its members to identify a preferred model for the delivery of AAC services and provision of equipment resulting in the identification of the 'Hub and Spoke' model.
- **The Bercow Report.** The final report of the Bercow review in 2008 was far-reaching and commented on a range of systemic barriers as well as highlighting examples of good practice in support of children's communication. This included consideration of communication service provision, workforce development issues, commissioning frameworks, funding, outcomes for children and young people and in particular a focus on the sustainability of the AAC sector with the implementation of a 'Hub and Spoke' model of provision as advised by the AAC Focus Group.
- **The Better Communication Action Plan.** The Government (DH and DCSF) responded to the Bercow Review with its own Action Plan in December 2008. This plan aimed to address some of the barriers facing children (0-19) with

SLCN and made a number of commitments to strengthen and improve AAC provision.

- **The Communication Champion.** Jean Gross CBE was appointed as the Communication Champion with a remit to address the issues identified in the Bercow Review, which would culminate in a National Year of Communication and later became the 'Hello' Campaign: <https://www.thecommunicationtrust.org.uk/resources/resources/hello-campaign-resources/> . The secretariat for her role was the Royal College of Speech and Language Therapy (RCSLT) and she was accountable to the Communication Council, which still exists today (2016) and is co-chaired by senior civil servants from DfE and DH. Details of Council membership can be found at: <https://www.thecommunicationtrust.org.uk/policy-and-practice/the-communication-council/who-sits-on-the-council/> , which includes an AAC representative, currently filled by Anna Reeves.
- **National AAC Coordinator.** Anna Reeves (ACE Centre Manager) was appointed to support the Communication Champion as National AAC Coordinator in order to put flesh on the bones of the 'Hub and Spoke' model and she established an AAC Sub-Group that met with the Communication Champion throughout her term of office and reported via Anna to the Communication Council. Whilst the remit of the Better Communication Action Plan was for children aged 0 – 19 years, it was acknowledged by the Communication Council that any of the Communication Champion's emerging AAC recommendations should address provision for all children and adults, and consequently there needed to be engagement with the Dept of Health. A specialised AAC service specification already existed within the portfolio of specialised NHS services, which were defined as low incidence high-cost regional services that could not be commissioned at a local level. However, specialised AAC services had never been commissioned effectively due to the lack of awareness and available data on need, costs and impact.
- **Developing the 'Hub and Spoke' model for AAC services and provision.** Under the guidance of the Communication Champion, Anna worked with Keren Down from FAST to create the report: "Specialised AAC provision: commissioning national services", (which is available with supporting documentation at: <http://www.communicationmatters.org.uk/page/national-standards-aac-services>) and summarised the key recommendations for implementation of the 'Hub and Spoke' model with supporting data relating to estimated costs, need and outcomes.
- **DfE AAC Grants.** Activity to support the effective commissioning of AAC services was supported by the Department for Education through a Small Grants Programme in 2012 and coordinated regional bids were submitted in order to:
 - Consult and involve key stakeholders
 - Systematically map existing AAC provision against the National Quality Standard (devised by Communication Matters)
 - Develop good practice guidelines for the development of effective local AAC teams

- Reach national consensus on proposed care pathway procedures by which to manage referrals to specialised AAC services
This activity was planned and delivered by existing specialised AAC services across England.
- **Positioning the AAC 'Hub and Spoke' model in Government policy.** The terms of office for the Communication Champion and National AAC Coordinator straddled the change in Government in 2010, which saw the emergence of two key pieces of legislation: The Children and Families Act 2014 and the Health and Social Care Act 2012, which facilitated the opportunity to position the recommendations from the Communication Champion's AAC Report within the framework of the new legislation. Communication Matters committed to fund focussed Public Affairs support from Whitehouse Consulting to assist with a lobbying campaign for the implementation of the Communication Champion's report.
- **Communication Matters engagement with politicians and peers.** Representatives from the Communication Matters Board of Trustees (Sandra Hartley, Janice Murray and Catherine Harris) met with Anna Reeves and a number of cross-party MPs and Peers on a regular basis to ask for their support in addressing the need to implement the 'Hub and Spoke' model of AAC provision within the emerging policy framework. John Bercow MP continued to ensure this issue remained on the political agenda as he was aware that this had been left unresolved since the publication of his recommendations in 2008.
- **Parliamentary Briefing Event** In September 2012, a Parliamentary Briefing event was organised by Communication Matters with assistance from Whitehouse Consulting and was hosted by Virendra Sharma MP to discuss the future commissioning arrangements for children and adults who require AAC services and equipment. A Lobbying toolkit was disseminated by Communication Matters to its members who used this to encourage their constituency MPs to attend.
- **BHTA and Communication Matters Parliamentary Reception** in March 2012, an event was co-hosted by Communication Matters and BHTA in the House of Lords at the invitation of Lord Rennard to raise awareness about AAC and the need for improved services and provision. The guest speaker was Rt Hon Sarah Teather MP who at that time was the DfE Minister of State for children with responsibility for SEN.
- **MPs and Peers supporting the case for improved AAC provision:**
 - Peers from the House of Lords:**
 - Baroness Walmsley
 - Lord Rennard
 - Baroness Tanni Grey-Thompson
 - Baroness Jolly
 - Lord Bradley
 - Ministerial engagement**
 - Rt Hon Andrew Lansley MP

- Bill Morgan (Special Advisor to Andrew Lansley MP)
- Sarah Teather
- Rt Hon Edward Timpson MP
- Earl Howe
- Rt Hon Michael Gove MP
- Rt Hon Norman Lamb MP
- Rt Hon Paul Burstow MP

Members of Parliament

- Rt Hon Robert Buckland MP
- Virendra Sharma MP
- Andrew Smith MP
- Rt Hon Damian Green MP
- Nick Herbert MP
- Fabian Hamilton MP
- John Cryer MP
- Dave Anderson MP
- Paul Maynard MP

- **AAC Adjournment Debate.** Paul Maynard MP for Blackpool North and Cleveleys was particularly active in supporting this issue, in part as a consequence of his own experience of speech & language difficulties resulting from cerebral palsy. Following a constituency visit by the Prime Minister to ACE Centre on 15th February 2013, Paul Maynard MP asked the following question at Prime Minister's Question time:

Paul Maynard (Blackpool North and Cleveleys) (Con):

"I know that the Prime Minister recently visited the ACE Centre in Oxford, and I am sure that he shares my view that it does a fantastic job helping young and disabled people to communicate more effectively using technical aids. What guarantees can he give that augmentative and assistive communication aids will be made available to more young people than is currently the case, so that everyone who could benefit from them is able to do so?"

The Prime Minister:

"I am really grateful to my hon. Friend for raising this issue. The ACE Centre, which was previously in Oxford and is now located in my constituency, has done incredible work for people with disabilities over many years. It is making the most of the extraordinary changes in technology. When I visited it recently, we looked at a whole raft of ways in which we could make sure that the NHS is making these things available to more people, and I am very committed to working with my hon. Friend and the ACE centre to make sure that that happens."

Paul also agreed to request an Adjournment Debate on the issue, which was allocated on 6th June 2013, entitled: "Future commissioning arrangements of augmentative and alternative communication services". Communication Matters responded by encouraging its members to approach their

constituency MPs to attend: <http://www.communicationmatters.org.uk/news-item/2013-debate-on-aac-commissioning> and supported his briefing for the Debate along with Anna Reeves. He faced Norman Lamb MP, then Minister of State for Care and Support at the Dept of Health whose portfolio included NHS specialised commissioning. Significant evidence in Paul's brief was drawn from the Communication Matters-commissioned 'Shining a Light on Augmentative and Alternative Communication' AAC Evidence Base research project: http://www.communicationmatters.org.uk/sites/default/files/downloads/projects/aac_evidence_base/2013_Shining_a_Light_on_AAC.pdf

- **NHS England funding for specialised AAC services.** Following the Debate, NHS England confirmed that additional £15 million annual recurrent funding would be made available from April 2014 for specialised AAC services and equipment provision for children and adults in England who met the service specification eligibility criteria. Services were identified within NHS England specialised commissioning regions who met the core requirements of the service specification D01/ S/b: "Complex Disability Equipment: Alternative and Augmentative Communication / Communication Aids (All Ages)".
- **Commissioning local AAC services.** Whilst significant progress had been made in establishing this funding for specialised AAC services, the commissioning of local AAC services and provision for those children and adults who do not meet NHS England eligibility criteria remains unacceptably variable across England. One objective for specialised AAC services is "to support the development of effective local AAC teams and care pathway procedures by which to manage referrals to specialised AAC services". NHS England has, however, no jurisdiction over local commissioning arrangements to meet this need.