

## Implantable hearing devices position statement

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### 1. Background

- 1.1 Children with bilateral severe to profound sensorineural deafness who receive limited benefit from conventional hearing aids are suitable candidates for using cochlear implants and the first child in the UK received one in 1987.
- 1.2 During the 1990's bone-anchored hearing aids became routinely available for children with permanent bilateral conductive deafness that are unable to use or benefit from conventional hearing aids.
- 1.3 For many years cochlear implants and bone-anchored hearing aids were the only implantable options for deaf children who did not benefit from conventional hearing aids. In recent years the range of implantable devices has rapidly expanded and is set to continue this trend.
- 1.4 In addition, the candidature range for each device has widened to include children with additional or complex needs, those with asymmetrical (better hearing in one ear than the other) or unilateral deafness (normal hearing levels in the better ear) and who may continue to use a conventional hearing aid in their better ear, and those with different types of deafness, such as Auditory Neuropathy Spectrum Disorder (ANSO).

- 1.5 Decisions for families are becoming increasingly complex and include considerations and choices such as:
- to have an implantable device or not
  - which technology to choose if their child is suitable for two different types (e.g. bone conduction hearing implant or middle ear implant)
  - devices within and across manufacturers ranges where several manufacturers compete (e.g. cochlear implants)
- 1.6 The range of currently available implantable devices includes:
- Bone conduction hearing implants (BCHI)
  - Active middle ear implants (MEI)
  - Cochlear implants
  - Electro-acoustic implants (hybrid cochlear implant / hearing aid)
  - Auditory brainstem implants (ABI)
- 1.7 Evidence on the long-term reliability of the newest types of implantable devices is not yet available.
- 1.8 The evidence suggests that the majority of children given a cochlear implant or bone conduction hearing implant are continuing to use their implants full-time into adulthood without any problems.
- 1.9 Unless specifically stated, statements in this policy refer to all services who offer one or more of these devices, and all children and their families who are candidates for these devices or currently use them, and who use these services.

## **2. Our policy**

- 2.1 National Deaf Children's Society is committed to a holistic approach to supporting deaf children where their education, health, social and personal needs are met in a co-ordinated way. We believe that implantable hearing devices are one part of this approach and not an alternative to it.

### **Ensuring Informed Choice**

- 2.2 We expect public services that support deaf children and young people to provide information and advice in a way that supports informed choice.
- 2.3 National Deaf Children's Society will also support families in making informed choices for their child by:
- providing clear, unbiased, factual information for families
  - encouraging honest and open discussion of the key issues of which parents need to be aware and that professionals need to address
  - working with other organisations to promote research in implantable hearing devices and ensure that the results are accessible to families
  - providing opportunities for parents to contact other parents, deaf adults and professionals.
- 2.4 Implantable devices are not suitable for all deaf children. Assessments should be offered to parents and implantable devices considered alongside all other technical and non-medical alternatives.
- 2.5 National Deaf Children's Society acknowledges that whilst implantable devices are an option for some deaf children, some parents will choose not to have one for their child. We support their right to make such decisions if they so wish,

providing the child's language and communication needs are not neglected or a young person's own informed choice is not being overruled.

- 2.6 There are also a very small number of young people who are choosing not to use the equipment they were fitted with when much younger. National Deaf Children's Society supports their right to make such decisions.
- 2.7 Deaf children and their families should not have their informed choice diminished by the ability of support services to support the child and the hearing technology they use. For example, education services should be able provide the necessary specialist support to ensure that deaf children can access teaching and learning irrespective of the technology used.

### **Ensuring Effective Professional Practice**

- 2.8 We expect services to comply with nationally developed standards. National Deaf Children's Society will continue to work with government agencies and professional groups in developing good practice guidance and quality standards that reflect the views of parents and young people.
- 2.9 Our Quality Standard documents expect that implant teams working with children will:
- provide information about the technology which is clear, jargon-free and accessible
  - ensure a multidisciplinary approach
  - provide parents and children with effective counselling and support, whether or not the child receives an implant
  - ensure parents and children are given appropriate time and space, particularly after confirmation of deafness, to consider all the information and the implications of implantation
  - ensure that parents are not put under pressure, prior to or following an implant, to change communication methods that work for them and their child
  - give parents realistic information about the potential outcomes for their child
  - ensure parents are given information on potential device failure and risks of surgery; including the anaesthetic, surgical risks, and loss of residual hearing
  - ensure parents considering an implant understand that their child will continue to be a deaf child after implantation and that the child's support needs are met with and without the implant being worn
  - ensure parents are provided with relevant safety guidelines appropriate to their device and of particular relevance to children
  - encourage families considering an implant for their child to meet other deaf children, with and without an implant, and provide the opportunity to meet deaf adults
  - ensure the child is, wherever possible, fully involved in the decision-making process and procedure
  - ensure that children with an implant receive the highest possible standards of lifelong care, with smooth transition to adult services.
- 2.10 We will work with healthcare commissioners to ensure adequate referral pathways are commissioned for families opting for implant assessment, procedure and follow-on care.

2.11 National Deaf Children's Society will encourage and participate in research into the long-term outcomes including educational performance, employment opportunities, psychological, emotional and social development of deaf children with an implantable hearing device.

### **3. Further reading**

[Cochlear Implants: 2016](#), The Ear Foundation

[Cochlear implants for children and adults with severe to profound deafness](#), National Institute for Health and Clinical Excellence, 2009

[Cochlear Implants - A guide for families](#), National Deaf Children's Society, 2016

[Bone anchored hearing aids; Information for parents and families](#), National Deaf Children's Society, 2010

[Quality Standards in Bone Anchored Hearing Aids for children and young people](#), National Deaf Children's Society 2010

[Service Specification No. D9a - Cochlear Implants](#), NHS England, 2013

[Clinical Commissioning Policy: Bone conducting hearing implants \(BCHIs\) for hearing loss \(all ages\) \(Ref: NHS England: 16041/P\)](#), NHS England, Jul 2016

[Quality Standards Cochlear Implant Services for Children and Adults](#)