Specialised AAC services for people with MND:
evidence of the current position

Introduction

i. This paper is the MND Association’s first publication on the subject of specialised augmentative and alternative communication (AAC) since the election manifesto ‘Don’t Let Me Die Without A Voice’ in September 2014.[1] We selected this topic as the focus for our campaigning up to the general election because of growing evidence of problems with AAC delivery in England. Despite the many positive developments over recent years, from the work of the Communication Champion onwards, in clarifying responsibility for communication support and identifying how it should be delivered, people with MND increasingly reported to us that the system was not meeting their needs. Our efforts to engage with NHS England on the matter earlier in 2014 had produced assurances that improvements were imminent, which unfortunately were not borne out in reality.

ii. In the absence of demonstrable improvements in services for people with MND during 2014, the All Party Parliamentary Group on MND picked up the issue and published a substantial report, ‘Condemned to Silence’, in January 2015.[2] This identified systemic reasons for the problems, principally that the shift to national commissioning for specialised AAC by NHS England, while offering a highly promising design, had not been established in a timely fashion, and in some areas existing local pathways had begun to break down in anticipation of the arrival of the new arrangements.

iii. In the six months since that report, there have been many substantial institutional developments. The specialised AAC services defined in the service specification for specialised AAC (‘hubs’ in the proposed ‘hub and spoke’ model) now have contracts with NHS England. An additional hub serving the East of England is being developed, and the gradual extension of the population covered by the Barnsley hub is underway.

iv. We also understand that numerous further developments are imminent. A new version of the service specification is due to go before NHS England’s

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[1] http://www.mndassociation.org/wp-content/uploads/2015/05/20140919-Manifesto-amends-FULL.pdf

[2] http://www.mndassociation.org/wp-content/uploads/2015/05/20150126-Full-APPG-report-Final-for-web.pdf

Trauma Programme of Care Board, and then the Clinical Priorities Advisory Group, for approval and publication by August. A person with MND has been invited to sit on the clinical reference group for complex disability equipment. Guidance for CCGs on their responsibilities for non-specialised AAC is in advanced preparation.

v. Since the publication of the APPG report we have had constructive meetings with the Minister for Care and Support, and with NHS England. At the latter of those meetings, senior leaders in NHS England acknowledged, and apologised for, the extent of the problems to date, and gave a commitment to increase NHS England's efforts to address them, which we welcomed as a positive development.

vi. There has therefore been substantial activity around this issue, and the position today is in some ways very different from that just six months ago. What matters above all, of course, is whether services for people with MND have undergone improvement and are now meeting their needs more consistently. This paper draws together the evidence and intelligence available to the Association on the current state of support for people with MND, ahead of a second meeting with NHS England on July 14th.

1. Key analysis

i. We have been unable to identify substantial evidence of improvements to services for people with MND since the APPG report was written. The available evidence base has substantial limitations; nonetheless, several sources of data and intelligence are available, and taken together they lean towards suggesting that there have been minimal improvement to services in practice. There remain indications that services are sometimes too late, and that people with MND are still dying without a voice.

ii. We would however greatly value any more robust evidence that NHS England can bring to the table; it may be that our sources are too limited to paint a full picture. We also acknowledge that the reasons for ongoing difficulties may be more complex than just issues with the newly-established hubs (for instance to do with increasing demand or supply chain difficulties), and that in two areas (the East of England and parts of Yorkshire) the new hub provision is still being developed.

iii. Nonetheless, we are disappointed not to be able to identify evidence of improvements, and invite proposals from NHS England on what steps it will be taking. Undoubtedly much work is going into setting up the new hubs, but they are still suffering from the slow start made in 2013-14. Is there more that can be done to boost their performance or accelerate their establishment?

iv. We also wish to hear proposals about the interface between the hubs and both the ‘spoke’ AAC services and general-purpose local speech and language therapy services. Past discussions, and the evidence presented in this paper, make clear that this is vital: CCGs must understand what they are required to commission; local SLTs must know how to navigate the system to secure the right support for people with MND; and ‘spoke’ AAC services must be available to ensure that the hubs are supported to manage sensible caseloads, appropriately prioritised.

v. The MND Association has a role to play in advising the NHS on the best approach for people with MND, and supporting them to access services. We remain very willing to work with NHS England in this capacity, and are pleased to have had such positive dialogue with NHS England recently. Nonetheless, we must ask NHS England for firmer evidence that its efforts have improved, or will quickly improve, support for people with MND in this vital aspect of their care.

2. Sources of information

i. Identifying the quality of any service delivered to people with MND represents a substantial challenge: the MND population is small (5,000 people in the UK at most) and only a sub-set of those people will be accessing a given service at any one time, as the disease progresses in a complex variety of ways. Focusing only on England reduces the numbers involved further, albeit that there is considerable turnover within this population, as people with MND die and new cases are diagnosed at a rate of 30% every 12 months. This paper therefore draws together a range of data and intelligence from which the state of services can be assessed, but we acknowledge that this represents a potentially imperfect picture.

ii. The sources of available evidence will be outlined below, along with some over-arching conclusions. The following section will then explore the specific characteristics of the current system as they emerge from the evidence.

a. Survey of speech and language therapists

i. The MND Association conducted an online survey of speech and language therapists (SLTs) who work with people with MND between June 11th and July 6th 2015. It was promoted via the Association’s Regional Care Development Advisers (RCDAs), who work locally with health and care professionals and decision-makers; it was also promoted on Twitter by the Royal College of Speech and Language Therapists.

ii. The survey attracted 43 respondents, which is a small sample. For comparison, the APPG’s call for evidence attracted responses from 432 people who work with people with MND, mostly health and social care professionals, of whom 110 were SLTs. We therefore do not attempt here to draw detailed conclusions from the data generated by this survey, but it does offer some broad insights and some valuable qualitative information. The full results are presented in an appendix to this paper.

	APPG inquiry - all respondents %	APPG inquiry - SLTs %	June-July survey 2015 survey %
Excellent	10	7	5
Very good	38	38	35
Average	25	39	37
Poor	15	15	21
Very poor	0	2	0

Table 1
In your opinion, how would you rate the level of communication support offered to people with MND?

iii. The survey asked for respondents' overall impression of the communication support offered to people with MND, using the same question as the APPG had asked. As Table 1 and Figure 1 show, SLTs who responded to the APPG were somewhat more positive about services than health and social care professionals as a whole. Respondents to the more recent survey offered comparable responses; if anything the results were somewhat less positive than the APPG reported, but it is not possible to say for sure that this is a product of anything other than the small sample size.

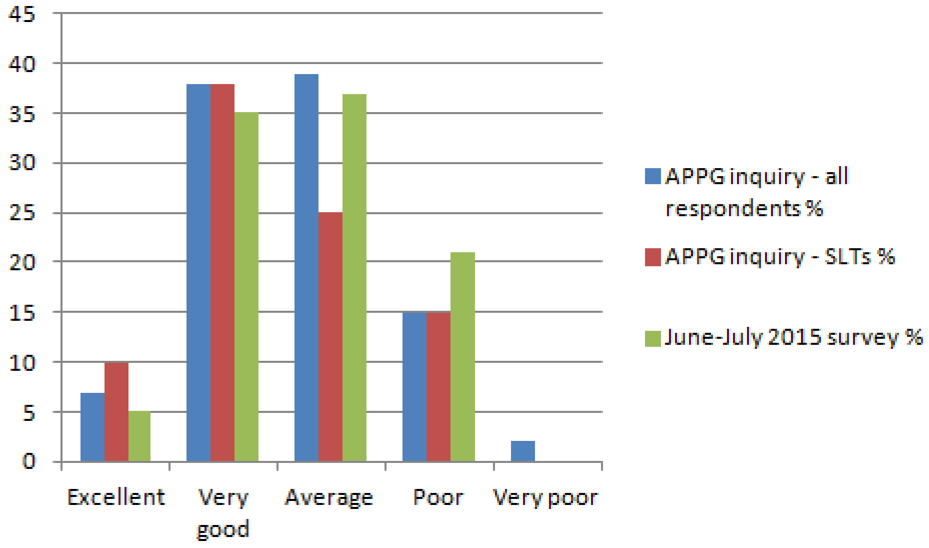

Figure 1
In your opinion, how would you rate the level of communication support offered to people with MND?

iv. The survey also asked respondents whether they had noticed any change in the support offered to people with MND since the APPG's call for evidence in November 2014. For the most part, the responses showed a picture of stability – certainly the sample size makes it impossible to drawn conclusions from the small number of responses that indicated deterioration in respect of assessment and the provision of low-tech aids. These responses contrast sharply with responses relating to hi-tech aids, however, where a much less positive picture emerges. Again, we do not wish to place undue weight on the exact numbers, but we are concerned at the markedly different pattern of responses. If there have been improvements since November, they are not evident in these results.

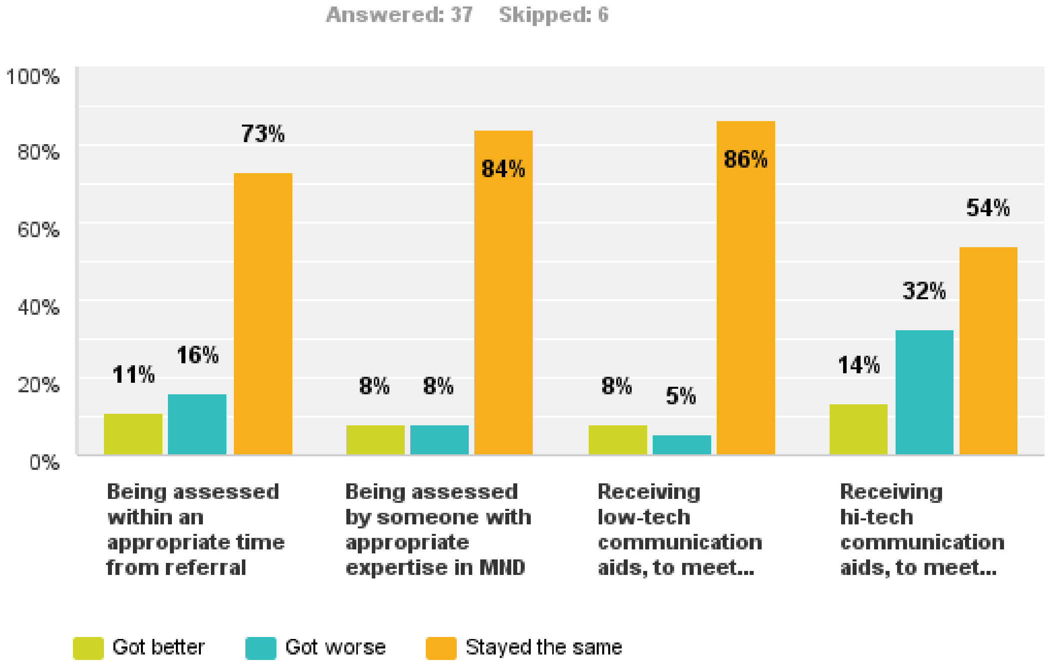

Figure 2
Thinking about the period from November 2014 to now, in your view how did the following aspects of communication support change for the people with MND you work with?

b. Other Association data and intelligence

i. The MND Association funds equipment and other support for people with MND when either it is outside the scope of what statutory services are obliged, or can reasonably be expected, to provide, or *in extremis* when statutory provision has proved inadequate. We therefore have data on our own provision of communication support, and can to some extent draw inferences from this about the state of NHS provision. We also have regular contact with the specialist AAC providers ('hubs'), other NHS services and suppliers to the NHS, and can derive intelligence about provision from that.

ii. In our own submission of evidence to the APPG inquiry, we noted that we had funded some items of AAC equipment when NHS provision had proved too slow, in the expectation that our costs would be reimbursed.[3] Happily, we can report that we have now had reimbursement in one case, the cost of a loan picked up in a second, and a credible assurance of future reimbursement in a third. Through our work with the NHS on this issue we are now confident that similar arrangements can be made, if necessary, in the future.

iii. Less positively, demand for support grants from the Association for use on communication aids continues to rise, as shown in Figures 3 and 4

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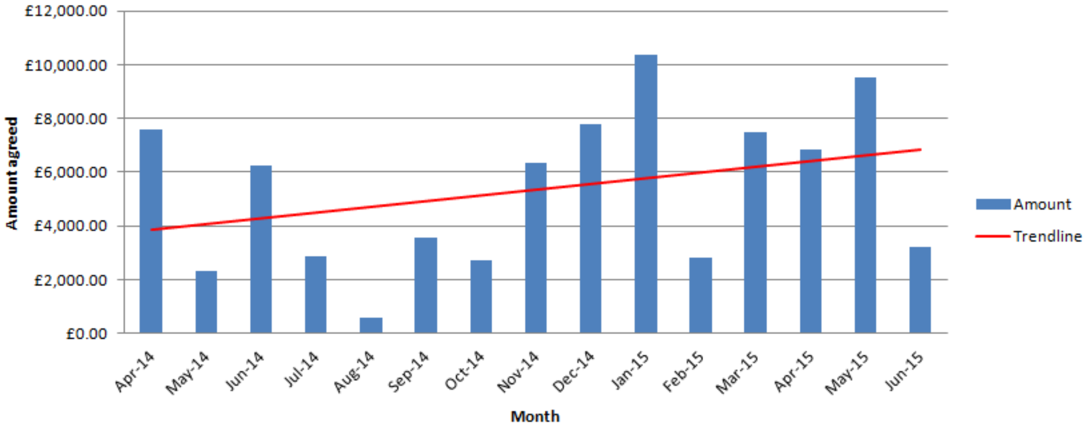

Figure 3

Amount agreed in MND Association support grants for AAC equipment

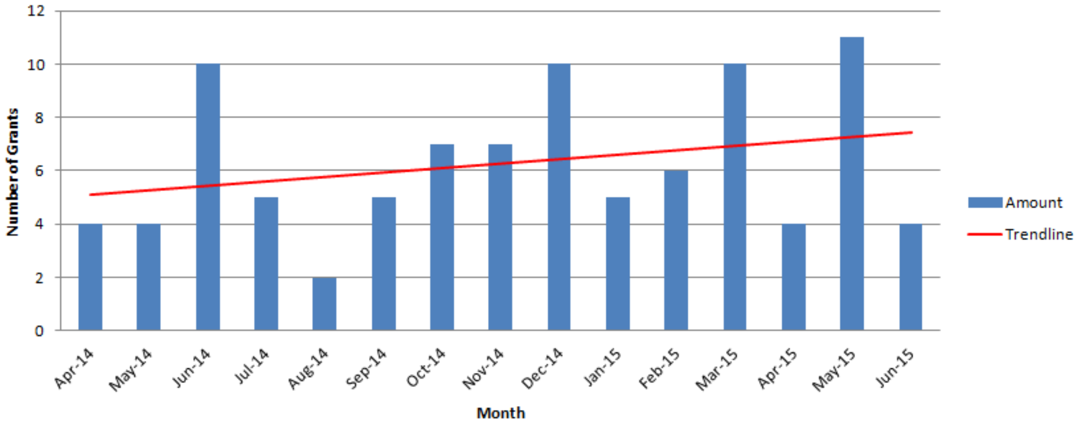

Figure 4

Number of MND Association support grants for AAC equipment

iv. Additionally, we log each query that comes into us in relation to AAC. Many of these result in a support grant being issued as shown above. As the above charts suggest, queries are unevenly distributed over time; viewing them qualitatively, however, they give evidence of many of the characteristics noted in the APPG report: in May and June, correspondents

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[3] http://www.mndassociation.org/wp-content/uploads/2014/12/mndassociationsubmissiontoappginquiryfinal.pdf

variously reported problems finding a hub willing to accept a referral, very lengthy waiting times, an unsuccessful attempt to use an Individual Patient Treatment Request to secure support and a presumably erroneous decision by a CCG to fund an eye gaze system.

v. More positively, a report of an expected waiting time of two weeks for an assessment by ACE in Oxford was sent to us in May, which would suggest that the prioritisation criteria in the service specification are being implemented well there.

vi. We also approached the hubs for an update on their current waiting times. They consistently indicated that they did not wish to provide the information, for a combination of reasons: the data is already being made available to NHS England; gathering it is a complex exercise; and the situation within each hub may change quickly as further progress is made. We believe this is a fair response and therefore have not pursued the information further, either via informal approaches or through Freedom of Information requests. Naturally we hope that NHS England will be able to provide insight into current performance levels among the hubs.

vii. Additionally, we have attempted to explore the geographic area covered by each hub, which has proved to be a complex question. In principle any hub can accept a referral from any part of England, but in practice they are allowed to prioritise patients local to their area. Several hubs have been taking referrals from the area to be covered by the East of England hub when it is up and running, although we understand that currently these referrals are being passed to the Compass service in the Royal Hospital for Neuro-Disability in Putney. No data is held centrally by NHS England on the extent of each hub's 'patch'.

c. Communication Matters website updates

i. A further source of information is the Communication Matters website, which hosts a useful and comprehensive list of all the hubs, including contact details, staffing levels and referral processes.[4] It also includes updates on progress made by some, though not all, hubs.[5] These are summarised here (the dates given are the date associated with the update on the CM website). All centres listed had contracts in place with NHS England at the time of their update.

Electronic Assistive Technology Service East Midlands (EATS) - June 2015

- Developing care pathways and processes
- Recruiting new staff
- Meeting key contacts in local services to inform them about the new service

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[4] http://www.communicationmatters.org.uk/page/contacts-assessment-services-england

[5] http://www.communicationmatters.org.uk/page/updates-hubs-england

- Currently unable to accept referrals.

Access to Communication and Technology (ACT) Birmingham - May 2015

- Undertaking a recruitment drive to increase capacity substantially; expected to be mostly complete by the end of July
- Priority referrals for specialist assessment are being offered an appointment within 8 weeks; standard referrals being added to waiting list
- The waiting list contains over 100 people, the longest wait being from September 2014
- People on the waiting list being asked if they still want an appointment, and those outside the West Midlands reviewed for possible transfer to a service closer to them
- Numerous project groups established to improve and speed up the care pathway, engage with local teams and deliver other improvements; expected to run for two years.

ACE Centre NW, Wessex &Thames Valley - April 2015

- Recruitment to expand capacity has been undertaken in both centres
- A waiting list was opened in April 2014 when the business case was submitted; a significant backlog of referrals currently exists, and consultancy capacity has been brought in to address this
- Dates are being ring-fenced for referrals who meet the prioritisation criteria
- Work is ongoing to raise awareness of the new arrangements with local commissioners.

Assistive Communication Service (ACS) London - March 2015

- The service was previously commissioned to cover four London boroughs, and now covers seven; contact has been made with many therapists in the new boroughs
- Priority referrals are being seen within six weeks
- A training programme is being planned to up-skill local teams and ensure more appropriate referrals
- A new sub-contract has been established for engineering and workshop use for bespoke mounting and switch access.

Bristol Communication Aids Service (BCAS) - February 2015

- BCAS had been operating as a specialised service since June 2013 by invoicing the Area Team directly
- Baseline funding from the Area Team was identified and agreed, identifying historical AAC funding by CCGs up to that point, in January 2015
- Recruitment has been made into two new posts and one existing post; it is underway for several more.

ii. Even from these reports, certain themes can be observed. Recruitment is ongoing in many hubs, and is perhaps not proving as difficult as the APPG report suggested it might – although few hubs report having their full complement of staff in post yet.

iii. The delay in setting up the new system is still being felt, however: several centres report long waiting lists and backlogs of referrals, while even priority referrals are taking six to eight weeks to be seen (where stated); the service specification states that regular assessments should be completed within six weeks and priority assessments more quickly, so the spec is still clearly some way from being implemented. We note that the centre where we received a report of lower waiting times for assessment, of two weeks, is ACE in Oxford, where days are set aside in anticipation of receiving priority referrals.

iv. While the Communication Matters website is a valuable resource, we are somewhat concerned that the information provided in these useful updates is not available for all centres, and is not available via NHS England.

3. Ongoing problems with specialised AAC

i. Within the various sources of evidence available, it is possible to identify certain recurring themes. This section sets these out, and identifies that the challenges within the system are multi-faceted, and have at least to some extent moved on since the APPG report was published. Nonetheless, despite being somewhat fragmented and soft, the evidence does suggest a picture of ongoing difficulties more than a picture of sustained improvement.

ii. While we do not intend to duplicate the content of the APPG report, we particularly wish to draw attention to its fifth chapter, which presented substantial first-hand testimony about the devastating impact of communication problems on people with MND and those around them. This should be kept in mind when considering the impact of, for instance, long waiting times for an assessment or communication aid.

a. Hubs struggling to deliver for people with MND

i. There is no doubt that the operational position of all hubs has advanced considerably since the APPG report was published. In the queries submitted to the Association since our previous meeting with NHS England in April, and in the free text responses to the survey of SLTs, indications of this have begun to emerge – seven responses or messages we received suggested this in total, although sometimes in qualified terms.

It has only recently got better. Previously it was not clear who would fund communication aids. We approached the CCG who declined funding and referred us to NHS England. [...] We now have a clear pathway for obtaining *funding, however, this is only if the patient's hand function is likely to deteriorate within 18 weeks of referral.*

- SLT survey respondent from south London

The hub that we were using could refer to NHS England for the equipment directly. This had two effects, firstly it freed up my time from trying to find a funding stream. Secondly it was a reliable, if slightly slow funding stream.

- SLT survey respondent from Bedfordshire

NHS England provision is beginning to make a difference but I think it still takes too long.

- SLT survey respondent from Buckinghamshire

ii. More commonly however, this progress appears not to be translating into sustained delivery for people with MND. Difficulties manifest themselves in numerous ways: long waiting times (18 reports across both sources), a failure to accept assessments carried out by someone other than the hub (one report), people with MND dying before support is provided (two reports, suggesting multiple instances), incorrectly high thresholds for assessment or failure to accept anticipatory referrals (three reports), people with MND being obliged to self-fund or go without (three reports), reliance on charitable funding (nine reports, and NB Figures 3 and 4 above) or a general inability to secure support (18 reports). Examples of these reports are presented below.

The delay in setting up the local arrangements for specialist commissioning resulted in all external funding processes for communication aids being severely disrupted - this is only just beginning to sort itself out but I do not yet have confidence in the systems.

- SLT survey respondent, location not given

Low staffing levels at [hub].Extremely long waiting times and [the] client's often passed away before [a] communication aid could be put into place.

- SLT survey respondent from Birmingham

We are still not getting assessment from our hub in an appropriate time frame. On occasions it has just been too late for patient with MND (despite referring them 'early'). Even once assessed the time frame for getting any high tech aid is far too long for someone with MND, and is still causing significant concern and distress for patients.

- SLT survey respondent from Surrey

I have a patient who needs eye gaze. [...] I have been trying to secure funding for a device [since] October 2014. I have tried our local AAC hub in Lincoln and the one in Birmingham. I am making no progress despite [the patient's neurologist] trying to assist. I have had the patient's wife on the phone this *morning – she is desperate. He has no hand function and no means of communication.*

- Email to the Association from an SLT

[When people are unable to access hi-tech equipment] we have to rely on the patient and the family securing their own funding, or work on using other strategies and low-tech communication charts to aid communication.

- SLT survey respondent from Surrey, who indicated that people with MND are often unable to access hi-tech aids they have been assessed as needing.

b. Lack of awareness and understanding of the system

i. As the hubs get up and running, a new barrier to people with MND accessing support from them appears to be a widespread lack of awareness among SLTs and others of how the new system is intended to operate. The APPG identified this as a problem, and numerous hubs have begun to put measures in place to reach out to local services, as noted above.

Being assessed within an appropriate time from referral	Being assessed by someone with appropriate expertise in MND	Receiving low-tech communication aids, to meet needs identified in an assessment, in a timely way	Receiving hi-tech communication aids, to meet needs identified in an assessment, in a timely way
Stayed the same	Stayed the same	Got better	Stayed the same
Stayed the same	Stayed the same	Stayed the same	Got worse
Stayed the same	Stayed the same	Stayed the same	Stayed the same
Stayed the same	Stayed the same	Stayed the same	Got worse
Got worse	Got worse	Stayed the same	Got worse
Stayed the same	Stayed the same	Stayed the same	Stayed the same

Table 2

Thinking about the period from November 2014 to now, in your view how did the following aspects of communication support change for the people with MND you work with? (Respondents from Hertfordshire only.)

ii. Within the SLT survey responses, Hertfordshire emerges as an illuminating case study of this problem, as no fewer than six SLTs responded from the area. Of these, four reported working for a service commissioned by CCGs, but two were unsure who commissioned the service; all have the same employer. Their views of how services had changed since November 2014 diverged, particularly in respect of hi-tech aids, as shown in Table 2.

iii. From the free text responses, it appears that a local service, or at least budget, has been supplanted by the new specialised arrangements, and that only some SLTs feel able to navigate their patients through the new system.

We received much needed increased funding and were able to access high tech AAC equipment very quickly. This is now not the case.

At present, there is no funding to purchase high tech communication aids as the budget has been withdrawn.

We can no longer access funding immediately for high tech AAC. Due to the decision to centralise the funding and assessment processes for more complex high tech AAC the length of time people are waiting has significantly increased.

iv. For one respondent, training appeared to have been helpful in supporting SLTs to make better use of low-tech aids:

I think SLTs became more confident assessing needs and selecting appropriate low tech AAC following our in-house trust-wide training during one of our county-wide meetings.

v. Confusion appears to exist about which hub people should be referred to. In the future it may be the new East of England hub in Cambridge, but at present we understand that Compass is taking these referrals. It is not clear which hub or hubs the respondent below is referring to.

The AAC service is not in our area as we are still awaiting a local service. They were accepting referrals but have now stopped and we are being directed to another non-local service. I am not aware of anyone with MND having been seen by it yet.

c. Local services: sometimes driving improvement, sometimes a barrier

i. The relationship between local and specialised services came into focus in numerous responses to the survey. Sometimes this illustrated the need for education about the new systems noted above; at other times, it identified either particularly helpful or particularly problematic practice among local services. The balance was even, with five examples of each among the free text responses and emails to the Association.

CCGs don't know what they're doing. What to commission or who to commission it from.

- SLT survey respondent from East Yorkshire

Increase in staff expertise due to training/skill-mix in department due to employment of new staff. High volume of patients through MND clinic (coming to our hospital as key centre) and many of these do not have local SLTs - this is leading to long delays in seeing an SLT in the first place and consequently to equipment provision.

- SLT survey respondent, location not given

Both got worse and improved. Difficulties with our regional communication aid centre lack of staff and resources. Improvement with availability of iPads within the Department for those clients who were appropriate.

- SLT survey respondent from Herefordshire, with reference to services between April 2013 and November 2014

The outcome of this is that currently, Dorset-wide, there is no funding for AAC for any patient who is not complex enough to qualify for ACE centre assessment/funding. This will include any MND patients who can directly access an iPad.

- Email to the Association, following an unsuccessful attempt to access AAC via an Individual Patient Treatment Request

ii. Although it did not emerge conclusively from the survey, we believe that one substantial reason for the reported pessimism about hi-tech aids may be confusion among local services and their commissioners about their responsibility to commission text-to-speech devices for people whose needs are not, or not yet, complex. These could be either traditional, dedicated text-to-speech devices, or tablet computer-type devices.

d. Other possible problems

i. This paper, like our manifesto and the APPG's report, has focused on institutional issues associated with commissioning, and for good reason: the upheaval in commissioning introduced by the Health and Social Care Act 2012 has been substantial, and it is documented that provision in respect of specialised AAC has come on-stream belatedly. However, there may be additional factors which either have contributed to recent difficulties or may hinder progress in the future. These points are speculative: they arise from 'soft' intelligence gathered by the Association, and were not evident in the major evidence-gathering exercise conducted by the APPG.

ii. **Growing demand**

It has been suggested to us that AAC caseloads of people with MND are increasing, markedly in some areas, despite the overall MND population not exhibiting any substantial rise in numbers. Increased reports of difficulties in accessing hi-tech aids in particular may therefore be partly a result of hitherto suppressed demand becoming more apparent, perhaps as a result of an increase in general awareness of the possibilities offered by technology, and acceptance of computers and similar devices into more aspects of daily life. If this is the case, it has substantial implications for the NHS: it would suggest that until this increase in demand is documented and has levelled off, it is not possible to estimate true levels of need (and therefore of required funding and staffing) accurately.

iii. **Supply chain issues**

Given the importance of hi-tech products to many people with MND as their disease progresses, it is vital that the supply of these devices should be prompt, reliable and affordable to the NHS, in order to avoid any delay to a person with MND in accessing them. It has been suggested informally to us that the supply chain could be made to operate more effectively than it currently does: the NHS often buys from specialist suppliers who are not themselves the manufacturers of the equipment; some may be reluctant to offer a comprehensive package of after-sales support for their device to the person with MND, as this could expose them to risk of the sale ultimately being unprofitable for them. Similarly, they may be reluctant to hold items in stock without a firm order, entailing a delay when a piece of equipment is needed. There is clearly potential for the NHS to use its purchasing power to stimulate a more responsive supply chain, although this may require collaboration between different hubs, which would need to be done with care to avoid unfairly distorting the market. It is not clear to what extent these issues are hindering support to people with MND, but the potential for them to do so clearly exists.

Conclusion and next steps

i. We would like to hear evidence from NHS England of the efficacy of its action to date, and clear commitments to further action on the issues outlined above. The key areas for attention appear to be the development of the hubs, their interface with local and 'spoke' services, and the wider functioning of local SLT services.

ii. We also invite comment on the speculative points we identify: to what extent do these seem to NHS England to be causes of difficulty in delivering services?

iii. We are also keen to play our part:
   - We can provide effective channels of communication to SLTs who work with people with MND, via our regional staff and network of care centres
   - We have updated our AAC pathway to reflect the new system, and have already shared it with NHS England
   - We will be happy to comment on any new guidance or similar documentation advising NHS practitioners and institutions of the best approach in respect of MND
   - We have a dedicated AAC coordinator who can advise local services and assist in coordination between different sources of support, including the MND Association locally or nationally when appropriate.