

Comments on the draft service specification D01/S/b: Complex Disability Equipment – Communication Aids (Specialised AAC Services)

Introduction

- i. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are up to 5,000 people living with MND in the UK. A third of people with the disease die within a year of diagnosis, and more than half within two years. There is no cure.
- ii. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.
- iii. We welcome the new version of the service specification for specialised AAC: we have always supported the design of the new system, and have been frustrated only at the problems and delays in delivering it since NHS England assumed responsibility for specialised commissioning in April 2013, and the new arrangements officially came into effect in October 2013.
- iv. We understand that there may be a further proposal to split the specification into two documents: one specifying the service, the other setting access criteria. We strongly recommend against this. All specifications for specialised services co-commissioned by NHS England contain both elements, and we would not support making an exceptional amendment to the AAC spec alone. Nor would we support a proposal to re-cast specifications for all specialised services at this stage: NHS England's track record in respect of service design and formulating clinical policies suggests that any such exercise would serve only to introduce further substantial delays. NHS England should concentrate its resources on delivering the existing specs, which are for the most part sound, to a high standard.

Comments

- i. One of the recommendations of the report 'Condemned to Silence: Inquiry into Access to Communication Support for people with MND', published in January 2015 by the All Party Parliamentary Group on MND, was that NHS England, "should publish the current version of the service specification for [specialised] AAC on its website."

- ii. Our discussions with NHS England subsequently made clear that the version of the specification in circulation at the time of the Group's report, watermarked 'Interim For Adoption From 01/10/14' was never in fact ratified by NHS England's internal processes. The current draft will therefore be the first update to the spec since the first iteration came into effect in October 2013.
- iii. We were supportive of the 2014 version, which offered some small but welcome amendments to the 2013 spec, and likewise we support the proposed new version, which broadly incorporates these changes and makes some additional but minor modifications. Some of these are changes to wording which we do not believe affect the substance of the specification (if NHS England has in fact made these changes in the expectation of their having a substantial impact, it should issue explanatory notes). Here we offer comment only on matters that we feel may have a direct bearing on the support available to people with MND.
- iv. The only substantial addition to the specification that we can see is the new table under heading 4 'Applicable Service Standards' (page 10) setting out core requirements for what each hub must provide. This appears sound to us.
- v. Under 4.2 'Applicable standards set out in Guidance and/or issued by a competent body' we would like to suggest that our AAC MND pathway be added.¹ This has been developed by the MND Association with Communication Matters, whose Quality Standard for AAC Services is already listed in the spec. We are due to be undertaking a joint communications exercise with NHS England and possibly Communication Matters, in which we expect the pathway will be utilised; it would therefore make sense to signpost to it in the specification. Numerous other service specifications include an appropriate range of condition-specific guidance, so we believe that the pathway's focus on MND does not debar it for inclusion.
- vi. Additionally, we note that the list of providers appears not to have been updated from the 2013 specification. There has been very welcome progress in commissioning and developing new AAC hubs since the original spec was published, so it would be appropriate to include a full list, along the lines of that currently on the Communication Matters website.² We also recommend that the centre at Addenbrookes in Cambridge, which is currently under development, be listed, with an appropriate explanatory note regarding its status and plans for its services to come on-stream.
- vii. The statement about anticipatory assessment and referral in 3.4 is unaltered from the October 2014 draft and we therefore support its continued inclusion. We would, however, recommend having some reference to it in the timescales mapped out under Appendix 1, and also to the need to provide faster support for people with rapidly progressive conditions; the latter is set out clearly in the text of the spec, so it would be helpful to have some note making clear that the 18 week

¹ <http://www.mndassociation.org/aacpathway>

² <http://www.communicationmatters.org.uk/page/contacts-assessment-services-hubs>

timeframe from referral to provision outlined in Appendix 1 is not appropriate for cases involving rapid progression.

- viii. We would also welcome further references between this specification and specification D01/S/c, relating to environmental controls. Specifically, both AAC and EC can involve the use of electronic assistive technology (EAT), which is defined in the EC spec in clear but relatively narrow terms. For people who would benefit from EAT simply in order to use a computer – an increasingly essential part of daily life – but who may not yet have lost their speech, there may be a risk that they struggle to secure appropriate support from the NHS. A clear statement that this responsibility rests with specialised EC services, to avoid confusion about whether AAC services might be expected to step in, would be helpful – notwithstanding that the two should work closely together and may in some cases be the same provider organisation.
- ix. Finally, following meetings with NHS England we have been assured that data collection using a single national dataset has now been initiated. We suggest that this update of the spec creates a useful opportunity to outline the nature of this dataset and collection exercises, even if only in broad terms, in the interests of transparency and ensuring awareness of this requirement across the system.

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