



THE ALL-PARTY PARLIAMENTARY GROUP  
ON MOTOR NEURONE DISEASE

## CONDEMNED TO SILENCE

INQUIRY INTO ACCESS TO  
COMMUNICATION SUPPORT FOR  
PEOPLE WITH MND



## CONTENT WARNING

THIS REPORT INCLUDES FRANK DISCUSSION OF THE EFFECTS OF MOTOR NEURONE DISEASE AND THE CONSEQUENCES OF POOR CARE FOR PEOPLE WITH MND. SOME READERS, PARTICULARLY THOSE WHO HAVE BEEN PERSONALLY AFFECTED BY MND, MAY FIND IT DISTRESSING.

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## EXECUTIVE SUMMARY

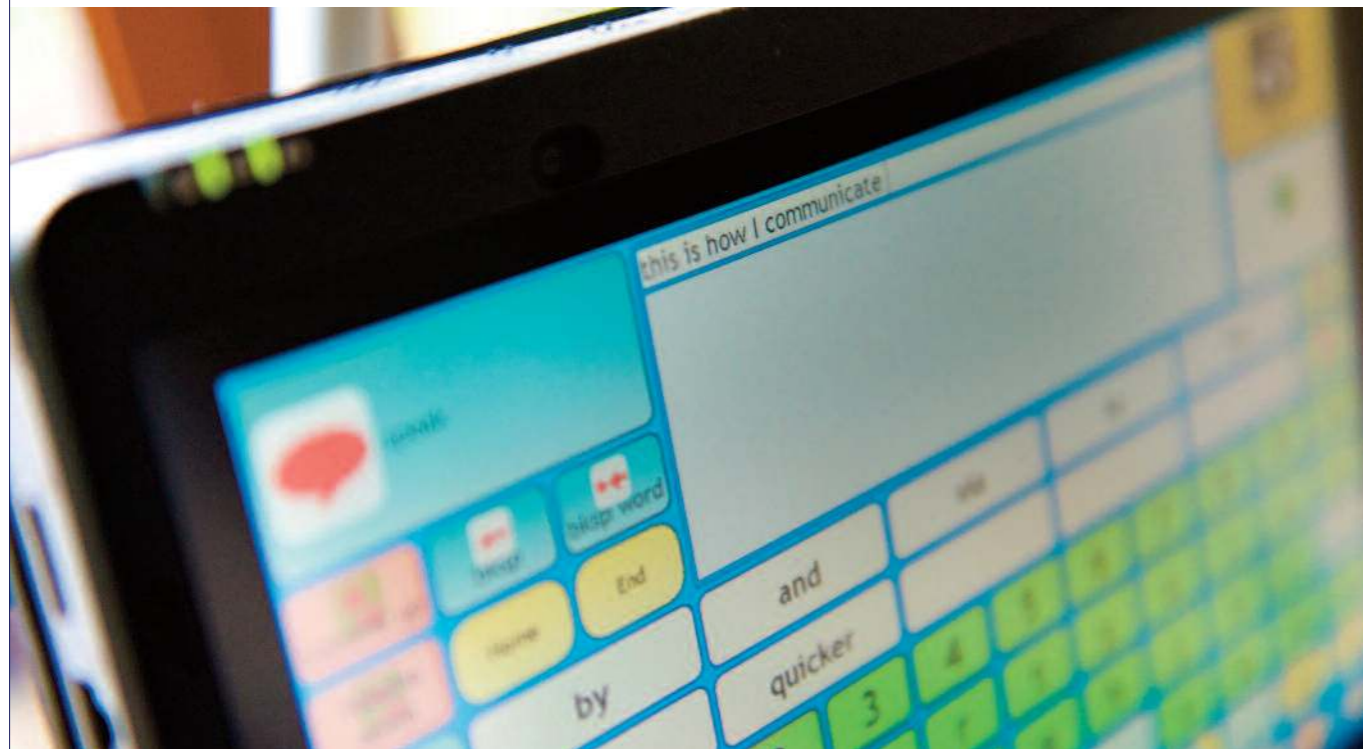
### 1.0 OVERVIEW

People with MND who have communication difficulties are not receiving the services that they need. Although there are pockets of excellence, there are also areas where services are letting people down. The underlying causes of this variation differ somewhat between the nations and regions of the UK.

People who are left without a voice have their wellbeing compromised. The impact of not being able to communicate is devastating for people with MND and those around them. Some people with MND are dying while waiting for equipment they need, and sometimes even dying while waiting for the initial assessment.

Despite technological change revolutionising the opportunities available to people with MND who lose their speech, many people with communication impairments are not benefiting from new technology.

This inquiry examined the current state of communication support for those affected by MND, comparing what is thought to be happening with what individuals are experiencing. 1,692 people – including healthcare professionals and people living with MND – responded to our survey and several attended sessions to give further evidence.



### 2.0 NATIONAL POLICY IN ENGLAND

The evidence and testimonies received from healthcare professionals and from individuals with MND indicated that NHS England has not as yet successfully implemented its plans for better communication aids.

As a result of the Coalition Government's 2012 reforms to the NHS, meeting communication needs is now clearly the responsibility of NHS England. This represents major progress from the situation beforehand, when individual communication aids had to be funded by whatever ad hoc mixture of health, social care, charitable and other funding could be found.

Evidence we received showed that in too many areas services are poor. The promise of a consistent service specification for the whole country is not being delivered. Areas particularly found to have poor services included Surrey, Sussex, Birmingham, Worcestershire and West Yorkshire.

### 3.0 WALES, SCOTLAND AND NORTHERN IRELAND

There is no statutory duty on the NHS to fund communication aids in Wales, Scotland or Northern Ireland. The devolved administrations may wish to consider whether or not to introduce a statutory duty.

Provision in north Wales appears to be strong, although we were also told that journey times to the Walton Centre in Liverpool are a barrier for some. In south Wales there were concerns expressed about the capacity of the specialist communication centre at Rookwood to meet the volume of referrals.

In Scotland, communication aids supplied by MND Scotland are the major source of support for people with MND. MND Scotland suggested that the 2012 report 'A Right to Speak' did not lead to any substantial improvement in augmentative and alternative communication (AAC) provision in Scotland. First Minister Nicola Sturgeon has recently announced £700,000 of funding to double the number of MND nurses in Scotland, which should be welcomed.

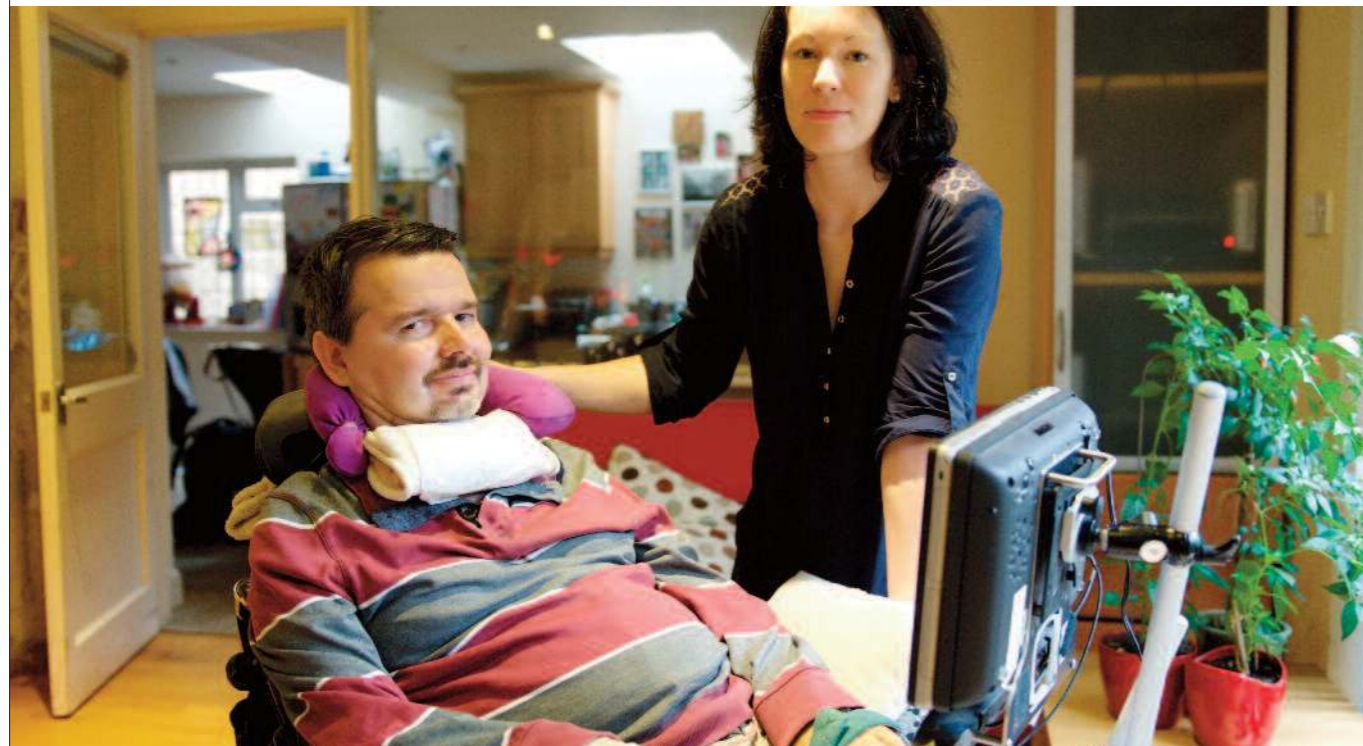
Survey responses indicated that AAC services in Northern Ireland seem to be effective, with a specialist centre in Belfast providing support to local speech and language therapists (SLTs). However, difficulty and slowness in securing funding for communication aids was apparent in Northern Ireland.

### 4.0 THE STATE OF SERVICES ACROSS THE UK OVERALL

Currently the NHS funds communication aids for fewer than half the people with MND who need them.

People with MND are sometimes prioritised for assessment and treatment, but not as consistently as many believe the disease warrants. Where prioritisation occurs, this often seems to be because of the good will of individual professionals, and not because of a clear policy within the NHS.





## 5.0 THE IMPORTANCE OF COMMUNICATION TO PEOPLE WITH MND

The impact of losing one's voice is devastating in many ways.

- Many people with MND describe it as the worst aspect of the disease
- For some, it can seem to undermine the individual's morale fundamentally and even appear to hasten the end of life. It is socially isolating: people struggle to keep up in conversations, and often eventually give up and shun social contact
- Losing the ability to speak is often described as losing part of the individual's personality; to carers, it can seem as though the person they love is not there any more, even while they are still alive
- Communication problems can often lead to bad temper, ill feeling and permanently changed relationships within families
- Many practical tasks, including anything involving a phone call, become impossible
- It can be hard to communicate essential care needs, for instance if a person is in danger of falling while being moved between chairs
- Hospital stays often result in appalling indignity, suffering and lack of care because nursing staff do not realise that the person with MND cannot communicate
- It makes the end of life particularly hard: important choices about care cannot be communicated, and final words are left unsaid.

## 6.0 HOW PEOPLE WITH MND EXPERIENCE DIFFERENT TYPES OF COMMUNICATION SUPPORT

Testimony made it clear that tablet devices and smartphones were very useful for people with MND, although their usefulness declines when people begin to lose function in their hands.

Lightwriters were generally viewed by those giving evidence as heavy and outdated, although some people with MND and speech and language therapists (SLTs) felt they still have a role to play, either because older people find them easier to use, or as short-term solutions.

For some people, MND brings cognitive as well as physical change. This can drastically interfere with the ability to use a communication aid, particularly if it renders it difficult to spell, or to recognise that their speech has deteriorated.

Low-tech solutions can be highly useful, depending on the individual and their circumstances. A high-tech communication aid is not automatically right for everyone or at all times.

The training given to people on how to use aids provided appears to vary enormously, and many people are not given the support they need to make use of their equipment.

Self-funding of communication aids is very common, particularly on consumer electronics. The least well-off are more likely to be excluded from the benefit they can bring.

The limited choice of accents in modern synthetic voices can be upsetting to people who naturally spoke with regional accents.

Awareness of voice banking among people with MND is low. The technology is immature and does not always produce a synthetic voice that is either intelligible or recognisably like the person's original voice.

Some people with MND are able to use funding from the Access to Work programme to obtain communication aids to allow them to remain in work.

## 7.0 WORKFORCE AND TRAINING ISSUES

The majority of speech and language therapists who responded believed that their workforce is not currently adequate to meet the needs of people with MND. There are too few speech and language therapy (SLT) posts, both specialists and generalists.

There were concerns in England that the new specialised AAC hubs may not be able to recruit the specialist staff they need. One hub has advertised and failed to recruit. We were told that sufficient numbers of new therapists are being trained, but that the problem was that there are not sufficient posts being funded for them to go into.

Our survey found pessimism among SLTs about the future of their profession. Increased demand from an ageing population and a growing squeeze on SLT funding and numbers may create a crisis.

## 8.0 THE ROLE OF CHARITIES

Charities have traditionally played a major role in meeting the communication needs of people with MND. Despite the introduction of new obligations for NHS England to provide funding, the MND Association is planning to increase the amount of money it spends on communication support in England.

MND Scotland believes that communication is the highest area of unmet need among people with MND in Scotland.

There is widespread support among people with MND, carers and care professionals for the principle that the NHS should fund communication support for people with MND.

NHS England's policies currently do not allow it to reimburse a charity where that charity has stepped in to provide equipment that should have been NHS England's responsibility. This should be rectified.

## RECOMMENDATIONS

- 1 NHS England should implement its service specification for AAC as an urgent priority.
- 2 NHS England should investigate why the implementation of the specification was delayed.
- 3 The Secretary of State for Health should investigate the problems with specialised AAC for people with MND in England.
- 4 NHS England should publish the current version of the service specification for AAC on its website.
- 5 The Royal College of Speech and Language Therapists should investigate whether there is the potential for a crisis in speech and language therapy.
- 6 Throughout the UK, specialised AAC provision should be closely integrated with environmental control, wheelchair and computer access provision. There should be no 'gaps' where health and wellbeing could be improved by aspects of technological support. A concerted effort to raise performance is needed to ensure that people with communication impairments and other disabilities benefit from advances in technology.
- 7 The NHS should develop clear policies so that tablet devices may be funded for use as communication aids, with other functionality intact so as to contribute to the wider wellbeing of the individual.
- 8 The NHS should investigate options for establishing loan banks of modern communication aids.
- 9 The NHS should ensure that people with communication difficulties receive appropriate care when they are admitted to hospital. Nursing staff should receive training on the implications of communication difficulties for patients. Appropriate communication aids must be available in hospitals.
- 10 The NHS should prioritise people with MND for anticipatory speech and language assessments, striking an appropriate balance between the requirements of individual patients and the often rapidly progressive nature of MND.
- 11 In order to assure the ongoing quality of provision and drive future improvements, the NHS should collate data on the provision of communication support, including:
  - Number of referrals to each service
  - Equipment delivered
  - Times between referral and assessment, and between assessment and delivery
  - Numbers of assessments and re-assessments
  - Outcomes for patients and carers.
- 12 The NHS, the MND Association, the Royal College of Speech and Language Therapists and Communication Matters should engage in a sustained programme of communication, education and training, once the specification is implemented, to ensure that speech and language therapists understand how the programme is intended to operate for people with MND.
- 13 Lightwriters should be recognised as having a more limited role in the mix of available communication support than in the past. Other than for select user groups who cannot use more modern devices, and possibly short term aids, they are generally not preferable to tablets and similar devices. It should not be easier to obtain NHS funding for a Lightwriter than a tablet device
- 14 The National Institute for Health and Care Excellence (NICE) should ensure that all aspects of communication for people with MND are thoroughly reflected in the guideline it is currently developing.
- 15 Training should be given much more consistently to people who are issued with communication aids on how to use them.
- 16 Manufacturers of communication aids with synthetic voices should include options for regional accents.
- 17 Voice banking technology is not yet mature. Once it is available, it should be appropriately publicised to people with MND.
- 18 NHS England should develop a policy around the circumstances in which it will reimburse a charity for communication aids, and specifically approve this when the charity has provided it.
- 19 The Minister for Care and Support should clarify his parliamentary reply of December 15th 2014 in light of the evidence we present about the current status of specialised communication support services.
- 20 The voluntary sector should arrive at a common understanding of what its role should be in supporting care in this field, without impinging on any statutory duty on the NHS.
- 21 Research should be conducted into the link between communication, wider wellbeing and longevity in people with MND. If it is found that communication support demonstrably improves quality of life and/or longevity, this should be reflected in clinical practice and guidance.
- 22 Research should be conducted on how many people with MND could benefit from eye gaze technology, to inform future purchasing decisions.





## CHAPTER 1 INTRODUCTION

### 1.1 ABOUT THIS INQUIRY

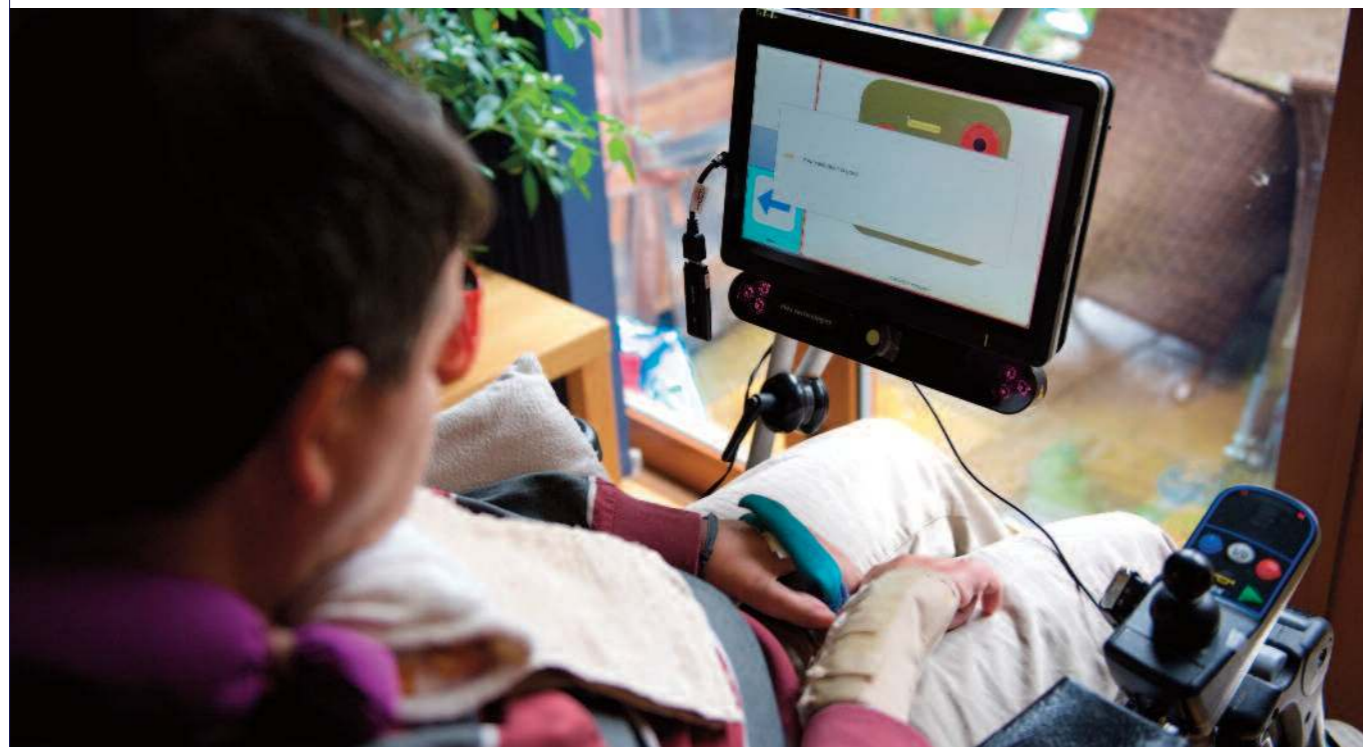
The All-Party Parliamentary Group (APPG) for Motor Neurone Disease (MND) is a cross-party group of MPs and Peers with an interest in MND. We agreed in May 2014 to hold our second inquiry on the subject of access to communication support for people with MND living in England, Scotland, Wales and Northern Ireland.

The inquiry has sought to determine whether people with MND can:

- access the communication support they need across the four countries
- establish the extent of variations in the provision of specialist communication assessment and equipment provision
- identify both examples of good practice and gaps in services.

A call for evidence was issued in September 2014, inviting written submissions from England, Scotland, Wales and Northern Ireland, including from people with personal experience of motor neurone disease, patient organisations, individual health and social care professionals, organisations representing health and social care professionals, commissioners, regulatory bodies, equipment providers, scientists, and policy makers.

Online questionnaires were developed by the Picker Institute which offered different questions to people with MND, carers / former carers / family members, and health and social care professionals. Oral evidence sessions were held at Westminster over three days in November.



Written responses to the call for evidence were received from 1,692 individuals:

- 350 people living with MND
- 115 current carers of a person with MND
- 421 former carers of a person with MND
- 374 family members of a person with MND
- 432 people working with, for or on behalf of people with MND (mostly health and social care professionals).

Many respondents with MND completed the questionnaire using assistive technology, while many carers, former carers and relatives also took the time to relate and revisit often distressing experiences. We are deeply grateful to them, and to all of the busy health and social care professionals who found or made the time to submit evidence.

Oral evidence was provided by:

- Liam Dwyer, person living with MND
- Anna Dwyer, Liam's wife and carer
- Sarah Ezekiel, person living with MND
- Susan Lodge, person living with MND
- Gill Stevenson, carer for her husband Ron, a person living with MND
- Bob Bestow, Head of Direct Services, MND Scotland
- Cathy Harris, Chair, Communication Matters and independent SLT
- Chris James, Director of External Affairs, MND Association
- Julia Johnson, Clinical Specialist, Royal College of Speech and Language Therapists
- Karen Pearce, Director of Care (South), MND Association.

We wish to thank everyone who gave their time to come to Westminster and tell us about their experiences.

Written submissions were received from the MND Association, MND Scotland and the Royal College of Speech and Language Therapists.

Notes on evidence presented in this report:

- Due to rounding, percentages shown in charts may not sum to 100
- We have endeavoured to reproduce written evidence as it was presented to us; however, typographic errors and some items of spelling, punctuation and grammar have been corrected.

## 1.2 INTRODUCTION AND ANALYSIS

### BOX 1

#### KEY FACTS ABOUT MND AND HOW IT AFFECTS THE VOICE

*Up to 5,000 people are living with MND in the UK at any one time:*

- *approximately 250 in Wales*
- *approximately 120 in Northern Ireland*
- *approximately 400 in Scotland*
- *the remainder in England.*

*30% of people with MND die within a year of receiving their diagnosis, and over 50% die within two years.*

*Between 5% and 15% of people with MND develop frontotemporal dementia.*

*Slightly more men (56%) than women (44%) have MND; however, this imbalance evens out after the age of 70.*

*30% of people with MND present with bulbar symptoms (affecting speech and swallowing).*

*80-95% of people with MND develop bulbar symptoms during their illness.*

*Over 50% of people with MND at any one time have impaired speech to some extent.*

*MND compromises a person's ability to speak in numerous ways:*

- *The muscles in the tongue and lips become weak, making it hard to form consonants and causing the person's speech to sound slurred*
- *The vocal cords become weak, making the voice sound hoarse, low pitched and monotonous*
- *Muscles in the chest become weak, affecting the breathing and making the voice soft and weak*
- *The soft palate can become weak, giving the voice a nasal quality.*

- i. This inquiry has identified some difficult issues. In one respect, these flow from the nature of MND: the loss of speech commonly causes anguish and frustration among people with MND, and those around them. The ability to communicate is central to a person's wellbeing.
- ii. This is made worse by the inadequacy of communication support to people with MND across the UK as a whole. Our inquiry identified inconsistent support across the UK.
- iii. In England, the NHS is now obliged to fund specialised communication aids, but there is no requirement for statutory funding in Wales, Scotland or Northern Ireland. In many parts of those nations, effective local pathways and systems for delivery exist. Their delivery for people with MND can at times be effective.
- iv. Changing technology offers possibilities to people with communication impairments unimaginable ten or even five years ago. Communication aids such as eye gaze systems are more readily available. Off the shelf consumer electronics such as smartphones and tablet devices can provide relatively cheap and user-friendly communication aids.

## CHAPTER 2

# NATIONAL POLICY IN ENGLAND

## 1.1 NHS ENGLAND

Specialised communication aids – or augmentative and alternative communication (AAC) – are commissioned directly by NHS England as part of its specialised commissioning remit. This is a substantial step forward: no clear obligation had previously existed for the NHS to fund specialised AAC. The new arrangements for specialised commissioning commenced in October 2013. In 2014, NHS England allocated £15million of ring-fenced money for specialised AAC services from its 'convergence fund', established to assist services across England to reach mandated national standards.

As of December 2014, 14 months after the new system commenced, NHS England had not commissioned specialised AAC services. This is despite explicit assurances from its two chief executives that the new arrangements were in the process of being initiated. Former NHS Chief Executive Sir David Nicholson and current NHS Chief Executive Simon Stevens both wrote to MPs whose constituents had been let down by the NHS's lack of provision, in March 2014 and December 2014 respectively.

On the second of these occasions, Mr Stevens wrote on 5th December to Sam Gyimah MP offered strong assurances about the current state of services. The MND Association replied that:

- None of the £15million had yet reached the 13 provider 'hubs' for specialised AAC and none had signed a contract with NHS England.
- Only one hub was recruiting the necessary staff in December 2014, while one other had attempted to recruit and failed. Others were awaiting signed contracts.
- Providers were either not accepting referrals, or placing people with MND on long waiting lists for an assessment.

We do not believe that either Sir David Nicholson or Simon Stevens intended to mislead, but the information they provided did not match the testimony we received from healthcare professionals or those living with MND.

On December 15th, in reply to a written parliamentary question from Glyn Davies MP, the Minister of State for Care and Support, the Rt Hon Norman Lamb MP, repeated some of Mr Stevens' assurances. He stated: "The 13 AAC providers selected are in the process of recruiting the required additional specialist therapy staff. Services are already accepting referrals and patients are being prioritised according to their clinical need, with priority being given to patients with life limiting conditions." Again, we do not believe that the minister intended to mislead, but his reply does not match the testimony we have received.

We were concerned about the letter submitted to the inquiry by Richard Jeavons, NHS England's interim Director of Specialised Commissioning, on 21st November. It stated that delays had been caused by 'some unanticipated issues' but did not specify what they were. It went on to say:

*This delay was regrettable, however, I am pleased to be able to inform you that the final allocation of funding to providers of AAC took place in October 2014 and contracts should now have been enacted between the area teams and providers.*

A further letter from Mr Jeavons was received on 22nd December, which said:

*During the past month good progress has been made in establishing the contracts which need to be in place between the service commissioners and the nominated providers. The following four Area Teams have agreed and signed, or will have signed by the end of December, contracts... with supporting implementation plans: Yorkshire & Humber, Leicestershire & Lincolnshire, Cheshire, Warrington & Wirral and Surrey & Sussex. [...] All 13 of the identified clinical services are accepting referrals and multi-disciplinary assessments are being offered to patients. Priority is being given to patients who have a life limiting condition. [...] We will be keeping progress under monthly review.*

The MND Association has found that, as of the end of December 2014, only the Cheshire, Warrington and Wirral area team (AT) has signed a contract. The other ATs remained in discussions with the providers over contractual terms. The Association also found that the identified clinical services are not consistently accepting referrals or carrying out assessments; it has been informed that one provider has asked to be supplied with funds from NHS England on a case-by-case basis, in advance of a contract being signed, but this request has been refused.

On 2nd December, during a House of Commons debate on the NHS Five Year Forward View, the Chair of the APPG, Madeleine Moon MP, raised the non-delivery of specialised AAC with the Secretary of State for Health. His response was as follows:

*With the greatest of respect to the honourable Lady, I will very happily look into the concerns she raises, but what we are talking about today is more money going into the NHS because the Government got a grip of public finances and got the economy growing. That means more money for people with long-term conditions, including people with motor neurone disease. The hon. Lady should therefore welcome today's announcement.*

We hope that the Secretary of State will make good on his pledge to investigate the issue. The disparity between the evidence from healthcare professionals and the leadership of NHS England is concerning.

On 18th December we were also sent a response by NHS England to a Freedom of Information (FoI) request. The response stated:

*For the areas covered by the East Anglia, London and South Yorkshire and Bassetlaw Area Teams of NHS England, this service is commissioned by local Clinical Commissioning Groups (CCGs) and Local Authorities.*

This information was not mentioned by Mr Jeavons, by the minister, in any letter we have seen from the chief executive of NHS England, or in any evidence submitted by the MND Association. Whether CCGs and local authorities have retained responsibility in these areas, or on what basis this was decided, is unclear. The response was also unable to provide information on the number of people served by each provider who had MND, the number of staff employed by each provider, the number of SLT posts currently vacant, and the number of eye gaze systems provided to people with MND. It was also unable to provide information on current waiting times, and instead directed us to the service specification, which sets out what waiting times should be in theory.

Both the FoI response and the minister's parliamentary reply provided the web address of the 2013 version of the service specification, not the version that has been in force from October 2014, which is in the public domain but has not been published on NHS England's website

## 2.2 AREAS FOR IMPROVEMENT

The NHS's responsibility for specialised AAC is set out in its service specification for 'Complex Disability Equipment: Augmentative and Alternative Communication / Communication Aids (All Ages)' published in 2013 and revised in 2014, the latter version nominally having force from October 2014. This states that the communication needs of people with complex disabilities and health needs will be met by the NHS. The specification was developed by the clinical reference group (CRG) on complex disability equipment. CRGs are bodies of clinicians, with some patient representation, that advise NHS England on its clinical policies and decision-making. The CRG has a sub-group specifically on AAC.

It must be emphasised that this is a major step forward from the position a decade ago. The specification draws on the work of the Communication Champion to identify how complex communication needs should be met. The Communication Champion was appointed as a result of the Bercow Report, commissioned by the Labour Government in 2007. The new settlement represents the culmination of work over a number of years under successive governments, and is a welcome development. Previously, communication needs were not clearly the responsibility of any agency, and were addressed locally by a mix of NHS, social care, charitable or other funding.

Under the new NHS structure, specialised commissioning is undertaken by ten of NHS England's 27 ATs – see Box 1. They, in theory, benefit from commissioning guidance issued by the CRG's AAC sub-group in June 2013, and revised in 2014 (having force from October). They have identified 13 'hubs' to provide specialised AAC services, supporting local speech and language therapy (SLT) services as 'spokes' – see Box 2.

### BOX 2

#### THE NHS ENGLAND AREA TEAMS RESPONSIBLE FOR SPECIALISED COMMISSIONING, 2013-2015

- *Birmingham and the Black Country*
- *Bristol, North Somerset, Somerset and South Gloucestershire*
- *Cheshire, Warrington and Wirral*
- *Cumbria, Northumberland, Tyne and Wear*
- *East of England*
- *Leicestershire and Lincolnshire*
- *London*
- *South Yorkshire and Bassetlaw*
- *Surrey & Sussex*
- *Wessex Area Team.*



## BOX 3

## THE 13 PROVIDER 'HUBS' FOR SPECIALISED AAC IN ENGLAND

The 13 specialised AAC hubs identified for commissioning by NHS England are:

- Kent Children's and Adult's Communication and Assistive Technology Service
- Regional Communication Aid Service, Newcastle
- Barnsley Assistive Technology
- Compass Assistive Technology Service, Royal Hospital for Neurodisability
- Chailey Heritage Clinical Services, East Sussex
- North West Assistive Technology
- Access to Communication and Technology (ACT), Birmingham Community Healthcare NHS Trust
- Bristol Communication Aid Service
- ACE Centre – Oldham
- ACE Centre – Oxford
- Lincolnshire AAC Service
- Communication, Learning and Technology Service, Great Ormond Street Hospital for Children
- Dame Hannah Rogers School and young adult provision and AAC assessment service, Devon.

NHS England is currently seeking to add a 14th hub, in London.

The specialised AAC service outlined in the specification, and clarified in the commissioning guidance, has the following key features:

- Priority will be given to patients with a rapidly degenerative condition such as MND
- Patients will be assessed in the most appropriate location, which could for instance be their home, by competent, experienced personnel and in conjunction with other services where appropriate
- It will be possible for patients to use equipment which the assessment concludes could be suitable for them for a trial period
- Training on how to use any equipment will be provided as necessary, including extra training to take account of any cognitive impairment
- The user and their equipment will be regularly reviewed, at an interval suitable for each individual patient's circumstances (more frequent for someone with a rapidly degenerative condition)
- Equipment will be adjusted, or new equipment provided, as shown to be necessary by the regular reviews

- People with degenerative illnesses can be referred to specialised services in anticipation of future need
- Assessments can be carried out by one of the 13 hubs or, if more appropriate, by the local SLT service (funded by the CCG), who can then refer the person to the specialised centre
- A person is eligible for specialised AAC if, among other things, they have impaired limb function, multiple disabilities or a need for specialist switches or a device that integrates communication support with other functions, such as environmental controls
- A person may be eligible for a specialised assessment, even if that assessment finds they do not immediately need specialised equipment.

This is a clear and comprehensive framework that places people with MND firmly within the remit of specialised AAC services.

## 2.3 THE EXPERIENCES OF PEOPLE WITH MND

The most recent evidence received by this inquiry indicates that the £15million of NHS England funding was disseminated to ATs in October but has not been transferred to providers. There is also £7.5million ear-marked for environmental controls (EC – for instance, remote controls for lights and curtains within the home and often integrated with communication aids).

Evidence submitted indicated a highly mixed picture across England. In some areas, the traditional pathways involving mixes of NHS, social services, education authority and charitable resources have persisted. In others, they have collapsed. In some cases, CCGs appear to be stepping in to fund AAC which is not their responsibility.

The immediate consequence for people with MND is long waiting times for equipment or an assessment, meaning a person with MND and their family are unable to communicate. In the worst cases, people with MND die while waiting for assessments or equipment; many respondents to the call for evidence stated that they have seen this happen.

Submissions by speech and language therapists (SLTs) stated that local assessments can often be obtained, but the person cannot be referred to a specialised hub and therefore cannot obtain any equipment they need. The reasons given for this were that there is no process, there is no money from NHS England, or even that there is no money from the CCG. This response from an MND Association volunteer typifies this scenario:

*In my experience people with MND have been assessed as in need of communication aids - they have even been visited by representatives from IT companies and a suitable aid has been suggested. But the cost for this equipment is high; there is apparently no money in the CCG budget; NHS England who are supposed to be providing funding have no procedures in place for this. The person with MND is then expected to fund the equipment themselves - usually with the help of the MND Association. Sadly I'm unable to give examples of good practice, as to date I have no experience of this in my area.*

## BOX 4

EVIDENCE FROM PEOPLE WITH MND, CARERS AND PROFESSIONALS  
OF THEIR POOR EXPERIENCES OF AAC PROVISION IN ENGLAND

*I have been offered communication aids to try but after 18 months I have still not been provided with a system that works. The major problem is that from trying a piece of equipment it takes up to 14 weeks to fund and obtain the equipment, with a degenerative illness this period is far too long and the illness has progressed giving me less of a chance to get to operate and program the system without support.*

*My therapist says there are no funds to help me to talk.*

*My neurological nurse referred me but her position went and has not be replaced in this area so many people with MND don't get help early enough. [...] There is very little expertise in talking machines in this area and most of England. I contacted some Scottish speech therapists about some equipment as they know far more about them.*

*The initial contact to see a SLT is some weeks. An assessment 3 months+.*

*I have been denied access to or refused permission to apply for AAC by the ATs and by our CCG.*

*We were only able to borrow an iPad with text to speech app for two weeks as there is only one available for the whole area. If it worked and was useful it was up to you to buy one yourself. No option of a Lightwriter, eye gaze or anything else. Dad was given the ability to communicate for just two weeks and then basically it was tough luck, find £400+ and sort yourself out!*

*When I first started making enquiries in 2013 for the replacement eye gaze system, it was obvious that there was complete confusion amongst most NHS staff. The first point of contact is meant to be your speech therapist. Unfortunately mine was entirely clueless about the funding and even after consulting her superiors, who were equally clueless, just told me to contact NHS Specialised Services who control this type of funding. The speech therapist didn't want to get involved. Subsequent communication with anyone in the NHS has been equally frustrating and when the MND Association stepped in after six months, the NHS were still in disarray.*

*We have close links with the Bristol Communication Aids Service which can assess for and now fund equipment as required. This is an excellent service, but very stretched. Although they prioritise people with MND, their waiting times are 16 weeks, which can be a long time for some people with MND. Two people I was supporting passed away before they could get an appointment last year. We have a small stock of equipment like Lightwriters which we issue all the time, and occasionally we use the MND Association where there is no alternative.*

## 2.4 AREAS OF ENGLAND THAT ARE OF PARTICULAR CONCERN

There appears to be considerable variation across England in the state of specialised AAC provision, with some local arrangements remaining effective despite the failure to implement the service specification, others having deteriorated in its absence. Numerous specific areas were identified within the evidence to the inquiry where services appear to be particularly problematic. The relevant evidence is set out below.

**Surrey and Sussex:** the MND Association highlighted this area as one where problems are particularly being reported. They cited cases where:

- A man reliant on eye gaze to communicate could not secure funding for a new system to replace his life-expired old one; this was funded by the MND Association, with a promise of reimbursement from the NHS
- A man has been told he needs an eye gaze system but cannot have one because he already has an environmental control system (this does not appear to be based on any guidance or specification); the NHS actively suggested approaching the MND Association for funding
- A man was refused an assessment for his clearly changing communication needs, and advised to approach the MND Association for funding
- A woman's communication aid was eventually funded by the CCG using an individual funding request (IFR); IFRs are intended for use on interventions not routinely funded by the NHS, not interventions mandated in service specifications; more worrying still is that it was the CCG who granted the IFR, not NHS England
- A woman died while under threat of having the eye gaze system she relied on taken away, because it had been loaned on a trial basis and the provider wanted it back for other patients
- A man was given such a long waiting time for an assessment that he has effectively been denied one; he is on a long waiting list at one centre, while another is now refusing to see people from his area.



**Birmingham:** very long waits for assessment at Access to Communication and Technology (ACT) were repeatedly reported.

*Communication technology services in this area have just been cut. Speech and language therapists (SLTs) usually refer. It can take time for referrals to be acted on and due to cuts in funding communication aids are fairly basic.*

*Locally we are able to provide assessment and put low-tech and some high-tech support in place in a timely way, however on occasion we have sought the advice and support of the regional centre ACT especially regarding eye gaze and their response time has been extremely slow. Most recently patients have been offered appointments from this regional service five months away and now I understand that they are not offering appointments at all.*

*I have liaised with ACT in Birmingham which can provide equipment to, for example turn on the television and aid equipment aids regarding iPads. Unfortunately there is a long waiting list. My clients have waited months for equipment which they need straight away, this limits their ability to communicate with friends, family and professionals.*

*Referral for assessment for AAC on average is taking 5 months and provision of equipment another 3-4 months. In areas further away from Birmingham they are being told that referrals are closed due to lack of capacity. People with MND often die before receiving an assessment/equipment.*

*No funding stream or pathway within NHS. Have a regional contract with ACT in Birmingham who should provide timely AAC for our clients but they are limited and often will not provide iPad or apps associated with them. This is often what MND clients want. As such we have to ask the commissioners on a case by case basis or approach charities.*

*Lightwriters are always funded by MND Association as they are not freely available through NHS. More complex systems such as eye gaze funded through ACT (regionally based NHS) but again not always in a timely manner. Have recently made a referral to ACT - they cannot offer my patient an appointment until at least March 2015 - a long time not to be able to communicate!*

**Worcestershire:** problems with referrals to ACT, the regional centre, appear to be compounded by cuts to local SLT services.

*Used to be good, with speedy referrals to speech and language therapists, but therapists now in short supply. Concerns that local plans are to reduce home visits and require people to attend clinics, which can be hard for people with mobility and language problems.*

*Long waiting list. Referrals have been known to be assessed by telephone and deemed not to need SLT from that assessment. Patients are seen just once then discharged; a new referral has to be made when communication deteriorates further. No urgent appointments available for swallowing assessments. Support for production of and assistance and training for use of low-tech aids is not forthcoming. I was told this morning by an MND patient that I (a physio) have been more helpful than the SLT. I have just returned from an assessment with ACT specialists, where the local SLT was due to attend but was not present. ACT are aware of the lack of service in our area. As a team we are very frustrated by the lack of SLT in our area.*

*There seems to have been a reduction in SLTs over past year, as staff move on and are not replaced, presumably for financial reasons. I have heard there are plans locally to discontinue specialist therapy services in community and require people living with MND to attend clinic for assessment by generic therapist, not necessarily SLT, which is likely to cause delays and difficulties for this group of exceptionally vulnerable people.*

**Plymouth:** respondents indicated that specialist funding is decided so slowly that patients' needs have usually progressed by the time a solution is provided.

**Bassetlaw:** funding decisions in Sheffield are done by the commissioning support unit (CSU). CSUs are normally under contract to CCGs, which suggests the CCG is funding in this area; this appears to bear out the statement in response to the FoI request that the CCG has retained responsibility here, although why this has happened and who sanctioned it remain unclear. A very slow process has resulted, and people are known to die before it is complete.

*The process of applying for funding for assessment and provision of an AAC device is the same whatever the neurological condition. However, I feel the slow process is worse for people with MND due to the rapid progression of the disease - as I said previously, people with MND are dying before they get an appropriate communication aid.*

**Hampshire:** a lack of therapists and funding pathways appear to be causing very poor provision.

*If someone needs a communication aid our hearts sink as we have to try to access companies and arrange joint visits with reps who are poorly equipped so can't complete the assessment and then fail to get back to us. Once this laborious process is complete which can take months we then have to jump through almost impossible extremely time consuming and confusing hoops to get someone somewhere to fund. I dread being allocated someone with communication difficulties for these reasons." This respondent works at Hampshire County Council, suggesting a failure of integration with the NHS, and/or a failure by the NHS to ensure effective provision locally, with social services attempting to fill the gap.*

*Access to SLT is limited due to the limited number of therapists. There are no specialist MND SLT therapists. Often patients purchase their own tablets and communication aids and there is no facility for accessing eye gaze systems.*

**Bromley, south London:** non-provision was reported, with a particularly concerning example of a communication aid being taken away from someone who had been using it on a trial basis.

*In the last two years we have been unable to secure any funding from the CCG for on-going input by specialist communication services. This has meant that patients do not get the communication aid they need and in one case a system on loan was taken away and the patient was not provided with anything alternate.*

**West Yorkshire:** local AAC funding appears to have been stopped. It is not clear from respondents whether this is a CCG-held local SLT budget or an old pathway for complex cases that has ended in the expectation of NHS England funding arriving.

*We used to go to the MND Association for Lightwriters when our stocks had run out. However, they are now used just for interim short term loans while waiting for iPads via NHS funding. As such our own stocks could cope with this demand. However over the last month our AAC budget has been taken away. Only one area (Bradford CCG) have funding available for AAC. Airedale and Craven CCG have stopped the funding for communication aids. We are going to have to investigate other charities for funding for iPads and potentially have to request stocks from the MND Association from now on.*

*The NHS has funded communication aids in the past, but the funding locally has been stopped for this year, probably as cost cutting. I do not know how my patients are going to be able to get the communication aids that they need.*



**Derbyshire:** job cuts appear to have downgraded local services.

*There have been recent changes within this SLT department resulting in the loss of most highly specialist SLT posts, so it seems unlikely that there would be such posts created for people with MND or other complex communication needs. Some SLTs develop links with other related services through their work. Three Grade 6 therapists form a "MND specialist network", which means they can access training on MND related issues and have more experience of working with people with MND, so they provide support to other SLTs within the department.*

## 2.5 AREAS OF ENGLAND WITH GOOD SERVICES

We must acknowledge that not all the reports we received were bad. Some areas appear to offer good services. They are set out here.

**South Devon:** *We now are using the hub and spoke model and accessing NHS England funding where we can. (The reference to NHS England funding is puzzling, as no hub appears to have been commissioned; it may be that the hub has started providing, in the expectation of being reimbursed by NHS England eventually.)*

**Hounslow, west London:** *Especially the reduction in cost of the eye gaze computer communication systems has made a huge difference to clients with reduction in speech and communication, as this allows them vital means of independent communication when dexterity is lost and other forms of communication (phone, iPad etc) can no longer be used. The reduction meant that funding is more readily available and approved!*

**Bath:** *In the past we have gone to the MND Association for funding of communication aids but we no longer need to do this.*

**Derbyshire:** *We used to rely much more on the MND Association for loaning of Lightwriters but this has been largely superseded by eye gaze technology so we tend not to ask for funding now, as our trust provides it. The NHS solely funds communication aids in our Trust... We have a system in place that allows instant loans and longer-term aids to be purchased which works very efficiently so that communication aids can be taken out and shown/ left with the patient at the very first appointment following referral if necessary.*

**Liverpool:** *We have a triage system which will flag people with MND as urgent. All initial intervention is carried out by SLTs with ongoing reviews also. We have a communication aids technician who keeps stock of all aids available. All visits with regard to establishing effective use of communication aids will be carried out by SLTs or communication aids technician (both with specialist knowledge).*

**St Catherine's Hospice, Lancashire:** At our hospice we have a stock of eye gaze for people to use.

*The south west is good, Bristol provide a very good services, and some companies in London have provided a very good service as well. They reach out to support people with MND at our request. Oldham and Barnsley have also been providing good services. [...] Nottingham and Lincolnshire as well, where the speech and language therapists worked with commissioners in setting up a pathway, and there are concerns that the new situation will interfere with their successful pathway. – Oral evidence from the MND Association, when asked to identify areas of good provision.*

## 2.6 MISUNDERSTANDING BY CARE PROFESSIONALS

A further symptom of the failure to implement the service specification appears to be that many professionals misunderstand how it is to operate. These misunderstandings often revolve around misconceptions about whether or when a person with MND might qualify for specialised support. Some SLTs are unaware of the changes, including the recognition of communication as a health need, and continue to approach CCGs or others for funding, usually but not always unsuccessfully. See Box 5.

The specification states clearly that anyone with a communication difficulty associated with a complex physical or learning disability can be eligible for specialised AAC, providing their understanding is not impaired to the same extent as their ability to speak. Eligibility criteria may be applied in anticipation of need arising, so a diagnosis of MND should be sufficient to qualify someone for assessment for specialised AAC from an early stage.

The specification clearly states:

*An individual may have a deteriorating condition and in these cases it is expected that services should anticipate their needs. The inclusion/exclusion criteria should be applied with regards to the anticipated abilities of these individuals within a clinically appropriate time period. Referrals can be accepted 'in advance' of these individuals presenting with a severe communication difficulty and should be sent at the time felt to be most clinically appropriate for the individual.*

### BOX 5

#### MISUNDERSTANDINGS OF THE NEW SYSTEM, EXPRESSED IN RESPONSES TO THE CALL FOR EVIDENCE

*One of the criteria is complexity and I have been told that people with bulbar MND where only speech and swallowing are effected would not fall into the criteria of 'complex' which means they have to go via our local pathway, ie have communication aids funded locally which is likely to take slightly longer. If the MND progresses to the limbs they would then be seen by our regional service.*

*Recent changes in funding streams for communication aids nationally now mean that it is more likely that any necessary high-tech aids will be funded through national commissioning. However, people with MND may not initially meet assessment/funding criteria, but may still wish to find out about what aids are available.*

*The MND Association have been called upon to provide funding for AAC with a number of patients in our service. However, I am aware that the CCG should be providing money for this purpose which is not currently being done.*

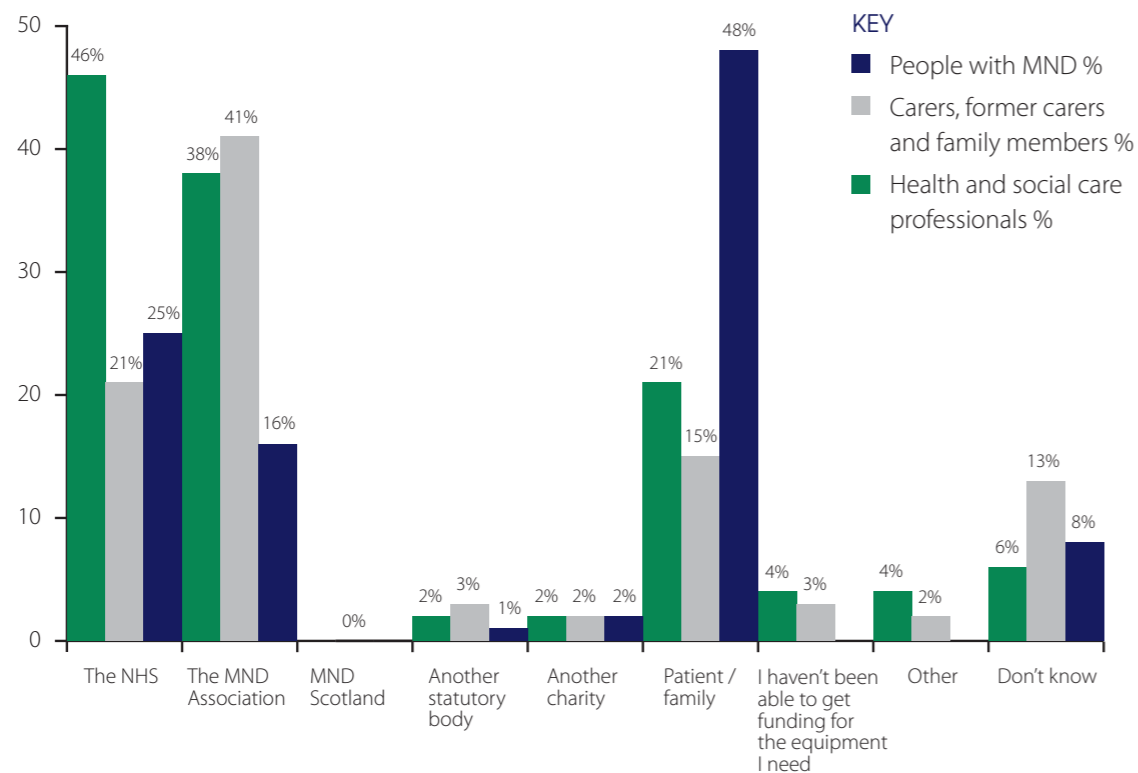
*We need a dedicated funding stream so individual applications for aids are not required. This should be a pooled budget from health, education and social care. Need clarity on what is centrally funded by NHS England and the local CCG.*

## 2.7 FUNDING OF COMMUNICATION AIDS

Identifying who pays for communication aids at present has proved problematic. NHS provision is not the norm, but quantifying the extent to which it takes place and the extent to which people are reliant either on self-funding or on charitable funds is difficult. Submissions from people with MND, carers, health and social care professionals and the MND Association all showed different answers, as shown in Figure 1. People with MND noted the NHS as the most frequent provider; carers cited the MND Association; and professionals cited self-funding.

FIGURE 1:

Who funds or funded the communication equipment that you use / the person you care or cared for uses or used / support and communication aids for people with MND in your area? (Tick all that apply)



The NHS is funding fewer than half of the people who need equipment, and at most only slightly more than the MND Association. This would suggest that the NHS is not meeting its obligations in full.

Survey data from the MND Association appears closer to the results returned by care professionals. In a survey of 950 people with MND:

- 53% of people who used electronic equipment to communicate indicated they funded it partly or wholly themselves
- 23% that the Association had provided it
- 23% that it had been funded from another source, including the NHS.

One possible explanation for the divergence in these figures is the self-funding of iPads and other consumer electronics. These are readily available to many people, and may not even be viewed by some users as a communication aid for the purposes of this question. Some people with MND are buying such a device rather than waiting for NHS provision. This blurring of the line between everyday consumer electronics and healthcare interventions could lead some people to turn to the NHS at a later stage than they might have done in the past. It should not, however, be used as an excuse for non-provision by the NHS of support it is obliged to offer.

The data suggest that the NHS funds communication equipment for fewer than half of the people with MND who need it. Self-funding appears common, which may be a symptom of NHS failings and the increasing availability of consumer electronics that can function as communication aids.

## 2.8 SYSTEMIC BARRIERS

A recurring theme in the written evidence was that some SLTs prioritise swallowing issues over speech, as a matter of policy. In one case, SLTs seeing inpatients could only look at swallowing needs. Someone with speech needs would have to be discharged and seen outside the hospital. The closure of cases leads to re-referral when a person's needs change, rather than allowing them to be seen quickly by the same SLT. Best practice is to keep a person's case open from initial referral to death, never closing it at all.

*In the hospital, the SLT team are not able to advise on communication anymore, but focus merely on swallowing assessments. This means that patients with MND admitted to hospital with communication needs have to wait until they get home to receive input.*

*We have a Specialist Regional Communication Assessment Service on site, but they are funded by outpatient monies and so will not provide resources (time or equipment) to inpatients. As inpatient therapists we manage communication difficulties as best as we can. For example, with pen and paper, or laminated sheets of paper and marker pen (if insufficient upper limb strength/ control pressure for pen and paper), simple alphabet charts etc.*

*Difficult to access even a speech and language therapy assessment at present due to longstanding staff shortages. After assessment patients usually discharged and need to be re-referred back into the system which creates unacceptable delays for this client group... Previously we had a speech and language therapist based part time in team so patients seen quickly and regularly reviewed - this was a much better.*

*Practice by therapists of discharging people once a 'solution' is provided can leave a person with progressive deterioration and the 'solution' becoming ineffective. MND requires professionals to be constantly planning ahead, and ready to respond as soon as the person is willing to accept a new solution.*

## CHAPTER 3

## WALES, SCOTLAND AND NORTHERN IRELAND

## 1.1 WALES

There is no statutory obligation for the NHS in Wales to fund specialised AAC. In north Wales, provision appears to be strong. The MND Association suggested the existence of a Disease Specific Advisory Group on MND may be responsible to raising awareness with the local health boards.

In south Wales, many respondents reported effective multidisciplinary working within which SLT services are well-coordinated. Concern was repeatedly expressed about a lack of communication aids. The specialist centre at Rookwood was often cited as the only source of such aids, and unable to meet demand. The range of concerns expressed about services in south Wales was not replicated in respect of the north. One MND Association volunteer commented:

*It is difficult to assess just how often MND Association is called upon to supply communication aids as to date the local NHS provision has been adequate. However, the local branch do have a bank of tablets that are freely available to those who need them.*

Another respondent noted that although the joined-up provision of SLT, neurology, occupational therapy and other services in the Walton Centre in Liverpool is of great assistance to many, the long journey required to get there can exclude some people with MND from benefiting.

In south Wales many respondents commented on the effective co-ordination of care services, including SLT. For instance:

*Good team working within Pembrokeshire. Regular meetings and educational support. Community Resource Team supports best practice- multi disciplinary meetings, rapid response to problems.*



In contrast:

*We are a small team in Hywel Dda covering an enormous region of Wales. MND is a complex disease requiring therapist with specialist knowledge. Due to issues with staffing we are at danger of not having enough specialist therapists available.*

*Within our service we are able to make low-tech communication aids e.g. communication books, alphabet boards etc. We have recently secured funding for an iPad for assessment purposes only but unable to give to patients for long-term loan. We also have some amplifiers for short term loan availability but limited on time frame. For other communication aids and more complex aids/adaptations we need to fight for funding or get families to self-fund. We have to wait for expert assessment from Rookwood Communication Aid Centre as funding requests have to be recommended by them following an assessment.*

*The biggest difficulty is lack of funding for communication aids and supporting technology. Not just for the patients, but for the therapists that support them. I do not have access to an iPad and am therefore limited in my ability to assess its suitability as a communication aid for my patients and also in my ability to be aware of available applications. Access is limited by the Health Board, whose IT department will not fund or support iPad devices.*

*In south Wales the MND Association has established networks for patients with MND and this has greatly improved the joined up care. Our patients are routinely reviewed as an MDT on a 3 monthly basis with follow up as required in the intervening periods. There is a dedicated Communication Aid Centre in Cardiff, however they are often overwhelmed with referrals and there can be delays between the time of referral to assessment, which on occasion can be too long for this client group. Once the assessment is undertaken and recommendations made however there is the issue of who should fund the necessary communication aid.*

*Locally within our department we prioritise all MND referrals due to the nature of the condition and try to see them asap. We provide assessment with our knowledge of current communication aids but with so many devices on the market we are not experts. There is a new app out all the time and we do not have the time/money to trial all of them. That is why we rely on specialist assessment from Rookwood. When getting specialist assessment advice from Rookwood Communication Aid Centre they do formally acknowledge and prioritise MND patients but this is still not soon enough and can be over 8 weeks. Once they assess and recommend they do not have devices to loan, they can provide a temporary trial and then make recommendations. It is then our responsibility to source funding.*

*As a service we always prioritise MND due to the speed it can deteriorate. We have an SLT who is very knowledgeable about AAC but is not qualified to formally assess, and we don't have access to all the AAC devices available. We are therefore reliant on Rookwood.*

*I have only ever used iPads as no other systems have been offered, apart from one lady assessed by Rookwood who has died still waiting for her wheelchair and communication aids.*



### 3.2 SCOTLAND

MND Scotland estimates that there will be a minimum of 120 people with MND who need AAC in Scotland at any one time. There is no statutory obligation on the NHS in Scotland to fund AAC. With no budgets for equipment being held by SLTs, funding must be found from whatever sources can be identified locally. MND Scotland told us that a communication aid loaned by them will in most cases be the only communication equipment a person with MND receives. In oral evidence, they described themselves as, "becoming the main facilitator of equipment to people with MND, not because we understand it better but because we are the ones who have the motivation to do so."

Specialist equipment is sometimes delivered by the Scottish Centre for Telecommunications and Communication Impaired (SCTCI), which can visit people with MND in their homes and provide equipment for trial. Referral may be via an SLT, but does not necessarily have to be. One criticism of SCTCI offered in evidence was that the training it provides on using equipment does not go beyond basic instructions at the time of delivery.

The Scottish Government issued a report in 2012 entitled 'A Right to Speak' and announced £4million for AAC services. The report stopped short of introducing a statutory obligation to fund. In 2014 the Scottish Government subsequently committed to an additional £700,000 to double the number of MND nurses in Scotland for a fixed period; these nurses will not be SLTs or come with additional funding for AAC, but may assist some people in accessing communication support.

BOX 6  
ACTIONS LISTED IN THE REPORT 'A RIGHT TO SPEAK'

- *Develop a National AAC Research Strategy*
- *Evaluation of AAC related data from individual and population based intervention programmes*
- *Implement use of nationally agreed data sets for AAC*
- *Implement use of appropriate outcome measures for all people who use AAC*
- *Development of national strategy to promote universal support for people who use AAC*
- *Implementation of national strategies to promote universal support for people who use AAC*
- *National services to design a planned programme of activity to develop capacity and competencies of regional and local services*
- *Establish multi agency regional AAC networks or centres providing support to local services and that are supported by national services*
- *National services to implement a programme to develop capacity and competencies of regional and local services*
- *Scottish Government will conduct an impact analysis on the transfer of national AAC services to the National Services Division*
- *Regional AAC centres/networks to have representation on local Community Equipment Management Groups*
- *Build on existing partnerships to agree priorities; policies and processes for AAC equipment provision*
- *Establish strategic links with Scottish Government Joint Improvement Team Workstreams for: (i) Equipment & Adaptations (ii) Telecare*
- *Local AAC care pathways to be agreed with regional and national services*
- *Local quality indicators to be developed and monitored.*

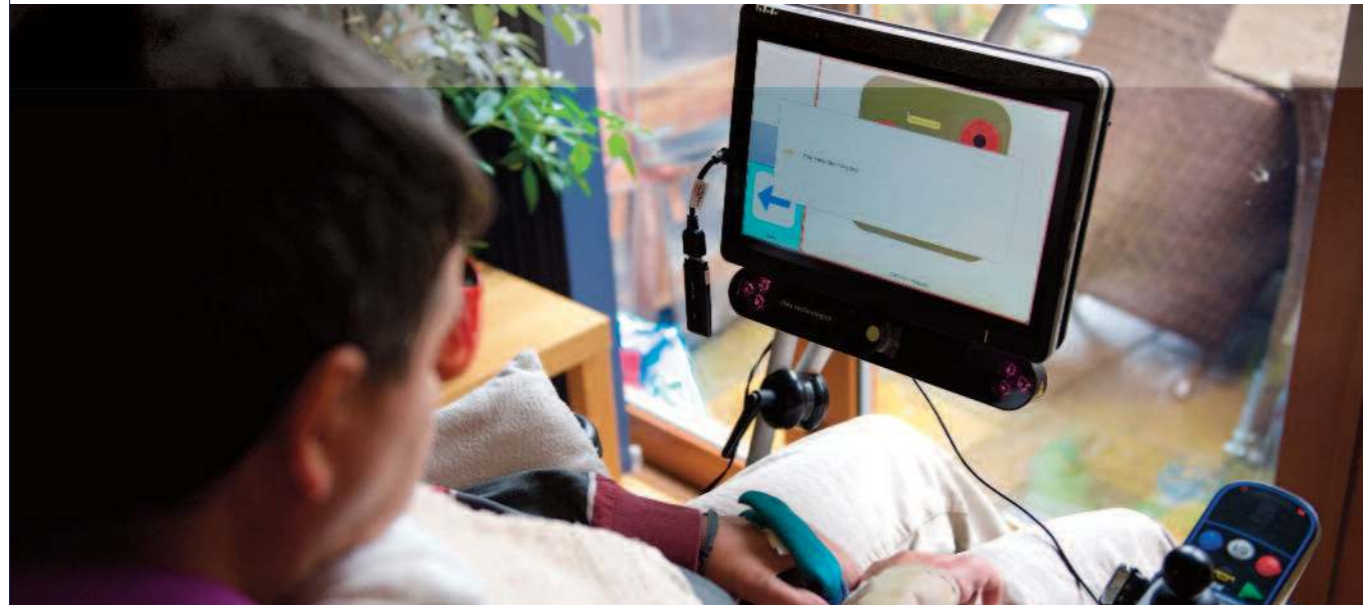
The division of the remaining £2.5million among Scotland's health boards offered little scope for investment in new equipment or services. Allocations to Orkney and Shetland would cover the cost of a modest amount of equipment at best.

TABLE 1  
GROSS SUMS ALLOCATED TO EACH SCOTTISH HEALTH BOARD FOR AAC  
OVER THE PERIOD 2012-15 FOLLOWING 'A RIGHT TO SPEAK'

Ayrshire & Arran	£184,408
Borders	£52,081
Dumfries & Galloway	£75,008
Fife	£171,199
Forth Valley	£136,560
Grampian	£239,232
Greater Glasgow & Clyde	£604,060
Highland	£157,244
Lanarkshire	£272,873
Lothian	£366,822
Orkney	£10,466
Shetland	£11,213
Tayside	£195,621
Western Isles	£15,200

In March 2014 a new technology fund was announced by NHS Scotland. Applications to it have now closed. It provided only a limited opportunity for people with MND or care professionals to apply for funding for new technologies.

In addition to Scotland's 14 NHS Boards, it has seven Special NHS Boards which address specific aspects of NHS provision. One of these, NHS National Services Scotland, has a National Services Division which is responsible for commissioning lower prevalence services on a national basis. The list of these services is much shorter than the equivalent list of specialised services in England. With perhaps as few as 120 users of specialised AAC with MND at any one time, the National Services Division might usefully explore whether these services could be commissioned on a national basis while at the same time introducing a statutory obligation to fund.



### 3.3 NORTHERN IRELAND

We received few responses to our call for evidence from Northern Ireland. The input we received suggests that there is an effective 'hub and spoke' model in operation for AAC, with local SLTs effectively supported by the specialist Communication Advice Centre in Belfast, either to identify a solution locally, or at the Centre. There also appears to be fast-tracking of people with MND in recognition of the nature of the disease.

One professional noted the same problems with slowness in agreeing funding. It also appears to be the case that nobody with MND in Northern Ireland is currently using an eye gaze device.

*MND patients who agree to a referral are fast-tracked by the regional Communication Advice Centre (Belfast) for assessment, AAC equipment loan, funding proposals for appropriate supportive communication aids, on-going and local SLT support. Not all CAC advice is direct to the patient: some patients refuse referral, however the local SLT may 'brainstorm' with SLTs at CAC in order to try to resolve communication problems. We always try to help patients locally first with existing equipment loans from within the Trust and with specific advice. There is local SLT support throughout disease progression for each patient referred with MND. The local Health and Social Care Trust can be quite slow to agree funding for an identified piece of equipment (as identified and proposed by Regional CAC) for supporting the patient's communication: the patient sometimes has died before ever getting the device; this happened with one of my patients. She died, and order / procurement of the device was cancelled or withdrawn by an unidentified person, so other MND patients could not benefit from using the same device.*

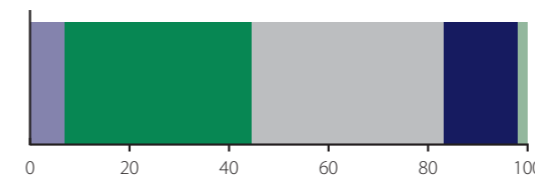
*We have a policy within our department to prioritise people with progressive neurological conditions where there is a likelihood of rapid deterioration in their condition. MND fits within this definition. In NI we have a Regional Communication Advice Centre (CAC) where we can refer clients for assessment of their AAC needs. The CAC also prioritise people with MND. If the local SLT has more limited experience of MND / AAC then he / she can access CAC services for assistance with assessment / loan periods and recommendations for funding. The CAC can also support more experienced SLTs and provide equipment for loan periods if that equipment is not available locally. The assessments by local and CAC SLT services can be carried out at the client's own home, in clinic or at CAC based on the client's particular needs. Our assessments and recommendations for AAC specifically take into account anticipation of future needs / changes in the condition and the ability of the AAC to meet those needs as the person's disease progresses*

## CHAPTER 4

### THE STATE OF SERVICES IN THE UK OVERALL

FIGURE 2:

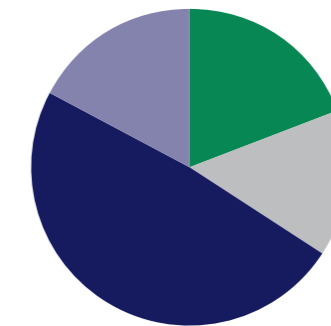
In your opinion, how would you rate the level of communication support offered to people with MND? (Respondents: health and social care professionals)



CATEGORY	%
Excellent	7
Good	38
Average	39
Poor	15
Very Poor	2

FIGURE 3:

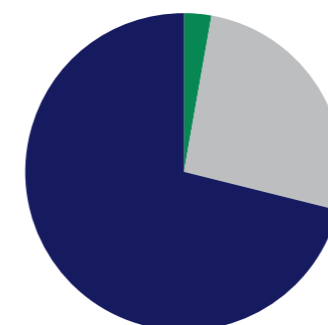
In your opinion, over the last 12 months has the provision of communication aids become: (Respondents: health and social care professionals)



CATEGORY	%
Better	19
Worse	15
No different	48
Don't know	17

FIGURE 4:

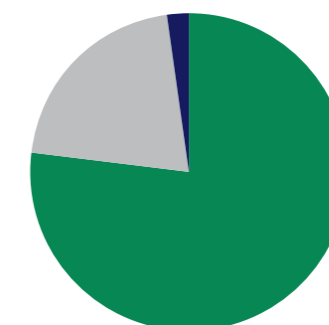
Do you think communication support is sufficiently resourced? (Respondents: health and social care professionals)



CATEGORY	%
Yes, definitely	3
Yes, to some extent	26
No	71

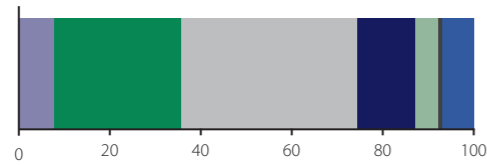
FIGURE 5:

Do you feel statutory services should provide more communication support for people with MND? (Respondents: health and social care professionals)



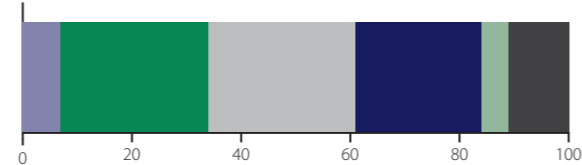
CATEGORY	%
Yes, definitely	77
Yes, to some extent	21
No	2

**FIGURE 6:**  
After you were referred, how long did you have to wait for the SLT appointment? (Respondents: people with MND)



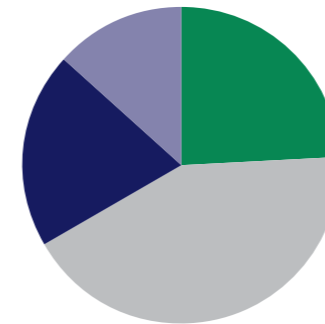
CATEGORY	%
A week or less	8
More than 1 week but less than 3 weeks	28
Between 3 and 6 weeks	39
More than 6 weeks but less than 12 weeks	13
Between 12 and 18 weeks	5
More than 18 weeks	1
Not applicable	7

**FIGURE 7:**  
From the time you were told you needed communication equipment, how long did it take to receive it? (Respondents: people with MND)



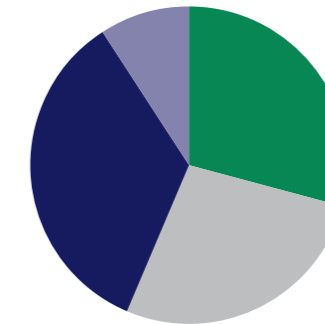
CATEGORY %	%
A week or less	7
More than 1 week but less than 3 weeks	27
Between 3 and 6 weeks	27
More than 6 weeks but less than 12 weeks	23
Between 12 and 18 weeks	5
More than 18 weeks	11

**FIGURE 8:**  
If you were provided with communication equipment, does it meet your needs? (Respondents: people with MND)

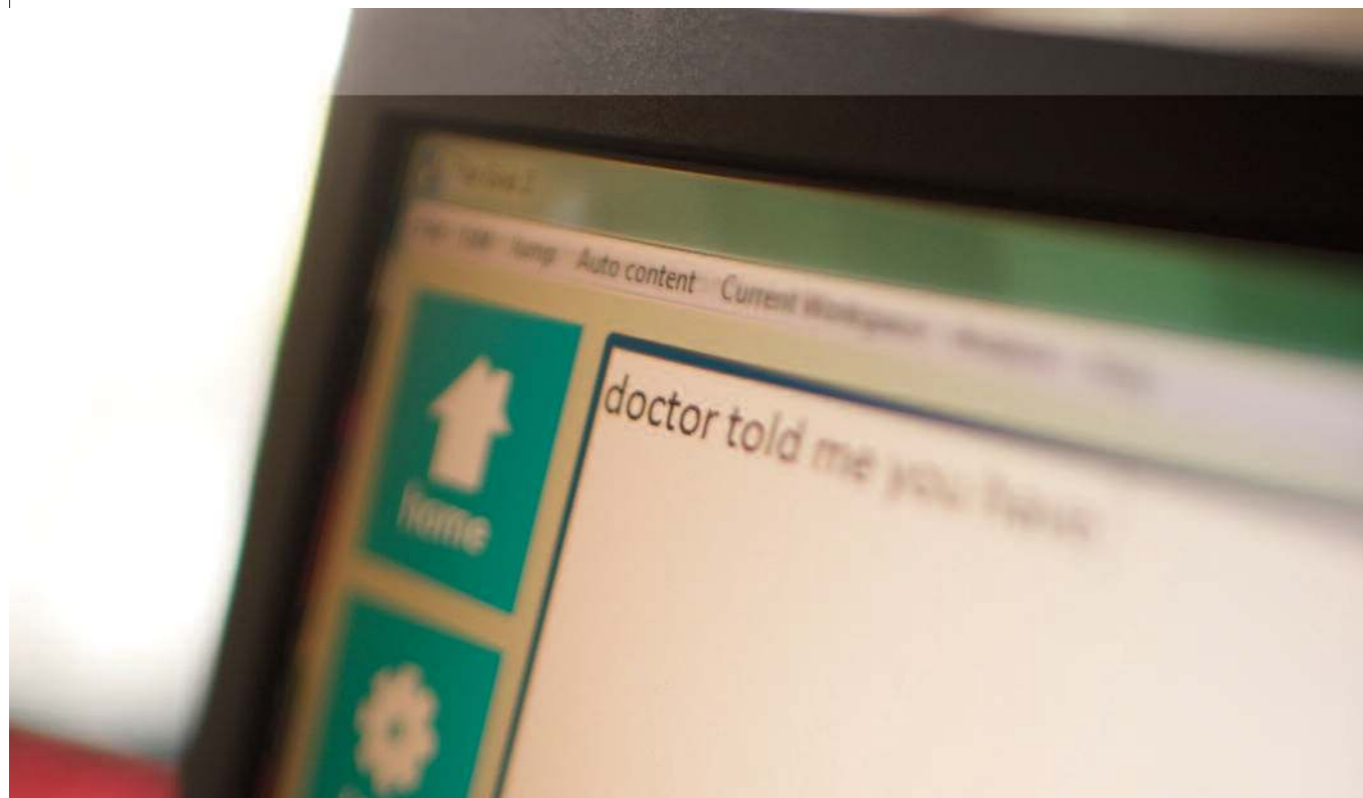


CATEGORY	%
Yes, definitely	24
Yes, to some extent	42
No	20
Not applicable	13

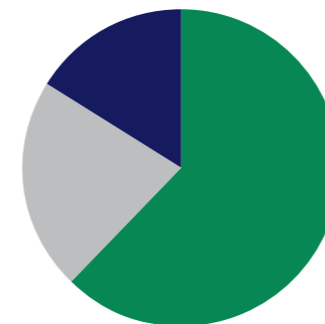
**FIGURE 9:**  
Do you feel you were offered sufficient choice of communication equipment, including high-tech solutions? (Respondents: people with MND)



CATEGORY	%
Yes, enough choice	29
Some, but not enough choice	27
Little or no choice	34
Don't know	9

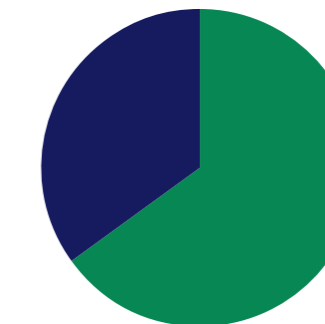


**FIGURE 10:**  
Were you offered sufficient training to use the communication equipment? (Respondents: people with MND)



CATEGORY	%
Yes	63
No	22
Don't know	16

**FIGURE 11:**  
Are you regularly reviewed to check the equipment still meets your needs? (Respondents: people with MND)



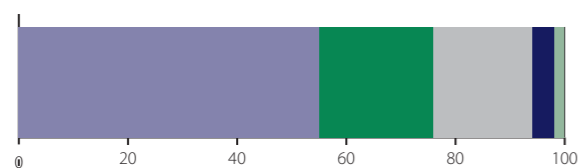
CATEGORY	%
Yes	65
No	35



A third of people with MND are not regularly reviewed to ensure that the equipment they are using still meets their needs. The reason for this was set out clearly in oral evidence by the Royal College of Speech and Language Therapists:

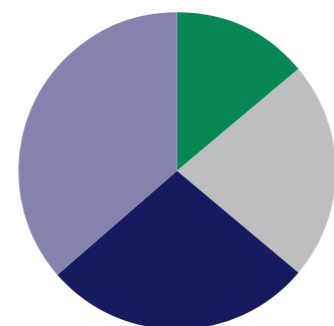
*In a deteriorating pathway, in a trajectory where somebody is likely to be dead within 3-5 years of their diagnosis, when you see their speech is beginning to go downhill, I would want someone reassessed every month at that stage. If you've seen them for a couple of months and they've reached a plateau you can extend the reviews, but I would think at least a month would be what is needed... But people often come to me and say they haven't been seen for six months or even a year.*

**FIGURE 12:**  
How far did you have to travel for your communication assessment? (Respondents: people with MND)



CATEGORY	%
No distance – it was delivered in my own home	55
Five miles or less	21
Between 5 and 20 miles	18
More than 20 miles but less than 50 miles	4
Between 50 and 100 miles	2
Over 100 miles	0

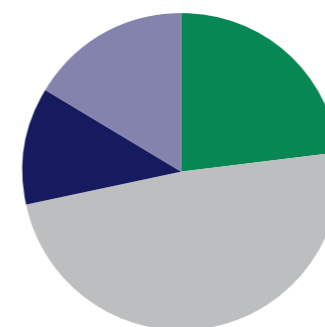
**FIGURE 13:**  
If you use a wheelchair, is it suitable for carrying your communication equipment in an acceptable way? (Respondents: people with MND)



CATEGORY	%
Yes, definitely	14
Yes, to some extent	22
No	27
Not applicable	36

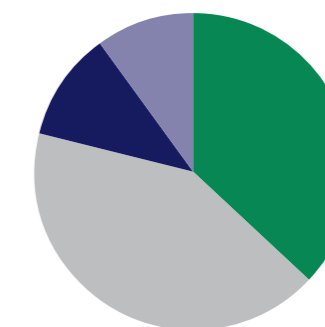


**FIGURE 14:**  
Are there links established between SLTs and other relevant services (eg wheelchair services and environmental control services) to ensure holistic assessment? (Respondents: health and social care professionals)



CATEGORY	%
Yes, definitely	23
Yes, to some extent	48
No	12
Not applicable	16

**FIGURE 15:**  
Do you feel the assessments anticipate the future need of the person with MND? (Respondents: health and social care professionals)



CATEGORY	%
Yes, definitely	37
Yes, to some extent	42
No	11
Not applicable	10

A major area of concern highlighted by submissions is whether and to what extent people with MND are prioritised for SLT and AAC within the NHS. While it would not always be appropriate to have a blanket policy that people with MND must be fast tracked – someone with limb onset and slow progression may not develop bulbar symptoms for some years – we would expect the nature of the disease to be appropriately recognised. A specialist speech and language therapists illustrates how appropriate prioritisation should operate:

*Referrals are prioritised on clinical need and risk to patients. Therefore, a patient with another condition or unknown condition may be prioritised above an MND patient if they have acute swallowing issues. MND patients are not automatically prioritised, but consideration is given to the actual presentation of the patient at the time of referral, as well as the knowledge that patients with MND may have a rapidly progressive condition.*

**BOX 7  
RESPONSES DISCUSSING THE PRIORITISATION OF PEOPLE WITH MND**

*The process of applying for funding for assessment and provision of an AAC device is the same whatever the neurological condition. However, I feel the slow process is worse for people with MND due to the rapid progression of the disease - as I said previously, people with MND are dying before they get an appropriate communication aid.*

*MND is a progressive condition, sometimes the deterioration is very rapid but often this is not reflected in provision of assessment. The majority of my patients have cancer and "the C word" opens so many doors for them, this is not the same for patients with non-malignant disease who often have to really fight for any services, not just communication support.*

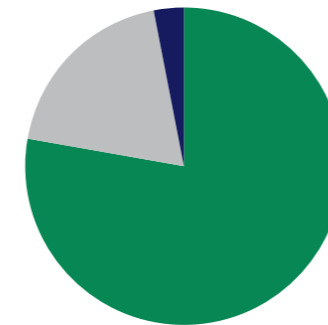
*We all prioritise MND initial assessments but not through a formal process, which would be better so that people don't slip through the net.*

*We have a well established AAC team with policies and procedures to ensure equitable access to communication aids and assessments across the county. New referrals are usually flagged to us by the MND co-ordinator to a SLT can be allocated quickly. From the point at which the individual has an open duty of care with our team they can contact us for a review at any point. Our SLTs ensure that intervention is ongoing to the point at which the person with MNDs care needs are met. usually people with MND remain open on our caseloads until they pass away. Our local MND co-ordinator holds monthly MDT meetings to discuss the needs of people with MND. None of the other progressive conditions get this level of multi-professional support.*

*Rather than it being about best possible practice in MND I think it rather highlights the lack of communication assessment and aids for other patient groups.*

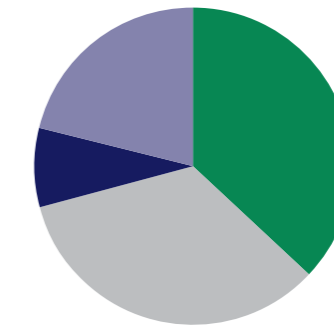
*The timing of the referral for specialised assessment is an issue, some people can be referred too early and you don't know what requirements they have. If the referral is not timely people are going to be prioritised but by then it may be too late. The skill of a professional team is to know what time to refer and having confidence in the specialised commissioning process that people will be seen quickly and appropriately and that there won't be delays in equipment.*

**FIGURE 16:**  
Do you think people with MND should be prioritised for SLT assessments because of the nature of the disease? (Respondents: health and social care professionals)



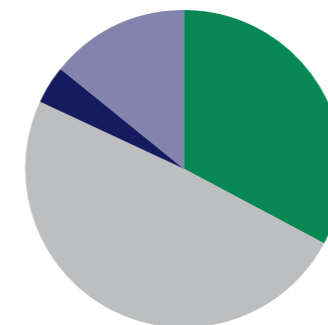
CATEGORY	%
Yes, definitely	78
Yes, to some extent	19
No	3

**FIGURE 17:**  
In your opinion, are people with MND already being prioritised for SLT assessments? (Respondents: health and social care professionals)



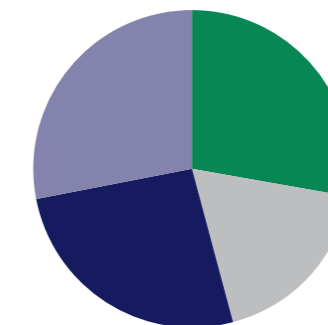
CATEGORY	%
Yes, definitely	37
Yes, to some extent	34
No	8
Don't know	21

**FIGURE 18:**  
If you feel people with MND are prioritised, is this: (Respondents: health and social care professionals)



CATEGORY	%
Through a formal protocol	33
Through informal staff practice	49
Other (please specify)	4
Don't know/unable to say	14

**FIGURE 19:**  
How well does the system meet the needs of people with MND compared to people with more stable or slower progressing communication difficulties? (Respondents: health and social care professionals)



CATEGORY	%
Better	28
Worse	18
The same	26
Don't know	28



## CHAPTER 5

## THE IMPORTANCE OF COMMUNICATION TO PEOPLE WITH MND

This chapter presents extracts from the evidence we received in which people with MND, carers, former carers and professionals outlined the effects of communication difficulties.

*Absolutely devastating for all concerned, especially mum, and as far as I am concerned the worst aspect of this truly awful disease. To watch someone daily with fear in their eyes, who cannot communicate with their family cannot be described or put into words.*

*Communication will be all my step daughter has left shortly. It means the difference between light and darkness!!*

*The speech failure occurred near the end of my wife's life. She was much weaker all round and loss of speech proved to be the 'last straw' in my opinion. She only lasted a couple of weeks more.*

*Without my ability to communicate to my family and friends, I would've died within weeks of losing my speech. I believe that my eye gaze computer has extended my life more effectively than riluzole [the only drug known to slow progression of MND].*

*It's almost impossible to overstate the impact of losing one's ability to communicate. It has a devastating effect on relationships with everyone. Of all the numerous disabilities which afflict MND sufferers, losing your voice is probably the hardest to cope with. From simple instructions regarding one's care to participating in social situations or explaining something to your kids, you are excluded from almost every aspect of everyday life.*

The socially isolating impact of MND was a recurring theme in responses. Many people with MND noted that even with a communication aid, they could not take part in everyday conversation: by the time they had prepared a message on their device, the conversation had moved on. Many reported simply not attempting to contribute as a result. Others said that they no longer welcome social contact, that they no longer go out, or that their friends and family no longer visit because it is too awkward. Communication aids were noted as being less effective in group situations, as they can be less audible.



*It's terrible and the worst aspect of MND for me. I can't join in with group conversations, even with my computer. By the time I've written my answer the conversation has moved on. However, I'm really grateful that I have eye gaze technology and can communicate with people.*

*It puts a barrier between myself and everyone else. By the time I have typed out something (even with predictive text) the conversation has moved on. Often I don't bother. If I try to communicate without my speech aid, my grunts sound bad tempered.*

*Mum withdrew within herself as her speech disintegrated. She barely spoke or communicated unless it was myself, Dad or the MND specialist or doctor.*

*Often one wants to join in conversation having got something to add, but then it is all too much trouble so one doesn't.*

The assumptions made when meeting a person whose speech is impaired include assuming that the person with MND is drunk, is deaf, or has a learning disability.

*It's tiring and frustrating trying to be understood. It's also upsetting for family and friends when they struggle to understand. You don't feel part of social occasions and although people are generally very kind you feel isolated. You start avoiding social situations because you can't stand the pity. People tend to speak to you like you have learning difficulties.*

*It is so frustrating trying to get my point across sometimes. I miss out on a social life because I can't join in conversations very much. One to one isn't too bad as I have Speak on my iPad but in a group situation the iPad voice gets drowned out. People think because you can't speak you're deaf as well.*

*My speech at first was slightly slurred and people thought I had been drinking alcohol which in itself was bad and knocked my confidence.*

*When I am out, together with walking problems, my voice gives people the impression I am mentally handicapped. I can still drive, but carry a letter in my car from my Neurologist in case I am ever stopped by the police, they could think I am drunk or on drugs.*

Many people report feeling that they or their loved one has lost part of their personality because they can no longer speak with their own voice.

*It is dreadful. My speech is all but gone now and I rely on iPad with Predictable [an app] and countless clipboards, pads and pens in each room. I was always a very busy professional lady who could cope with anything and everything but now I have to rely on my husband and I feel as if I have lost a huge part of my personality.*

*In 2004 I lost the voice that had been with me for 72 years, it was devastating. When, a few months later, I was diagnosed I went into a form of depression for 2 years although I don't think others were aware of how I felt. Everybody could understand what I was saying but it wasn't my voice which had always been an integral part of my being. I had always been proud of my ability to speak clearly, using my voice to express joy, sorrow, praise, displeasure, dislike and love. I believed it to be my greatest asset and it had served me well for forty years as a teacher and headmistress.*

*It's terrible. You grieve for the person as they disappear before you - speech is fundamental to so many of us and who we are, and not being able to communicate at a time of such great emotional distress, knowing that you are also facing a terminal illness, is devastating.*





The impact on families was regularly reported to be substantial, with communication difficulties leading to bad temper and permanently changed relationships.

*My family cannot cope with my loss of speech so they tend to stay away now as it makes them feel uncomfortable. My ten year old son cannot cope with it at all and now lives with his father. It has affected his personality and behaviour.*

*My daughter has never heard me speak normally as I was pregnant when diagnosed. I cannot express the frustration I feel trying to explain to someone who doesn't understand me what I need. It frequently ends with me in tears!*

*I cannot answer the phone now, even my wife cannot understand me. This can lead to frustration and arguments. [...] Devastating, I am ignored and no longer the head of the family.*

*Even with communication aids such as eye gaze systems, communication is still hugely compromised. Eye gaze is undeniably an incredible means of communication but it's certainly not conducive to flowing conversations. Ten-year-old boys aren't very interested in waiting around while you laboriously construct a sentence, especially if they think it's finally going to read 'no Xbox for a week!' Trying to teach something using eye gaze or trying to discipline using eye gaze is at best frustrating and ineffective respectively.*

*My husband has no speech at all any more, and cannot write, sign or gesticulate as his whole body is pretty much immobile also now. You can imagine his frustrations in trying to communicate even the simplest thing... We have a daughter, aged 9 on diagnosis but now 13, who has seen her dad disappear gradually from the big, capable man that he was [...] For a young girl to frequently hear her dad sobbing with frustration at not being understood, or for me to witness his anguish at not being able to help his daughter with a simple problem, is unbearable. We both feel that our daughter's ability to communicate with others herself has suffered as a direct result of this aspect of the disease.*

There are also practical implications of losing a voice. Use of a telephone becomes impossible. It can be hard for a person to communicate their care needs. These difficulties can in turn compound the strains placed on relationships by MND.

*Finances, business telephone calls were all taken care of by my husband, now I am having to take more responsibility for those telephone calls and I am very aware that my husband feels unhappy about this.*

*I find that when I am in my chair with my tablet in front of me all is fine, but if I am in the shower I can't get across what I am trying to say. Eg if my carer has me around the waist but I need my weight adjusting I get very frustrated and no one can understand me.*

*Some services connected with MND allow my wife to speak on my behalf but some domestic industries insist on me phoning them rather than email, which is impossible. [For] one company I [filled in] an online form requesting an email address [and] explaining my form of MND and all they did was to send me a phone number.*

*I am unable to use the telephone and so could never call for help if I needed. Shopping is still possible as it is only my voice that is affected not my limbs and with self-service checkouts at supermarkets I don't have to talk to anyone.*

*Voice-activated services like HMRC, BT and Vue cinema are a nightmare. Call centre operatives assume I am drunk and make excuses to end the call and persuade me to call back.*

When a person is admitted to hospital, they are likely to encounter substantial problems if they cannot communicate. These accounts of hospital admissions were among the most harrowing items of evidence submitted to the inquiry.

*Recently I had to go into hospital where I couldn't communicate with the staff because I didn't have my eye gaze computer with me. I couldn't tell them when I needed the toilet so did it all in my bed. I was choking and couldn't press the bell to get help and nobody knew I was in trouble. I needed medications at specific intervals to stop my muscles going into spasms, but couldn't tell anyone so just went into spasms and pain. In short, not being able to communicate with the hospital staff made me want to die because that was easier than lying in bed in pain and choking. Simply put, my eye gaze computer keeps me connected to life.*

*The greatest difficulty was when he was in hospital on a general ward and no one was aware that my brother had trouble with breathing. This meant that he could only give short answers. Eg Would you like a cup of tea? He would say no and then they would pass on to the next patient. They didn't give him time to get another breath and ask for thickened water. The staff nurse, when starting to complete the financial assessment stated after looking at the first question that she had no problem with understanding or communicating with him, scoring him incorrectly and moving on to the next question. It was only because I insisted on being there for this assessment that I was able to interrupt and get a true picture recorded.*

*My mother had bulbar palsy MND and lost the use of her voice, without the Lightwriter provided she was limited to communicating with others. Before she got the Lightwriter she was admitted to hospital, unable to speak she couldn't communicate with staff when a family member was not present. I got some blank postcards and wrote some phrases on for her to use. However, this proved as frustrating as being unable to speak as the staff were always too busy to wait for her to find a card to reply. Also as she was unable to swallow, she was unable to eat hospital food, they persisted in bringing her trays of food and even shouted at her a few times for not eating!! When she showed the card saying unable to swallow, talk or eat they just shrugged their shoulders and left.*

*My husband spent the last couple of weeks of his life in hospital without any communication. He could only write notes. He started with a drop foot August 2013, lost his voice by the end of January 2014 but wasn't diagnosed with MND until 24th June 2014. Admitted to hospital 29th June 2014, unable to swallow where he died 9th July 2014. He was treated shockingly and it has had a devastating effect on me and my family. We never received any support before or after and are still finding it hard to come to terms with what happened.*

*I could understand my husband, but problems arose when he went into hospital for an overnight procedure. He could not converse with the nursing staff, for instance to explain that he couldn't hold a cup or knife and fork so needed help, or to tell them that he needed his nebuliser so he could walk to the toilet. When he came out of hospital after a week's stay (discharge was delayed because they said he had caught a hospital bug) he was dehydrated, emaciated, and traumatised.*

*I worked with a gentleman in [redacted to protect confidentiality]. His communication needs were utterly ignored by ACT, the NHS assessment service. He died with a laminate card at the end of his bed. He was unable to describe discomfort, medical needs. He was utterly suicidal. If I did not work for a 'vested interest' I would have recommended that the family sue the NHS and specifically the therapists at ACT.*

The loss of a person's ability to communicate also exacts a heavy toll on those who care for them. There is the major burden of anxiety in trying to ascertain what someone wants or needs, and at times being unsure if one is right. Also commonly reported was a sense of isolation and loss, and missing being able to talk to their loved one. One former carer simply responded to our call for evidence on this subject: "Too distressing to write about this."

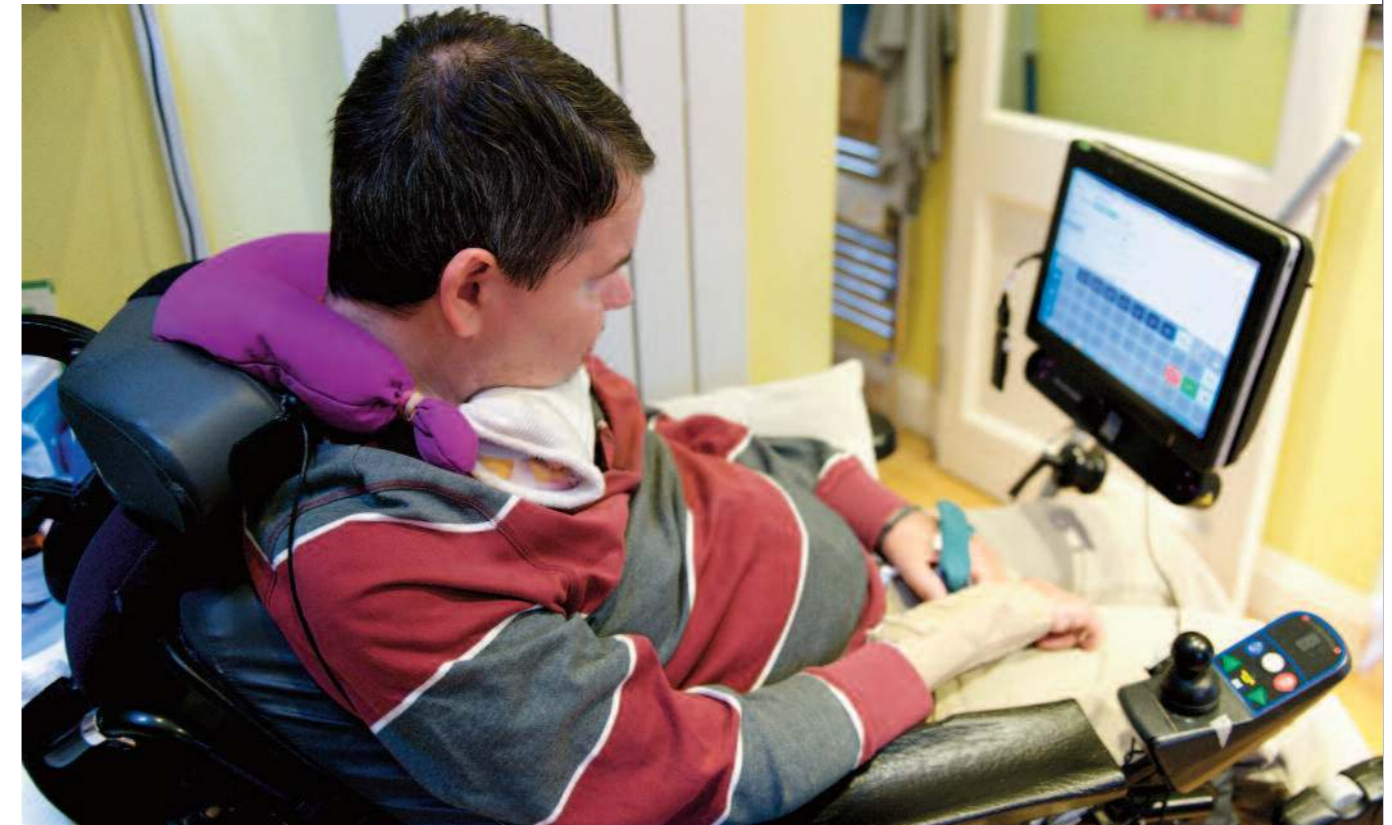
*Very tiring especially at the end of my husband's life when he was very ill with bronchial pneumonia and having hardly any speech, trying to decipher what he was saying at 2.30am when you had been on the go for 20 hours and very tired. It was frustrating all round.*

*My wife is stressed as she finds the loss of chatting very lonely, which is how I feel.*

*It is very isolating. Although my husband writes everything down he finds it difficult to contribute to the conversation when with a group of people. I also find meal times difficult when it is just the two of us and the silence is deafening!*

Communication difficulties were also widely held to present particular challenges when a person is at or approaching the end of life. Respondents commented on the challenges of making decisions, or changing decisions already made, about care preferences or the withdrawal of treatment. SLT respondents saw the solution as being improved therapy and provision of aids, while palliative care professionals emphasised the importance of making plans and decisions in advance. Both are important, but that high quality communication support is essential right up until the end, as people can and sometimes do change their minds on important aspects of treatment and care. Some respondents expressed the view that palliative and end of life care professionals can struggle to meet the needs of people with communication difficulties, although others felt that they had substantial expertise in this.

*A person who wanted to stop using his ventilation had great difficulty in expressing his wishes. Medical staff needed to know that he really understood the fatal implications of this action. Over several days he tried to say what he wanted and why... It is so much harder to have these conversations when you can't talk and are getting very tired. The staff were very patient and understanding in this case but made me realise the importance of early conversations discussing future plans, and how this does not often happen.*



*A current patient was diagnosed very late into the progression and hence not referred to speech and language therapy till very late. She was moved up the list as a priority but still had to wait - she unfortunately had already lost the ability to write / use finger typing - this has meant she is unable to communicate her advanced plan wishes or ability to write a 'Decision to refuse treatment plan'. As this lady has full capacity it is unfair that the opportunity was missed to allow her to voice her wishes in future planning.*

*A patient who was admitted to A and E could not communicate and I felt pressure was put on him by the family to have a tracheotomy and he lived a very miserable rest of his life with 24/7 care by two nurses, and had no quality of life. Maybe if he had been able to communicate better he would have had a more peaceful end.*

*It is extremely challenging to talk to someone about the complexities of their 'dying' when communication is compromised. One patient painted me a picture - it was the most effective way of expressing her misery.*

*Lack of communication for one gentleman led him to experience high levels of anxiety as he was not able to direct his care. This really was distressing as he would become upset and 'howl' for hours. Sad and upsetting to witness but frightening and terrifying for him. The memory of these scenes will remain with me forever.*

*A patient who had previously been very clear about her wish not to have a PEG feeding tube inserted was having increasing difficulties with swallowing. Her daughter was pushing for her to have a PEG fitted. The patient's speech was very unclear and she was no longer able to use writing to communicate. She did not have access to a communication aid. She was attempting to tell her daughter that her wishes remained the same, but the daughter was interpreting her speech differently from the team present. Eventually the daughter accepted her mother's wishes, but the conversation was very difficult and upsetting for the patient and her daughter.*



*There is not enough speech and language provision within hospices/palliative care services. Staff are relying on families to help them use the aids and remembering to charge the devices etc can be missed.*

*The key at present (whilst there are no totally effective communication devices available) is to ensure the person with MND is referred early enough to palliative care to allow advance care planning to happen once the palliative care team have built a rapport with the person.*

Care professionals gave mixed views on the usefulness of high-tech communication aids, some saying that fatigue and other interventions (eg face masks for non-invasive ventilation) rendered them less useful, but others saying they had seen them used to good effect right up until the person died.

*Most of my patients are using eye gaze communication systems at end of life pretty successfully although fatigue does have a significant impact on this.*

*One patient with whom I worked was about to use eye gaze with which she had become adept and comfortable, however as she weakened and became ill in other ways, she just didn't have the energy to manage the concentration and the simple devices with which she was familiar became more appropriate. She was very disappointed that she couldn't use it and that was a bitter blow to her and her family.*

*I have seen several people using communication aids very successfully in their last days.*

Numerous respondents cited cases where a person had been able to communicate at the end of their life, and this had contributed substantially to their ability to die with dignity.

*I recently went to a funeral of a person with MND. He had written an incredibly moving farewell self eulogy on his AAC. He stated he felt content as he had been able to manage his own death in a dignified and controlled way.*

*They were able to get all their last wishes down and wanted to write a letter to off load their feelings. Explaining their feelings in a verbal letter and expressing about how they felt about their last few days helped them die in peace and gave the family a lasting memory of the bravery and peace of their loved one.*

*Our lady with MND who was fortunate to have access to the eye gaze took a deterioration 5 weeks after the equipment was provided. Those 5 weeks were so empowering for her as they enabled her to re-engage with her husband, four sons and her family who lived in Italy and Hong Kong. She described them as 'life changing'. Very humbling!*

*I once personally spent an hour with a chap near the end of his life, he was desperately trying to tell me something. I was concentrating so hard. He was using a device to communicate by moving his toe on a switch to type. In the end his message was to say: "stop being so serious." Too often when someone has a communication difficulty we forget normal chit chat and just assume that communication is about want and need.*

## CHAPTER 6

# HOW PEOPLE WITH MND EXPERIENCE DIFFERENT TYPES OF COMMUNICATION SUPPORT

The responses to our call for evidence generated a wealth of information about the experiences and views of people with MND with regard to different types of communication support.

It is not our intention to attempt to identify how effective communication support services should be operated: there are numerous items of guidance in existence already. We believe that NHS England's service specification is a high quality blueprint for specialised AAC. There is no definitive guidance from the National Institute for Health and Care Excellence on the topic – we hope that communication will be fully addressed in the clinical guideline that NICE is currently developing.

We believe that a well-resourced specialist communication technology centre is an essential element of high quality support. This does not mean that everyone has to be seen in the centre, but it does mean that both equipment and advice from specialists for local SLTs must be readily available. Assessment should ideally involve both a specialist and a local SLT, and be integrated with assessment for other services such as environmental controls when appropriate.

Assessment should focus on the individual's needs and abilities, and not on whether they can use a particular item of equipment. It is not desirable for a representative of an equipment manufacturer to be a person's sole source of support, as one interviewee from a technology company noted in evidence to the MND Association: "SLTs should be the independent health professional in the process, it shouldn't be us or another company, I think it is important that someone else needs to be there."

Specialist centres must be able to purchase and recycle equipment in a timely way.

The rest of this chapter will outline the views given by people with MND on different types and aspects of support (see Appendix Two for an outline of different items and terms).





## 6.1 SPEECH AND LANGUAGE THERAPY

Perhaps inevitably, evidence from people with MND focused on negative experiences of speech and language therapy, with more positive aspects perhaps left unspoken. Themes in these responses included SLTs who were not expert in AAC or could not navigate the system to secure the support a person needed, or a focus on swallowing problems at the expense of speech.

*My speech therapist said she doesn't do technology and [I have to] find out myself but makes barriers to refer.*

*Our speech therapist only cared about swallowing. She did nothing for speech, however the occupational therapist was fantastic. [...] Having a multi-disciplinary team meant that a person with the knowledge and the interest (the OT) picked up for the inadequacies of a newly qualified very quiet speech therapist. This is fine by me, as the multi-disciplinary approach means that everything is covered by someone. This is not just a speech and language problem. For example because it was tackled by an OT one piece of kit covered making phone calls, changing TV channel, turning the lights on and speech.*

*The assessments were frequently too long so that Jim became overtired and distressed - assessment of his swallow needed to be separated from the assessment for communication devices - this never happened. I felt the SLT becoming irritated when Jim laughed, yet it was an involuntary laugh - it was part of the emotional lability that frequently comes with MND - despite my attempts to explain this it made no difference. For approximately one year before he died Jim was locked in - left with no way of communicating, to some extent this may just be that there was nothing he could cope with but I do wonder seeing some of the devices available now whether more could have been done.*

*My speech and language therapist is great, but she is not getting support from her employers the NHS.*

*SLT provision very poor at present in our area - swallowing assessments always prioritised over communication which is probably right but due to staffing shortages communication often overlooked. Clients should not be discharged and require re-referral as this creates further delays.*

While it may not represent orthodox speech and language therapy, this submission shows an effective approach to communication for one person with MND.

*We felt very useless, and failures at times, especially when after 10/15 minutes of trying to get a word we had to apologise to Dad and say we couldn't understand. I designed a game to try and relieve the pressure, so if we got a word like dressing gown (Dad pointed to it) I'd say right Dad I'm going to say three words that are to do with it. Cold, move it somewhere else, tissue from pocket. See if we got any response to that. If we did then we'd keep going with the three words and eventually get the story or what Dad wanted. An example of this was when he was in hospice he kept looking at the fire alarm on wall. So using this technique we found out that it had gone off in the middle of the night and there had been a lot of nurses around BUT also that he had been frightened as no one had come to see him (in a room on own with no speech or ability to move). We actually pointed this out to the staff who were amazed that Dad had told us. As you know with MND it doesn't make patient daft, they are just as intelligent but just unable to communicate.*

## 6.2 IPADS AND OTHER TABLETS

Smartphones and tablet devices emerge positively from the evidence, although the person with MND needs to retain hand function to use them. Some older people find them difficult. It was suggested by one witness that speech and language therapists are quick to deploy them because they work mainly with children, among whom they are well used. Nonetheless, those who use them offered almost universally positive comment on them in written evidence.

In some areas, the NHS is reluctant to fund iPads for fear that recipients will use them for things that are not obviously addressing their health needs. Some NHS bodies appear to be providing them with all non-communication functionality blocked. We caution strongly against this approach. We have already seen how devastating for a person's general wellbeing the loss of a voice can be. A device that counters this directly and enhances the person's general wellbeing by opening up new possibilities socially and logistically must be seen as meeting their health needs as a whole. At the centre of the currently fashionable 'House of Care' model for long-term conditions, for instance, is 'person-centred, co-ordinated care'. We would suggest that the use of iPads and other tablet devices for people with MND is a good example of how to provide this.

Widely used aspects of mobile communication technology often acquire a new significance to people with MND. Predictive spelling clearly makes life substantially easier, and simple text messages can be extremely useful in the absence of a dedicated app.

The tablet devices referred to are nearly always specifically iPads, as opposed to potentially cheaper Android or Windows-based devices. We are unsure if this is a result of the generic use of the term 'iPad', or if Android and Windows apps are not available to the same standard as Apple apps. Some respondents suggested that choice on other platforms is more limited.

*I was looking for apps for my tablet device; it seems they could help if I had an iPad but I have an Android tablet so we were limited to what we could use.*

*I have an iPad with the Predictable app. It works fine, but the iPad cannot be with you all the time. I did buy the computer and app myself and would like an iPhone which Predictable also works on. The problem is Apple products are so expensive compared with Windows and you cannot get any good deals, wherever you buy them the price is the same.*

*I was provided with an iPad with predictive speech. Initially I tested a Lightwriter and an iPad and chose the iPad as being slightly more in keeping with the modern world where so many people have iPads and so I would not be out of place. Not having a voice is extremely difficult and I believe the iPad with predictable speech is probably the latest gadget on the market. Until someone can come up with a lighter quicker way of communicating the iPad is the best in my opinion.*

*My mother found it extremely hard to use her iPad as a device to communicate. We have had consistent problems with the applications which has meant that she has had to abandon this way to communicate. Whilst this seems an excellent idea for someone of my age (mid 30s) it is so much harder for someone who is not IT savvy.*

*We were partners in a loving relationship. The ability to communicate was key in keeping us able to live a "normal" life for the two years right up till she died of respiratory [failure]. She did not want to be regarded as an object, but as a person. In the early days of her MND we went on holiday to the Canaries. On several occasions when I went to fetch her meals from the hotel buffet, I came back to find her chatting away enthusiastically to the Spanish waiter, using her iPad voice app! It was probably (apart from the lift we bought) the most important thing in her life.*

*She was given a piece of equipment, I think it was called a Lightwriter, effectively she typed words or phrases and a robotic sounding male voice (like Hawking) would speak the words, it was a huge piece of kit, bulky and ugly, the voice was terrible and did nothing for her confidence. We then went out and bought her a first generation iPad that had a free app called "Speak It" that was 100 times better!!!*

*Many therapists are now focussed on iPads; they are good for some people, but when it comes to using switches with iPads they slow down. I am not sure what the exact solution is, but we need to make people aware that there is more than just the iPad as a solution. Because much of the work of speech and language therapists is for children, they tend to be much more familiar with the children-oriented programmes than those for adults, and they tend to be recommending the same thing as they do for children, which aren't always the best for adults.*

*I have Prosser equipment which I haven't used yet but will do; I was given an iPad about 12 weeks ago that is locked for speech only. It took the ST department five years to get a few and I was the first guinea pig, and have the iPad for 12 weeks only and it has to go back. It has been invaluable as I had an accident and was in hospital for eight days. It meant I could explain to doctors my needs, my feed etc. I use the iPad daily with my carers and would be lost without it.*

*iPads have been great for lots of patients and less stigmatising. Weirdly, although they are cheaper than Lightwriters, commissioners seem to find funding them offensive, as "they might use them for other things!" [...]The Predictable app seems particularly useful for people with MND, [so long as] literacy remains intact. The new Lightwriters are also good for people who need something more straight-forward and robust - the predictive element is much more sensitive and people can give sentences with far fewer key strikes / scanning clicks.*

*Provision does vary, I did encounter a commissioner who thought the provision of iPads would cause a scandal if the Daily Mail caught wind that the NHS was handing out iPads to patients.*

*I have noticed a big change in use of iPads with the Predictable app usually. At one time, everyone had a Lightwriter as that was all we had. iPads are very effective for many people, more achievable in terms of funding (or people have them already) and are much more socially acceptable - lots of people sit in the pub with an iPad so for a person using it to communicate they do not stand out.*

*It is harder to support ongoing access to [tablet] devices as the disease progresses however as they are not designed with disability in mind. The dedicated communication aids, such as the Lightwriters, are still more appropriate for many of our clients with MND but I am increasingly experiencing people rejecting them due to their size and weight. The availability of eye gaze has transformed end of life care for some people with MND. However, eye gaze requires a huge amount of clinical time to set up and establish as an effective means of communication and therefore remains appropriate only for a very small number of people with MND.*

Beyond simply the nature of the hardware, the accessibility of social media was reported as a substantial help to people with MND.

*Knowing that I may lose my voice I am actively learning how to use social media eg Gmail, Facebook and Twitter. I am also leaning how to maximise all options on a new tablet purchased by me purely to prepare for a future without speech.*

*It's ironic that I was a very quiet person and now when I need to talk I find it difficult, I communicate a lot on Facebook and my friends say it's like how I used to be.*

### 6.3 LIGHTWRITERS

By contrast with iPads and other tablets, Lightwriters attracted very few unambiguously positive comments. Some respondents were former carers whose loved ones had used them some years ago; others noted that some older people found the relative simplicity of the Lightwriter preferable to a tablet; while some SLTs submitted that they have a continuing role in communication support, albeit sometimes only as an effective stop-gap.

More common, however, were submissions that criticised them as heavy, outdated, and equipped with unattractive voices. Numerous respondents recounted having tried a Lightwriter first, then switched to a tablet which they preferred.

Survey results from the MND Association backed up the more negative impressions. 23% of respondents indicated that the Lightwriter did not meet their needs – the worst score of any item of equipment.

In responses from professionals, it was often noted that Lightwriters are somewhat easier to obtain within the NHS than tablets, despite being both less well-regarded and more expensive.

*It was a heavy, slow Lightwriter*

*I was supplied with a Lightwriter, which I found ungainly and robotic. Difficult to carry around and slow to use.*

*I found the keyboard non intuitive, partially the space bar being moved to the side. There was also a comprehensive instruction manual that I found intimidating. This increased the anxiety I felt in using the machine and I didn't persevere.*

*I was loaned a light-writer which is very heavy and as I have problems with my spine I can't lift it. I could lift it initially but not carry it with me on my scooter. I live alone.*

*Approx October 2007 my father was given a Lightwriter and it was brilliant for him to communicate with, he called it his lifeline and it didn't leave his side. He nicknamed it Archie after Archie Andrews, because it gave him a voice.*

*Because my husband has good use of his fingers, the provision of a Lightwriter is the solution for his communication needs at present.*

*It was a typewriter so hard to use with MND – small keys that needed some strength. It had a small screen so a whole sentence could not be seen on the screen. The voice was artificial American in sound which very much upset my young children, but it helped in the short term.*

*The equipment given was over 20 years old, very bulky Lightwriter, smelled and was dirty. When I enquired about the updated model, it was not available in our local area.*

*Over the last 5 years (ie since I have been a consultant) I have seen the dwindling of Lightwriter machines. A number of the people with MND that I looked after did not want one, as they felt they would be cumbersome and difficult to use. I think the use of tablet devices with predictive text (eg iPad mini, Galaxy etc) have been lighter and easier for patients to use, but there doesn't seem to be a systematic way of getting funding for these in the way that it seemed to be part of a care pathway to get a Lightwriter. My understanding is that iPads are cheaper than Lightwriters, so I do wonder if they have not become offered in the way that Lightwriters were, is because they are not exclusively a medical device!*

*Recently iPad apps have been quite helpful. Lightwriters still remain helpful.*

## 6.4 POOR EXPERIENCES OF EQUIPMENT GENERALLY

Some respondents gained little or no satisfaction from any communication aid, for a variety of reasons.

*I have been provided with a system called EvoAssist, which is rather crude by current communication standards. It is NHS funded and costs charged by the supplier are extortionate to the point of obscenity. The in-service support is very poor.*

*It needs recharging too often which leaves me without any communication.*

*I believe that most of the communication aids are almost useless and most are used briefly at first then not used at all. In a quiet room they can work if the people listening have the time to tune their ears into the synthetic speech. I found I was invariably typing a message but rather than speaking it I would pass the device to the person who would read it. Quite simply I had a rather expensive substitute for a paper and pen.*

*My Mum is unable to use the Lightwriter (too complicated) Also unable to use an iPad (although we would have had to pay for this.) Mum has no IT skills and at 75 feels unable to learn new skills. Speech is now very bad. There does not seem to be anything suitable for her needs.*

*The speech therapist provided alphabet charts/similar, which were, in my husband's case, a very slow means of communication. She did try eye gaze technology. This would have been very expensive - about £10,000 in 2010. This would have been good to try on loan, but not to buy, as my husband's illness affected his brain function, and we were not sure the equipment would be a longer-term solution.*

## 6.5 GOOD EXPERIENCES

Many respondents reported substantial benefit from the use of more sophisticated communication aids. A small selection is included here.

*The Servus system (with the tablet and the Tobii Eye-gaze add-on) has made my wife's life liveable by giving her a voice and a lot of independence as she controls the TV through it. Absolutely invaluable. Everyone should know about these aids and everyone should have access to them!*

*The communications team gave many options and trialed them with me before I decided on headmouse as the most user friendly equipment for my needs now and in the future. I have ongoing contact with the team who work to adapt my equipment as my needs change.*

*I am able to communicate sufficiently. The SLT was involved when my speech deteriorated. I got the equipment at point of need because they asked for eye gaze assessment half a year before I needed it. That was just in time.*

*My husband cannot move any of his limbs so he has an eye gaze. With this piece of equipment he can keep in touch with friends through social media and email. He can also access the internet for watching any programmes/films, shopping online. He has the environmental package which enables him to turn lights on and off, change television programmes and importantly get my attention with the alarm if I am elsewhere in the house. Without this communication device my husband would be so alone and lose the small amount of independence that he has.*

*Boogie boards seem to be taking over from pen and paper and are more convenient particularly when out and about.*

## 6.6 POOR EXPERIENCES OF EYE GAZE

Eye gaze technology has opened up communication options for people with MND, but not everyone reported positive experiences.

*We were then provided with an eye gaze system. The sales rep from the company tried to set it up and pretty much failed. Neither us nor the company rep could calibrate it properly, and so after several attempts it was left unused and sent back shortly after. I was astonished they were charging the local health authority around £15,000 for this equipment, when it seemed little more than a windows laptop with some infrared devices attached.*

*The best would have been eye-gaze, but I have a breathing mask which interferes with communication via the eyes. I use a thumb-touch system at present.*

*Provided with Tobii eye gaze attached to a monitor which means I can't use outside home.*

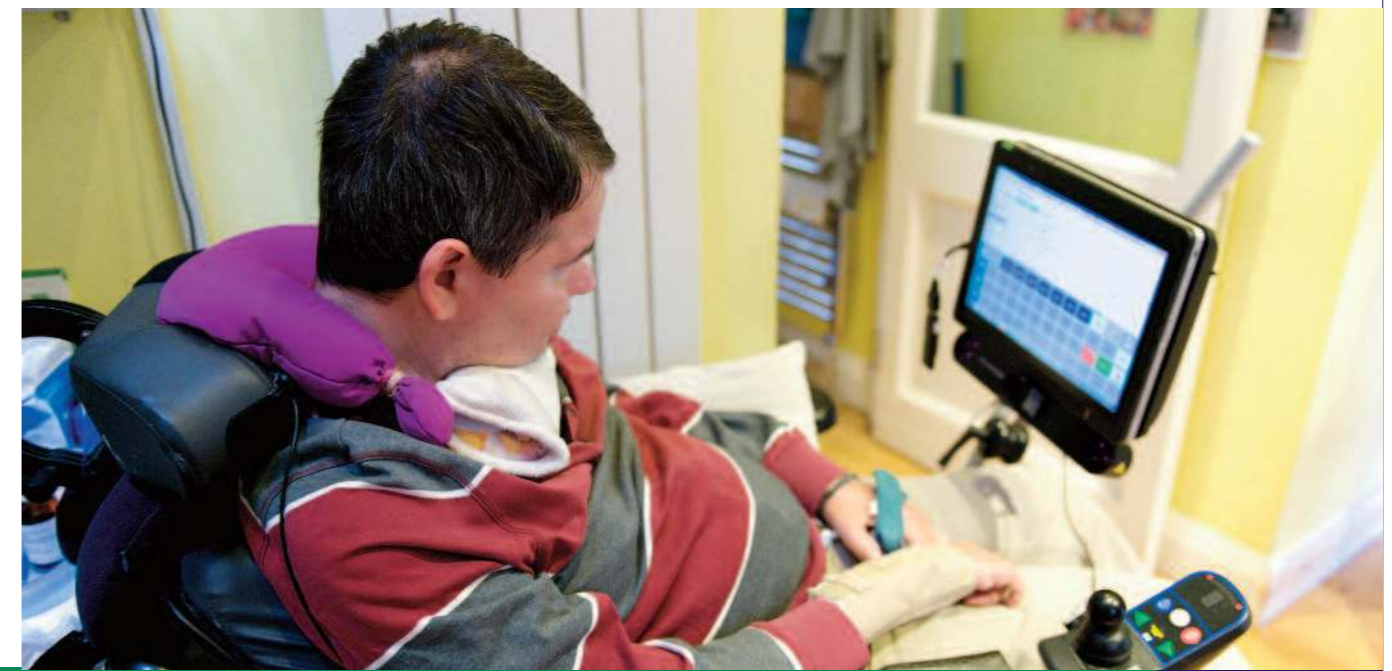
*Eye gaze system which, while slow, does enable full communication if the "listener" is patient. However, there are bugs in the operating system which can mean the machine crashes randomly, leaving the user without communication. There are also issues with low light levels when the eye gaze system cannot track the retinas. This is also a problem where someone wears glasses or has early cataracts.*

*My husband had an Apple Mac not a PC; none of the equipment supported a Mac. When he realised he could not access his computer anymore, for him the lights went out.*

*Eye gaze would be great if it was cheaper and easier to set up. The after sales was not good for my patient and each new piece of equipment needed to make it work was very costly. They also charge for demonstration and follow-up teaching.*

It may be that some of the negative points about set-up complexities, or the limitation of the equipment are being addressed as the technology develops. At least one respondent noted progress in respect of set-up compared to how it used to be:

*The ease and speed with which eye-gaze systems can now be configured to meet individual requirements is incredible*



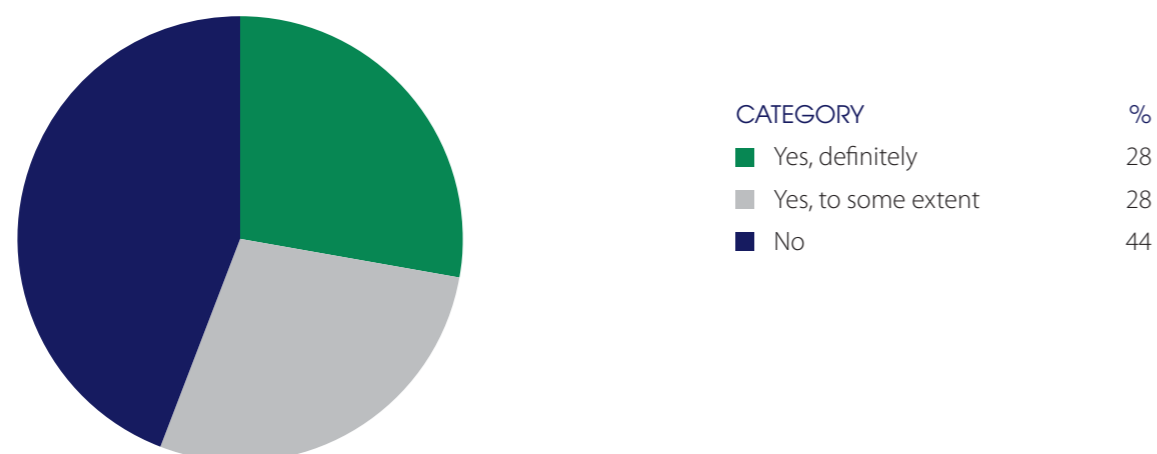


## 6.7 COMMUNICATION AND COGNITIVE CHANGE

A common feature of all communication aids that use text is that they rely on the person using them being literate and remaining so. Cognitive impairment can interfere with a person's ability to use such methods and devices. More than half of the carers and former carers who responded to our call for evidence indicated their loved one had experienced cognitive change.

FIGURE 20:

Has the person you care/cared for experienced cognitive change? (Respondents: carers)



*It was a speech typewriter. My Mum used it a little but was very frustrating for her because she lost the ability to spell, therefore it was very hard to understand what she wanted to say.*

*At first it seemed OK (Ruth didn't like computers), but she seemed to be giving up, until I read that MND could affect cognitive thought. When I realised that, I deduced that she was struggling to spell the words in the GRID, so I got the SLT specialist to show me the picture version and I programmed that to be suitable for Ruth's needs and she was off and 'speaking'.*

*As we knew that Jim's speech might be affected we talked a lot early on, but it was so difficult when the FTD put in another barrier - he would write things on the Lightwriter that made no sense, yet it was clear he thought they did. It is hard to say how much this hurt and how difficult my daughter and I found it. Jim was funny and caring - and then he couldn't communicate - we just don't know how this added to his suffering.*

*I had a patient last year with a fronto-temporal dementia who was an IT specialist before he developed MND. As his dementia progressed, it became increasingly difficult for him to use his tablet effectively but he had little awareness of this.*

*One gentleman who had experienced a decline in his cognition as a result of MND. He lived alone and had limited social support. He could not reliably use his Lightwriter when introduced as a result of his cognitive impairment. He was also unable to recognise his speech decline and plan for future needs due to his cognitive impairment which meant he had very little communication support in place at end of life.*

*A worrying case - a gentleman who had a Lightwriter, but wouldn't use it because he was 100% convinced that his speech was perfectly intelligible, when in fact whatever he tried to say came out as garbled rubbish....and he would get very distressed with his family because he thought they were 'having him on' - awful for everyone.*



*Can be very difficult. I had one family where the children were denying any FTD, but could not escape the problems their mother was having when she was perseverating [repeating a word or phrase no longer appropriate to the conversation] in messages via Lightwriter or pen and paper. It did, however, start to help them to see she was having problems beyond the physical and meant their support began to be given at a more appropriate, cognitive-friendly level.*

*I have had one client with MND whose cognitive impairment was so severe in terms of reduced initiation, reduced ability to learn / remember, reduced attention / concentration, in addition to visual and coordination issues that it was not possible to find a communication aid (device) solution for him. In this case SLT input involved advice to family / carers on how to support verbal / non-verbal communication to optimise communication / interaction.*

There are other impediments to text-based communication aids, for people who are not literate, who speak little English, or who have a hearing impairment and used to rely on sign language.

*Rare case where the patient was deaf and dumb, British sign language was his first language hence when he lost his upper limb movements and dexterity it became a challenge to provide any form of communication aid, as all equipment is designed for the English language or alphabet. Pictorial aid was very limited and unable to communicate difficult conversations and support patient to make choices right for him.*

## 6.8 LOWER TECH SOLUTIONS

High-tech solutions are not the only solution. More basic solutions can often be highly effective, depending on the patient and their circumstances.

*When we purchased the Megabee this meant that my husband could then communicate urgent needs to others (but this was restricted to them knowing how to operate the device and was better with some people who just seemed to be able to 'read' the machine better than others).*

*One lady became expert with an e-tran - such that the night before she died she won a game of bridge using it to make her bids!*

## 6.9 TRAINING ON EQUIPMENT

We received mixed evidence on the adequacy of training to MND patients with communication aids and carers.

*It wasn't particularly user friendly, we didn't have the right IT equipment, we didn't receive sufficient training and were rather left to ourselves to develop our use of it when there were many other priorities.*

*As it was an iPad app, it was quite easy and my husband was told the basics and worked it out for himself. He didn't really need training.*

*A gentleman came with the Tobii eye gaze to demonstrate and run through things with both of us, the speech and language therapist was also present. My husband and I also went to the trust that was helping to fund it for another chance to operate the eye gaze and they let us borrow one until the one ordered for my husband arrived. It was made clear at the time that we could telephone either the trust or contact the eye gaze support team for any queries we had.*

*My husband was given a machine and told by the speech therapist that she did not know how to use it but surely we could figure it out. This was something my husband was never really able to get the best out of and after he died I found out there were other people out there who could have helped and I am angry that the speech therapist did not know about these people.*

*At one point we had to ring the help line every time we used the equipment as there was a fault which kept re-occurring, this was eventually solved by replacing the computer. Someone who did not feel comfortable with the equipment could well have thought that they were causing the problem and given up.*

*The Lightwriter is not very complicated, so extensive training was not required.*

*I used an iPad already but was new to this recent technology. I listened to the provider about the app but my late husband was extremely poorly by the time he got the iPad. This should have been compulsory from the start of diagnosis and not be left until it is too late.*

## 6.10 SELF-FUNDING

Many respondents spoke about funding equipment themselves. To those who can afford it, this appears to be an easy way of circumventing long waiting times for equipment delivery. Those who cannot fund equipment themselves are hit hardest by poor provision. For eye gaze systems, self-funding is an option for relatively few people because of its relatively high cost.

*The equipment was a very old Lightwriter, while I could still speak it was OK, but having been without speech for five years, we purchased our own, as like everything else it took too long and did far too little to meet the disease's effects.*

*I was advised what I would need but we bought it ourselves.*

*I bought my iPad myself.*

*Sometimes people with MND choose to buy their own equipment as they prefer to remain as independent as possible - for many this is part of their coping. We respect that! But we do emphasise when meeting them that we're always there should they want to see/approach us. The family of a person with MND may choose to buy e.g. an iPad for them, which then remains property of the family. We always offer support to fund the appropriate communication app.*

*I arranged a trial for an eye gaze solution for my late mother. My mother's condition was quite advanced by this time and costs for the equipment were very high. My mother decided she didn't want to invest in the equipment.*

*We purchased a further communication aid ourselves as this could not be provided within a reasonable length of time (had we waited for it to be provided my husband would have died before it arrived). This was an electronic version of a Megabee which allowed us to be able to use it when we were not at home. We donated this to our local SLT to use with others with MND. It cost us £600, which we felt was a small price to pay for my husband to be able to communicate.*

*Individuals are now more likely to seek own solution such as the purchase or use of a tablet and software. They are self sufficient and take more ownership of AAC and better able to communicate via text, instant messaging, social network etc. if able to access these.*

### 6.11 HAND FUNCTION

The importance of hand function was a recurring theme in the evidence: its presence or absence can make a difference to a person's communication options, and if it is lost after the ability to speak, the progression of the disease means that communication options can be closed off.

*I was given a Lightwriter which I couldn't use because I'm paralysed.*

*It is very frustrating losing the ability to speak, I use Proloquo4text on my iPhone and iPad, this is a very good app, but still not the same for speaking. I have two children which I keep in touch with via text, Whatsapp etc but when I lose use of my hands this will all have to be reviewed.*

*My husband can speak but has lost the use of his hands so cannot answer the phone. This makes it hard to call him if I am out and means he cannot call me if he needs to. For this reason he cannot be left alone so between me and my two teenage children we stay with him.*

*It was fine at the time it was given and worked well, but MND is progressive and there was a length of time when my father was unable to communicate at all. In other words once he was unable to operate the Lightwriter with his hands, no alternative was offered or suggested.*

### 6.12 VOICE GENERATION

A few respondents observed that even the modern synthetic voices available on more sophisticated devices are often a disappointing substitute for the person's original voice.

*The app for my iPad offers me the choice of a posh Englishman or an American. I am Scottish, why can't we have regional dialects?*

*My beautiful father was a Geordie, a very humble, polite and happy man. He was the centre of our family. When he eventually got given a Lightwriter by the MND Association, it had an American accent. My Dad was embarrassed as it didn't sound anything like him. We used it with the sound off in most situations.*

### 6.13 VOICE AMPLIFICATION

Although numerous responses from SLTs made reference to voice amplification, fewer submissions from people with MND and carers did. It may be that these devices are niche devices for people with MND, and not without their problems.

*The belt-worn equipment was heavy, bulky and uncomfortable to wear. The throat microphone was not adjustable and thus picked up much extraneous sound from friction with my collar. People with whom I was talking found it distracting to hear a voice coming from waist level.*

*I was provided with amplification equipment, which takes some of the effort out of speaking and makes me more comprehensible to others. However, the excruciating feedback, which I haven't found to follow a predictable pattern, interferes with the communication exercise. When I turn the volume down to reduce the feedback, I lose amplification. It not only disturbs me and my friend, but it disturbs other people in my locality. I am therefore reluctant to use it. I have had three different amplifiers and they all exhibit the same problem. There is a further drawback that the equipment switches itself off after some time, again unpredictable.*

*The amplifier used to support my voice is fine when it works. But it produces screeching feedback which interferes with its effectiveness.*

### 6.14 VOICE BANKING

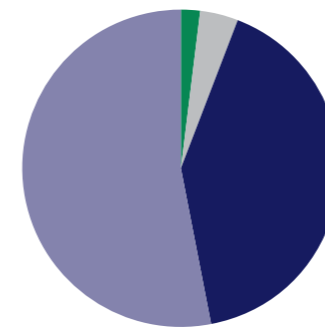
Awareness of voice banking is low. Few people with MND try it, and few SLTs have experience of it being used. The technology is currently quite limited. Respondents reported either giving up or seeing the person they were caring for giving up, without fully banking their voice.

Other respondents felt that the quality of the voice synthesised from the recorded samples was poor, in relation both to its intelligibility and its resemblance to the voice of the individual.

Many respondents who had not used it clearly believed it could have resulted in a higher quality voice and regretted not knowing about it, perhaps unaware of its mixed reviews from those with experience. The development of a new method of voice banking more suitable to people with MND is welcome news.

FIGURE 21:

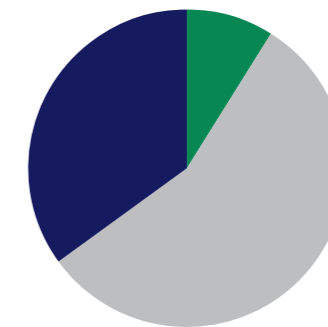
Do you have any experience of voice banking?  
(Respondents: people with MND)



CATEGORY	%
Yes, I have done it and use this version of my voice to communicate	2
Yes, I am currently doing it	0
Yes, I have tried it but didn't complete it	4
Yes, I have done it but don't use the version of my voice produced	0
No, I am aware of it, but have not tried it	41
No, I was not previously aware of it	53

FIGURE 22:

Do you have any experience of voice banking with people with MND?  
(Respondents: health and social care professionals)



CATEGORY	%
Yes, a lot of experience	0
Yes, some experience	9
Little or no experience	56
No, I am aware of it, but have not tried it	35



*My voice had deteriorated far too much before I learned about Voice Banking.*

*I do not like the speaking apps and wish I had been told about voice banking at time of diagnosis, as would have definitely used it and I think it would make the speaking apps sound more natural.*

*It took over a year to diagnose my voice problems as MND. There needs to be more awareness about this condition within medical profession. Had I been diagnosed earlier I could have maybe used the voice bank.*

*I routinely make digital voice recordings of my patients with MND and advise them to make personal recordings of messages/stories they may wish to pass on to their families when the time comes that their speech is no longer available to them. To date I have not had a patient who has wanted to use his/her own voice on any communication device provided and to be honest I don't know how I would access this technology - although I'm sure I could find out if the need arose.*

*I have used a version of this for a client and it was effective. However, usually by the time the referral has come through to our service the person's voice is already affected and is less useful for voice banking. Also the software is not widely available and is not as good as it needs to be at this time. In the future, this will come more into the mainstream and could be more widely used and available. The easiest way would be if it was included in the communication software.*

*I recently attended a local SLT network meeting where we looked at voice banking developments. I understand that the process involved in 'banking' the voice is extremely time consuming (14 hours+). The quality of the voice following this was not clearly recognisable as the voice of the person who recorded it so in that sense I feel it defeats the purpose of the voice banking notion. Indeed, the speech quality / intelligibility generally was of a much lower standard than that which is available on other computer generated / synthetic voices on AACs. I think voice banking is an excellent idea but feel that much more development is required before this would be as useful and acceptable as it needs to be.*

*It may be more natural but it may also be less understandable. We have been involved with the Natural Speech Technology project, which includes University of Edinburgh who are running the Edinburgh voice banking clinic, so are well aware of this technology. Although this is promising technology, more research is needed to see if it a) increases adoption rates of communication aids (and/or improves outcomes) b) produces more natural voices AND more understandable ones c) has less or more impact than other forms of voice/speech banking. MUCH more important in my view is our concept of language-banking - and this ties in with effectively mapping the whole communication pathway from start to finish and integrating services. For example - currently in many situations, a person uses a device while they can type, then swaps to a different device when they need to use a different access method. At this point they lose all the information the device was learning about their language - and this is at the most vital stage for that person to benefit from this. We intend to initially address this issue through promoting common standards with manufacturers (to allow language transfer) through our increased purchasing power; and through more effective service collaboration across the whole.*

*Only one person living with MND that I have been involved with did this. Her family funded it themselves, it took HOURS to bank and then in the end all she used was pad and pen and texting on her phone. I never did find out why.*

*It can be a tiresome process which for people with MND that takes too much of their perceived limited time. Also, as with other issues when working with the person with MND, they may not be emotionally or psychologically ready to think about the changes they may experience in the future such as loss of speech and voice.*

*I have experience of a patient's daughter voice banking for her communication aid - this worked well, and provided a more 'normal' voice for the person with MND as there are often complaints that voices are too robotic or posh (not indicative of the local area). However this was time consuming and I query whether SLTs have the time to complete this and often our clients may not have the skills etc. to complete this. Timing/set up etc. need to be taken into consideration.*

## 6.15 REMAINING IN WORK

For many people with MND, it can be important to remain in work for as long as possible; leaving work represents a significant and unwelcome milestone in the progression of the disease. Several submissions to us clearly illustrated how communication support can help people with MND to keep working for longer. They also show that the Access to Work scheme, administered by the Department for Work and Pensions (or the Department of Employment and Learning in Northern Ireland), can be an alternative source of funding for communication technology.

*Within 15 months I have progressed from the slightest slur in my speech to being unable to say a few words with considerable difficulty. In the last six months I have progressed from techniques to facilitate communication, through voice enhancement equipment, to using an iPad with predictors app. I am now having to consider eye gaze equipment. Throughout all this I have tried to maintain normal life as far as possible, but could not have done so without the support of family, friends, my employer and therapy services. Without the iPad provided by the neurological therapy service I would no longer be able to remain at work, go about my daily life, or talk to my family and friends.*

*Difficulty in day to day communication at home, with family and friends, everyday activities and aspects of work activities. I can no longer use the telephone. Chairing meetings at work has become difficult, although I still attend. Even with the iPad communication has become much slower, but I heavily use emails and text messaging.*

*My husband has MND and although he can still talk clearly he has lost the use of his hands so cannot access any form of communication equipment eg phone, or computer and cannot go out alone. We were told that he would have to wait several months for an assessment and even then they would probably not be able to help him as there was no funding for an eye gaze system which he needed. We were however able to secure funding for the equipment through Access to Work. Since then he has been able to continue doing website marketing work based from home. It also enables him to make phone calls using Skype, send emails, play chess, do the grocery shopping, watch TV on line, keep up with the news, etc etc. I can honestly say it has been fantastic for him quite literally keeping him alive mentally.*

*These considerations naturally go beyond remaining in work, into all practical aspects of life.*

*The ability to speak by typing sentences using eye movements is just one of many important uses of my communication aid. Equally important is the ability to control my environment, use the internet, use email and texts and do almost anything anybody else can do with a computer. This results in me being entirely independent, other than when physical intervention is needed. I am even in the process of buying a flat using my eyes. I arranged all the viewings, negotiated the price, organized quotes for adaptations, dealt with solicitors, scanned necessary documents, bought hoists and other equipment on Ebay and arranged dropped kerbs for wheelchair access with the council. So almost anything is still possible. Without this technology, I would only have been able to stare out of the window for the last five years.*

CHAPTER 7

WORKFORCE AND TRAINING ISSUES

Although our principal criticism of specialised AAC provision in England is the slow implementation of the service specification, we are deeply concerned by responses suggesting that the SLT workforce is not currently adequate to deliver a high quality service to everyone who needs it. Similar concerns emerged from evidence relating to some other parts of the UK. The pessimism among SLT respondents about the likely future of their profession was concerning.

7.1 EXPERTISE IN MND

Few SLTs are experts in MND. It is a relatively rare disease, and inevitably a small component of SLT caseloads. The Royal College of Speech and Language Therapists (RCSLT) told us that only about 20% of SLTs work with people with neurodegenerative conditions. The RCSLT said:

*The RCSLT believes that people with MND should have access to a speech and language therapist who is working in a team where there is support from highly specialist or expert practitioner in adult neurology to supervise their management of the dysphagia and communication problems in MND, however this could be a generic or junior SLT.*

An SLT echoed this view:

*In an ideal world we would have more less-experienced staff in the service to provide management to clients with MND with less complex needs. The highly-specialist SLT should then be seeing those with complex needs and also providing second opinions. However, in our current structure we do not have many specialist SLTs and we as a result are unable to have many generalist therapists as we cannot support them in their development. A client with MND does not HAVE to see a highly specialist SLT every time, but the less experienced clinician DOES need to feel supported enough to ask for assistance, or to be able to pass the case on if they feel they are struggling, in my view.*

However, specialist SLTs were reported to be few in number.

*Local SLTs want knowledge (of MND and AAC aids) but have such large caseloads and MND is such a small part of this. People can be reluctant to specialise as it can restrict their ongoing career opportunities... Specialist staff are very difficult to come by. If SLTs decide to specialise in AAC other competencies start to drop off and their career opportunities lessen.*

These problems can clearly be seen feeding through into the experiences of people with MND.

FIGURE 23:

Were you referred to a specialist speech and language therapist with expertise in neurology/MND? / Was the person you care or cared for referred . . .

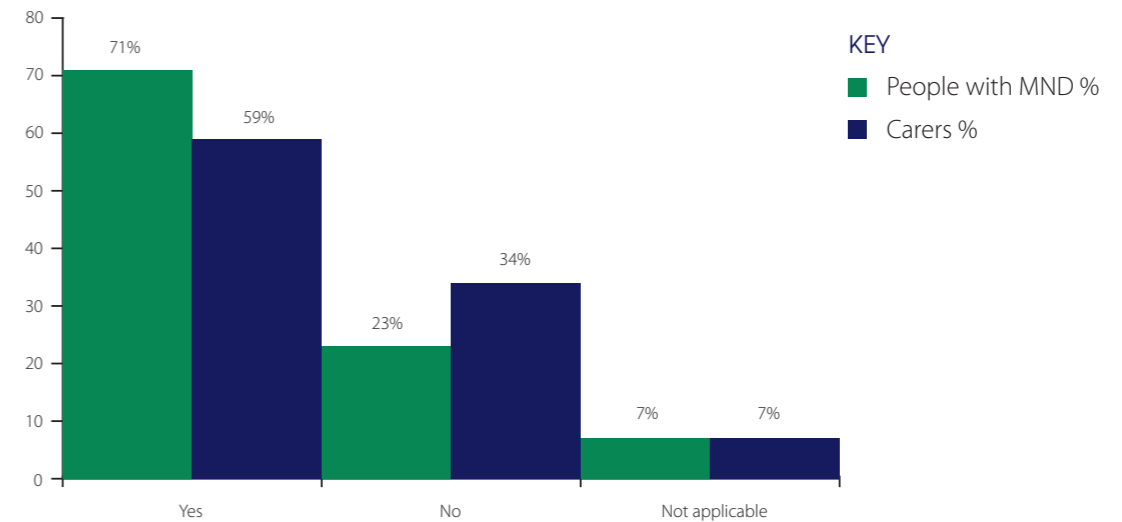
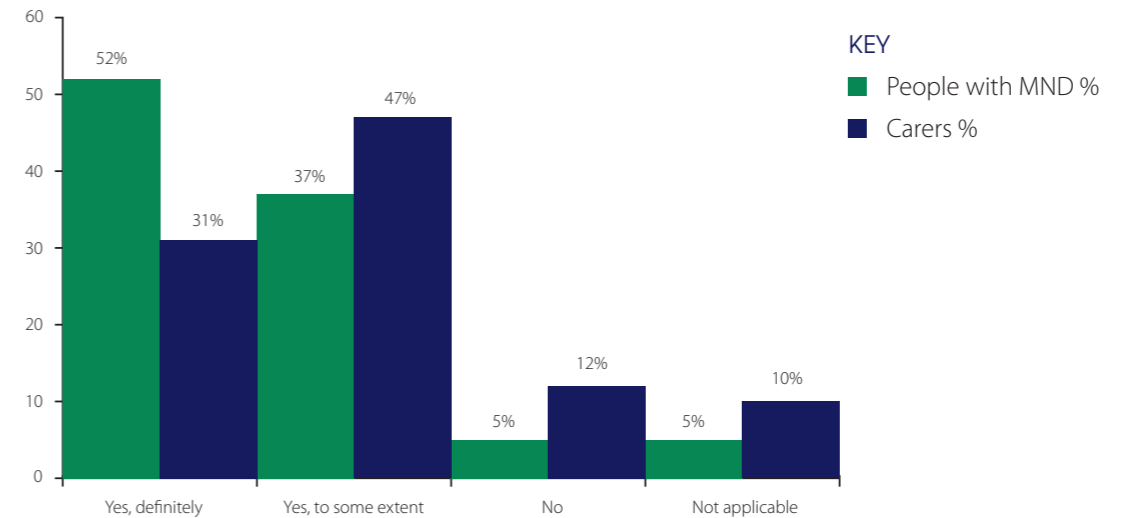


FIGURE 24:

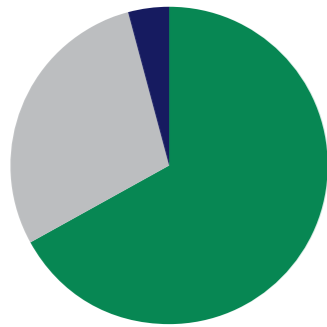
Did the speech and language therapist that you saw / the person you care or cared for saw know enough about MND?



A few people with MND and carers expressed dissatisfaction with the level of knowledge about MND possessed by the SLT who assessed them. We would like to see these scores improved. Carers were less positive than those they cared for.

FIGURE 25:

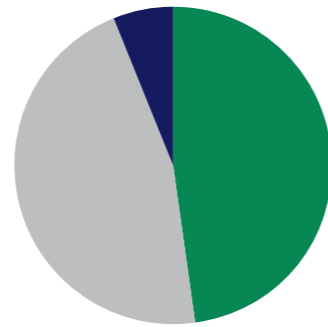
In your region, are communication assessments for people with MND carried out by a speech and language therapist (SLT) who is knowledgeable about the disease? (Respondents: health and social care professionals)



CATEGORY	%
Yes, definitely	67
Yes, to some extent	29
No	4

FIGURE 26:

Are communication assessments for people with MND carried out by a SLT who is knowledgeable about the range of Augmentative and Alternative Communication (AAC) available? (Respondents: health and social care professionals)

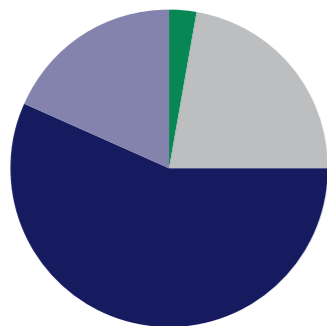


CATEGORY	%
Yes, definitely	48
Yes, to some extent	46
No	6

Professionals were more positive than people with MND and carers about the knowledge of SLTs undertaking assessments. This may be a reflection of the sample containing professionals who regularly work with people with MND.

FIGURE 27:

Do you think there are enough highly specialised SLTs to meet the current needs of people with MND and others with complex communication needs? (Respondents: health and social care professionals)



CATEGORY	%
Yes, definitely	3
Yes, to some extent	22
No	56
Don't know	18

The majority of respondents do not believe that there are enough highly specialised SLTs.

Evidence from people with MND, carers and professionals reinforces this.

*The speech therapist met my brother and had little knowledge of MND. She noticed that he had an iPad and told him about apps which would help. She referred to the wrong one and gave no further help. I actually found the appropriate app and loaded it for him. She had no further input and the carers were not really aware of him being able to access the support. All self help and a bit of an embarrassed muddle.*

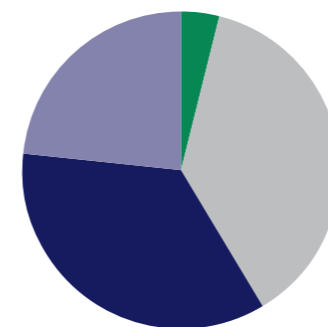
*An eye gaze was recommended. The speech therapist who was to carry out the assessment declared my sister too ill to take the test and that it was a waste of time in any case as it took 6 weeks to obtain one. She inferred my sister would no longer be alive by that time. My sister was unable to communicate at all by that time. She had been using a toe to point to letters on a letter board that my lecturer daughter had made.*

*Best practice in Leeds, where people are assessed carefully and receive what they need. Poor practice in other parts of my region where SLTs only offer [MND] Association-provided Lightwriters and consistently state they have NO budget for anything. Worst practice - Mid Yorkshire where a SLT stated the above AND that nothing else would work for people with MND. She clearly had no understanding or skill in assessing and even worse, she did not see any need to learn more. She also informed the local MND team that referrals would be treated as urgent, yet evidence has shown people waiting for 3 months for a first visit.*

Our call for evidence also revealed concerns about the expertise of palliative care staff in communication support and expertise among care professionals in supporting people with cognitive impairment to communicate.

FIGURE 28:

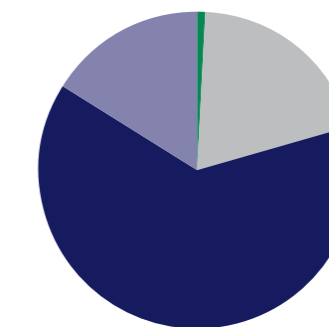
Do you think palliative care staff are sufficiently trained to support patients using communication aids to discuss their end of life wishes? (Respondents: health and social care professionals)



CATEGORY	%
Yes, definitely	4
Yes, to some extent	37
No	35
Don't know	23

FIGURE 29:

Do you think health and social care staff are sufficiently trained to support patients with cognitive impairment to communicate using equipment? (Respondents: health and social care professionals)



CATEGORY	%
Yes, definitely	1
Yes, to some extent	20
No	64
Don't know	16



## 7.2 RECENT CHANGES

Concerns were expressed that an intense period of recruiting by 13 or even 14 specialist hubs in England will not prove successful.

*Over the past decade there has been an erosion of funding into the SLT services and this has led to long waiting lists for assessment for both speech and swallow deficit. So fewer therapists dealing with an increase in referrals due to the ageing population and an increase in the diagnosis of neurological conditions.*

*There are limited opportunities for SLTs to continue to develop a specialist career. Funding for higher graded posts has been reduced over the past five years which has inevitably effected career paths for professionals. Different health trusts treat progressive neurological conditions differently - in some it is not considered a specialism and therefore not allocated the appropriate level of clinical expertise. AAC is often considered an adjunct to an SLT's clinical skills and not regarded a specialism in its own right. In order to ensure that high standards of care are expected, I believe that highly specialised professionals are necessary. Services are generally not well integrated as budgets and lines of management remain separate.*

*We have fewer SLT resources now and few SLTs at a highly specialist level, therefore it is less likely that people with MND will be able to see someone with experience with MND.*

*I do not think SLT is given the same priority as other therapies (physio, OT) when it comes to commissioning services. I think there is still very poor awareness of SLT among other professional groups.*

*Funding cuts within services. Restructuring, and when posts become vacant recruiting generic clinicians into posts that were previously highly specialist.*

*The simple answer is that there are not enough SLTs to cope with the current workload. We are all putting in extra hours and feeling as though we provide a less than adequate service at times because some of us cannot respond urgently to patients and this is especially important for patients with MND.*

*There seems to have been a reduction in SLTs over the past year, as staff move on and are not replaced, presumably for financial reasons. I have heard there are plans locally to discontinue specialist therapy services in community and require people living with MND to attend clinic for assessment by generic therapist, not necessarily SLT, which is likely to cause delays and difficulties for this group of exceptionally vulnerable people*

*As the SLT workforce roles are being downgraded, there are less and less specialist roles and more generalist roles therefore diluting the specialist knowledge.*

*Job opportunities for promotion are now very small and often the feeling is it is better value for money to employ a newly qualified than an experienced clinician. In spite of the Agenda for Change there is perceived a process of systematic downgrading with experience staff then opting to leave the NHS as a result!*

We heard in oral evidence from Communication Matters that the problem is posts not being available within the NHS, rather than insufficient numbers of SLTs being trained.

*We are training enough therapists, there aren't enough jobs for them to go to. There aren't enough therapists working in the community areas, people come out with no jobs and there aren't the posts to meet the number of people training. The numbers haven't decreased, it's just a growing need from the elderly population to a certain extent and the growing awareness of the disease, which is a good thing, but the elderly population is going to be a big mountain for us over the years as the staffing isn't growing to meet that. We're going to get more illnesses like MND and Parkinson's along with the other diseases which will have an increase with an ageing population.*

## 7.3 THE FUTURE OF THE SLT WORKFORCE

The Royal College of Speech and Language Therapy recorded comment on reduced SLT services in England as the NHS seeks cost savings:

*Increasing demand for speech and language therapy is likely to result from the ageing population, people living longer with long-term or neurological conditions and the increasing number of children with complex speech, language and communication needs.*

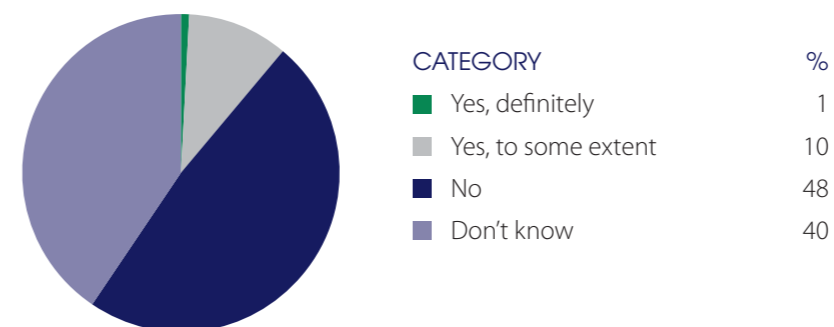
*Like other services, speech and language therapy services in every sector have to contribute to at least 5% cost improvements this year, and next year and the following year. The result is that there is less revenue to run existing services. This is at a time when referral levels are growing and the acuity of cases is increasing at both ends of the age spectrum.*

*The annual 5% reduction in expenditure (which is invariably 95% workforce costs) could result in a reduction in whole time equivalents (WTE) of over 1,000 over the next three years. With an increase in demand, due to the changing demographics (see above) and the changing policy environment, speech and language therapy services will struggle within these resources to meet future demand.*

Respondents across the board were clearly pessimistic about the future shape of the workforce.

FIGURE 30:

Do you think there will be enough highly specialised SLTs to meet the needs of people with MND and others with complex communication needs within the next 5 years? (Respondents: health and social care professionals)



*At present we have several experienced Band 7 SLTs who are able to provide specialist advice and assessment. However, with workforce reduction changes and planned changes due to cost cutting in the NHS the availability of experienced staff will reduce over the coming few years, meaning a poorer overall service for patients with very complex needs. SLTs here also link into an MDT for MND clinic/service, but are not specifically funded for attendance, so this comes out of general clinic time and is vulnerable to change due to changing Trust objectives.*

*The number of people getting to old age will increase therefore there will be an increase in swallowing problems. The workforce is overwhelmed and there will be more priorities and I think people with MND will be left later and later and not get seen when they need to be.*

*In my experience, the whole of the NHS and community care is under resourced. Services are set up for short periods of time and then things are changed - there is very little continuity of care. Patients with long-term progressive conditions are not prioritised properly, there is a huge lack of education for healthcare and community workers. Organisations are not able/willing to give time off for training and study nor is there sufficient education budget available for workers. This does not just apply to those working with MND patients but throughout the care system.*

*There have been recent changes within this SLT department resulting in the loss of most highly specialist SLT posts, so it seems unlikely that there would be such posts created for people with MND or other complex communication needs.*

*I am unaware of future funding of SLT posts. There has recently been some reorganisation within several trusts and there appear to be fewer more experienced SLT members than there used to be so I'm not sure about the future.*



## CHAPTER 8

# THE ROLE OF CHARITIES

### 8.1 THE EXTENT OF CHARITABLE SUPPORT

Charities have historically had a large role in meeting the communication needs of people with MND. NHS England's slowness in implementing the service specification has meant increased demand on charitable resources. The MND Association told us that it provisionally intends to allocate approximately an extra £150,000 of its funds to providing AAC in 2015-16.

MND Scotland submitted evidence that communication was the single largest area of unmet needs among people with MND, and that its policy is to devote 'a significant financial resource' towards both high and low-tech AAC equipment. It expects there to be a 'gross undersupply' of such aids for as long as there is a lack of a statutory obligation to fund them.

Written evidence from people with MND, carers and professionals emphasised the extent to which charitable resources compensate for poor statutory provision across the UK.

*I have used the MND Association to fund an iPad for a client which has been invaluable to him. I have previously wanted to request an eye gaze device for a client via commissioning at my trust, but before the request was approved unfortunately the client passed away. It is easier to get funding for device such as iPads [from the Association] which are lower in cost than anything more expensive.*

*NHS funding restraints - sadly - severely restrict provision of equipment so we are heavily dependent upon charitable support, which may also involve eg local Lions, Round Table groups and other charitable organisations. The loan equipment section at the MND Association is very good, their financial support for eg eye gaze equipment loan locally has been strong, and both SBASCH and South Bucks MND Association have funded iPads, apps for communication, and other communication aids. Without charitable support, we would not be able to support people with MND anywhere near adequately!*

*The MND Association have become a crutch for the NHS. If they do not fund it, very disabled people are left to die with no communication. A low-tech sheet is utterly degrading when you compare it to an IT solution.*

*As funding is not routinely provided by the local health board for communication aids, we regularly approach charities (The Sequal Trust, the MND Association local branch, SSAFA etc.) to fund communication aids for our patients. This can be a long process, sometimes taking months to complete.*

*When the MND Association were providing a Lightwriter loan system I would request a loan approximately once per year. One service user requested financial support to fund an iPad with predictable - via the regional volunteer. Probably used MND Association for communication aid provision 3 times in 6 years*

*I would say that the charities are the first point of call for funding communication aids in 100% of cases. As mentioned previously in my opinion there is an argument to say that the NHS should meet this need, in the same way as wheelchairs or hospital beds are provided.*



*If charities have funding available for communication aids I think it would be better channelled through assessment centres to ensure that people with MND have appropriate access to the ongoing support they require. Regional assessment centres and local teams cannot establish good and equitable coverage if patient need is being masked by charitable provision.*

*They will sometimes part-fund an item - but that means that it is someone's responsibility to acquire the balance of funding from other source/s. This should NOT be SLT's job - whose time is so overstretched as it is! This also causes problems with ownership and paying for servicing agreements for the item, and where it should go once the person with MND no longer has need of it!*

*My husband is still waiting for help with communication aids. It would appear that the aids are very expensive and the NHS can't seem to agree with the MND Association who foots the bill for such communication aids.*

There was evidence within the responses of confusion over what the MND Association offers by way of equipment loan or funding, whether this has changed in recent times and, if so, how. There were statements that the Association variously

- Does not fund eye gaze
- Funds iPads and eye gaze
- No longer loans Lightwriters
- Has recently decreased support
- Is the funding body to approach in the first instance.

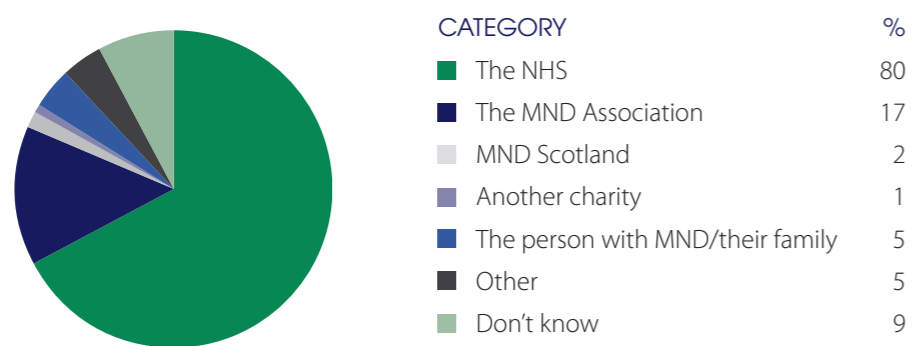
### 8.2 WHO SHOULD PAY TO MEET COMMUNICATION NEEDS?

As part of our call for evidence, we asked people with MND who they felt should fund communication equipment. The answer was clear-cut.

Figure 31: Who do you think should be expected to fund communication equipment for people with MND? (tick all that apply) PIE CHART

FIGURE 31:

Who do you think should be expected to fund communication equipment for people with MND? (tick all that apply)



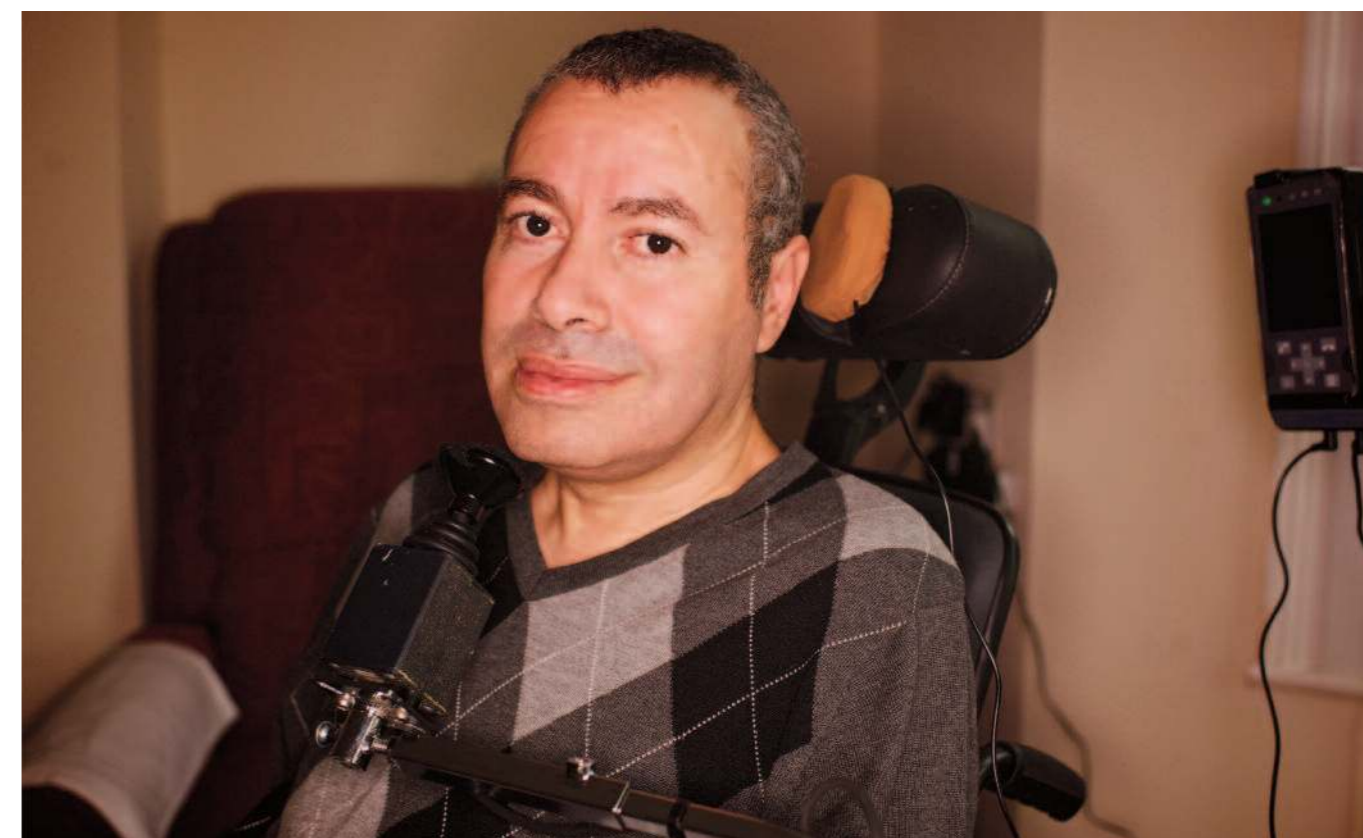
There was strong support for the NHS taking responsibility for funding communication equipment. Fewer than one in five respondents saw it as the role of the voluntary sector. Hardly any respondents felt that the individual or their family should be responsible. Professionals clearly expressed support for NHS funding.

*It is the responsibility of NHS and healthcare services to fund communication aids. Communication is a human right and should be statutorily funded - as are wheelchairs and aids to help with walking.*

*In general, people are often willing to purchase high-tech gadgets for technology that is mainstream and in everyday use, so even where severe communication disability occurs, there needs to be a degree of 'ownership' and personal responsibility. Widespread universal funding and resourcing should be based on personal needs and circumstances. My response sounds very cautious, but any expectation of unlimited automatic resourcing and provision by health professionals, charities or people with MND and their families requires some safeguards I think.*

### 8.3 NHS POLICIES AND THE REIMBURSEMENT OF CHARITIES

In England, charities are providing equipment that it is the responsibility of the NHS to provide. Just as we were closing this inquiry to new evidence the MND Association was able to confirm that NHS England has agreed to reimburse it in respect of one specific case, although the mechanism for this is unclear. NHS England's formal position on reimbursing expenditure is set out in a paper published in April 2013 on 'the boundaries between NHS and private healthcare'. This paper assumes that NHS funding to continue any treatment commenced privately will be by IFR, but does not allow for NHS reimbursement of a cost already incurred by a charity to cover for the NHS's failure to meet its obligations.





## APPENDIX 1

# CHRONOLOGY OF AAC REFORMS IN ENGLAND SINCE 2010

Based on the chronology submitted in evidence by the MND Association

### July 2010

The white paper 'Equity and Excellence: Liberating the NHS' is published; its proposal is for the NHS Commissioning Board (later known as NHS England) to take on specialised services.

### December 2012

A draft service specification on complex disability equipment is published for consultation; in its consultation response, the MND Association expresses concern about the proposed 18 week timescales for equipment.

### July 2013

The AAC sub-group of the complex disability CRG issues its first commissioning guidance

### October 2013

The specification comes into effect, making no changes of substance; the clear allocation of responsibility for specialised AAC to the NHS nonetheless represents a major development for AAC provision in England. No funding is allocated to pay for these services and no steps appear to be taken to establish them.

### February to March 2014

The 13 proposed AAC hubs submit their business cases to NHS England for approval.

### March 2014

Sir David Nicholson, Chief Executive of NHS England, responds to a letter from Dominic Raab MP about problems experienced with AAC by one of his constituents. His reply states that specialised AAC services will be available from April, and specifies:

- *the specification had so far been commissioned only from Birmingham Community Health Care Trust and Bristol Communication Aid Service*
- *"A bid to the NHS England Convergence Fund for £15 million has been successful and contracts are being agreed with the 13 centres for 2014/15. Patients can access these services through their local speech and language service."*
- *"I note from your correspondence that [your constituent] was offered an appointment with the Royal Hospital for Neuro-disability in Putney. As this is one of the 13 centres identified, from the 1 April 2014, the Royal Hospital for Neuro-disability will be able to provide [your constituent] with the technology required to meet his clinical needs."*

Sir David also writes to Liam Dwyer, an MND Association campaigner: "I apologise for the lack of clarity on how to access AAC services during 2013/14. NHS England has worked closely with patients and clinicians to establish comprehensive services which will begin to be rolled out from 1 April 2014 and will ensure that access to these services is improved."

**April 2014**

The MND Association confirms this news to its staff and to health and social care professionals. The chair of the AAC sub-group writes to the MND Association, stating that it is very unlikely that any of the hubs will be able to see patients currently, and confirming that “the status quo continues until funding has been agreed between the Area Teams and the specialised services”. The Association conveys this disappointing news to its staff and stakeholders.

**May 2014**

The allocations of £15million and £7.5million from NHS England Convergence Fund, for AAC and EC respectively, are available by this date. The timing and history of this allocation is unclear: we believe that £15million was initially allocated for AAC in 2013-14, then withdrawn and eventually reallocated for 2014-15.

**June 2014**

A Quality Assurance Framework is published; some hubs indicate privately that if they had had sight of this, they might have structured their bids differently.

**June 2014**

Karen Pearce, MND Association Director of Care (South), is invited to sit on the panel to assess the business cases for EC and AAC hubs.

**August 2014**

The Specialised Commissioning Overview Group meets and approves business cases (subject to conditions for some).

**September 2014**

Letters of intent are sent to hubs: they now know they are approved to be a hub, and the value of their contract; however, they cannot yet recruit or purchase equipment because they have yet to sign contracts with the ATs or receive funds.

**October 2014**

A two week ‘cooling off period’ ends and funding is transferred to NHS England ATs for AAC and EC (confirmed in email from NHS England to MND Association, November 2014).

**December 5th 2014**

Simon Stevens writes to Sam Gyimah MP, and 13 other MPs, in response to a joint letter raising concerns about the effects of ongoing AAC problems on their constituents. Mr Stevens’ letter states that the hubs are recruiting staff and accepting referrals. The MND Association writes to him to highlight that this statement is not borne out in reality.

**As at December 5th 2014:**

- No hub has been commissioned or received any funds
- A delay is occurring in London while a fourth hub is commissioned; existing hubs are required to review their business plans completely
- The Quality Assurance Framework remains in draft form
- Service problems continue to have a serious impact on the lives of many people with motor neurone disease.

**APPENDIX 2****ABOUT DIFFERENT TYPES OF SUPPORT****OVERVIEW**

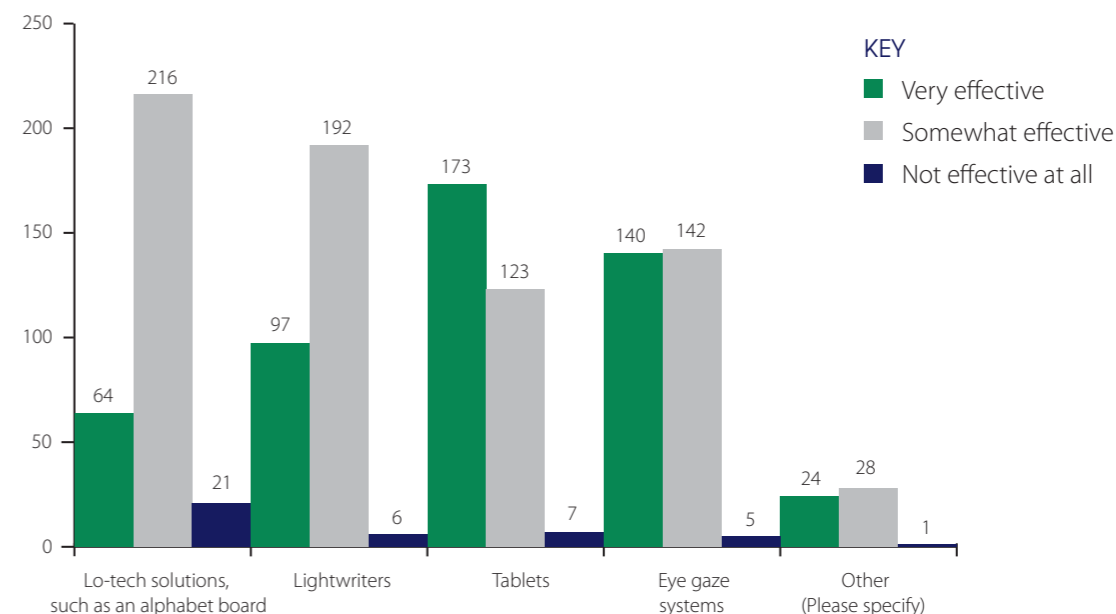
This appendix offers a brief overview of the different solutions available to meet the communication needs of people with MND. None is a solution of itself: to achieve good results, all rely on the correct support being available to help the person with MND identify the correct solution, and then learn how to use it. As needs change through the course of their illness, they must be kept under review and new solutions identified.

AAC is an expanding field: over 200 options are now available to choose from.

As part of our call for evidence, we asked health and social care professionals for their views of different commonly used solutions.

**FIGURE 32:**

Looking at the following communication solutions, how effectively do you feel they meet the needs of people with MND and carers? (Respondents: health and social care professionals)



Tablet devices received the best scores, with fair support for eye gaze. Lightwriters receive lukewarm support.

**LIGHTWRITERS**

For many years, Lightwriters were the mainstay of communication aids for people with MND. The user types a message, which is displayed on a screen or spoken in a synthesised voice. On some models, messages can be constructed via a ‘scanning’ mode to select from letters listed in sequence. They have been on the market for over 40 years, and rely on the user retaining some hand function.

### IPADS / TABLETS / SMARTPHONES

A wide range of software is available to make tablets and smartphones effective communication aids, either by displaying text or rendering it as synthesised speech. They rely on the user retaining a fair degree of dexterity, although some software has a 'scanning' mode where the app runs through letters or words, and the user indicates by a simple input when it has reached the desired one. Some tablets (MND Scotland specified Windows tablets in evidence to us) can be used with eye gaze technology, which could potentially be a cost-effective way of creating an eye gaze system.

### LOW-TECH AND SIMPLE SOLUTIONS

There are many simple solutions that allow a person with MND to communicate, without relying on sophisticated devices. These generally involve either producing text for someone else to read, or indicating with eye movements.

- Alphabet charts: the person points to the first letter of a word to clarify their speech, or spells out entire word
- Listener scanning, with alphabet or phrase charts: the conversation partner scans through the alphabet or a list of words and phrases, and the person with MND indicates when they have reached the desired one
- Eye transfer board (e-tran): a perspex frame fitted with blocks of letters or phrases, which the person with MND indicates with their eyes
- Megabee: an electronic version of the e-tran frame, into which the person's speech can be put as it is indicated, and can offer predictive spelling
- Boogie board: a small electronic writing tablet, which can be used instead of paper and pen or a dry-wipe board.

### VOICE AMPLIFIERS

MND can cause poor voice projection as the respiratory and abdominal muscles weaken. Wearable amplifier kits can be used to compensate for this.

### EYE GAZE

Technology to control computer devices with the eyes is developing very quickly. Eye gaze systems represent relatively expensive solutions. Some manufacturers now offer extremely capable 'all-in-one' packages including both hardware running a modern Windows system and eye gaze software such as The Grid 2.

### FACEMOUSE / HEADMOUSE

Software is available that allows for the control of a computer system using head movements with a switch (headmouse) or face recognition, for instance opening and closing the mouth, or raising the eyebrows (facemouse).

### BRAIN-COMPUTER INTERFACES

At the cutting edge of communication research is work on brain-computer interfaces. These allow a user to achieve a measure of control over a computer and the wider environment using their thoughts alone. This is a developing area, and not yet commercially available.

### VOICE BANKING

Synthetic voices are often viewed by people with MND as poor substitutes for the voice they have lost. Voice banking allows the person to record samples of speech, either to play back as set messages or to develop into a synthetic version of their own voice. Research is underway to develop ways to bank a voice sufficiently quickly and easily for a person with MND, while producing an intelligible and realistic simulation of their voice.



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