# Response ID ANON-K91M-P77D-4

Submitted to **Consultation on a service specification for Auditory Brainstem Implants (ABI)**
Submitted on **2017-09-07 12:29:48**

## General overview

### 1 What is your name?

**Name:**
Vicki Kirwin

### 2 Who are you responding on behalf of?

**Who are you responding on behalf of?:**
National Deaf Children's Society

### 3 What is your job title?

**Job title:**
Development Manager (Audiology & Health)

### 4 What is your email address?

**Email:**
vicki.kirwin@ndcs.org.uk

### 5 In what capacity are you responding?

**In what capacity are you responding?:**
Voluntary organisation / charity

**If you have selected 'Other' or 'Other public body', please specify:**

### 6 In what region are you based?

**In what region are you based?:**
N/A - National or regional organisation

## Service Specifications

### 7 Please indicate which service specification you would like to comment on:

Auditory Brainstem Implants (ABI)

## Service Specifications (continued)

### 8 Does the impact assessment fairly reflect the likely activity, budget and service impact?

Yes

**If you selected 'No', please tell us what is inaccurate? :**

### 9 Does the document describe the key standards of care and quality standards you would expect for this service?

No

**If you selected 'No', what is missing or should be amended?:**
Because of the similarities in patient groups, NDCS believes that a number of policies outlined in the commissioning specification for cochlear implantation are very applicable to service standards that families of children receiving auditory brainstem implants should expect and should be included here too. From p7 of the specification for cochlear implantation:

"Patients will be advised they have access to urgent medical support as per the standard access for acute ENT emergency care in the Provider unit.

The service will have appropriate policies which cover, as a minimum:
Device failure
Lost processor/s
FM policy and Assistive Devices
Upgrade of speech processor/s

Transfer of care pathway from/to another service

Essential repairs, consumables and spare parts will be provided free of charge to users. Users may be asked to pay for non essential items e.g. decorative covers, holiday loaners and for repair or replacement of parts or devices if damage, loss or failure is determined to be due to inappropriate care, with appropriate provision for appeal."

NDCS believes that all of these policies should include children with ABI since the issues of loss, use with other technologies (such as FM), upgrading of externally worn speech processors etc are all identical for the two groups. Parents of deaf children should be able to expect clear policies laying out expectations of service provision vs parental responsibility.

### 10  Please describe any equality or health inequality impacts which you think we should consider in relation to the proposed service specification, and what more might be done to avoid, reduce or compensate for the impacts we have identified and any others?

**Please describe any equality or health inequality impacts which you think we should consider in relation to the proposed service specification, and what more might be done to avoid, reduce or compensate for the impacts we have identified and any others?:**
None

### 11  Are there any changes or additions you think need to be made to this document, and why?

**Are there any changes or additions you think need to be made to this document, and why?:**
We have two suggestions:

Firstly in Section 2 - Data collection. “Progress with the ABI should be monitored through at least two assessments in the first year and then at a minimum annually after the switch on.” Again referring to the service specification on cochlear implantation, parents of a child with a cochlear implant can expect “at least three assessments in the first year” (p7). Given that this specification is written for children under the age of 5 years, NDCS feels that two assessments a year is not enough to monitor progress and act on any developmental concerns which may be arising. It is not enough to rely on reports from local professionals who are likely to have never met a child before who uses an ABI and have very little experience in this area. Additionally, we understand that development of listening skills with an ABI is likely to take a lot longer than with a cochlear implant and question whether annual reviews following the first two years is enough if a child may not reach their listening potential for a number of years?

Secondly, the statement on safety guidelines (p 4 Post-Operative care, 5th bullet point) is confusing. We can see from the engagement feedback document the reason why the statement “Written manufacturers safety guidelines as indicated for older children” has been made based on the manufacturers not being able to make safety guidelines available for the under 12’s. However, the point now reads as if safety guidelines will only be provided for older children. It should perhaps read “manufacturers safety guidelines written for children over 12 should be provided to all families, including those with younger children, along with an explanation of any key differences parents of younger children need to be aware of.” Or if the specialist teams believe that the safety guidelines are relevant without any key differences then perhaps “manufacturers safety guidelines written for children over 12 should be provided to all families, including those with younger children, until such time as ABI gain CE approval for under 5’s and specific advice for this age group is available.”

## Final question

### 12  Before completing the survey you must declare any financial or other interests in any specialised services.

**c:**
None.

NDCS is the largest charity in the UK working with families of children with all levels of hearing loss regardless of the hearing technologies or communication modes they use. The feedback provided is based on the questions and experiences of families who NDCS regularly engage with, via our Helpline, family events, online forums etc.