The response of Auditory VerbalUK to the National Institute for Health and Clinical Excellence Appraisal Consultation Document
Cochlear Implantation for children and adults with Severe to Profound Loss

We thank the Committee for the opportunity to respond to the NICE Appraisal Consultation Document.

We thank the Committee for the invitation to comment on the proposed date for review of the guidance on this technology stated in Section 8.2 as February 2011. Since commencing the review of the evidence for this consultation, there has been a proliferation of further research evidence regarding both the plasticity of auditory development in general and outcomes of bilateral implantation in children in particular. We would urge the Committee to state that the outcome of this particular is an interim guidance only and would suggest that the very recent research is either included within this particular consultation or else a review of the guidance be initiated at least by 2009. While it is unlikely that in such a period, a substantial body of research evidence would be published pertaining to the costs of educational support for profoundly and severely deaf children using CI in the UK, the research evidence from basic neuroscientists in the UK and elsewhere on bilateral cochlear implantation could be updated.

We note that The Board of Directors of the Hearing Committee of the American Academy of Otolaryngology Head and Neck Surgeons has approved a position statement for bilateral cochlear implantation which was published in February 2008 (William House Cochlear Implant Study Group: position statement on bilateral cochlear implantation. Otol Neurotol. 2008 Feb;29(2):107-8). It states “The William House Cochlear Implant Study Group acknowledges the findings reported in the literature and strongly endorses bilateral cochlear implantation in profoundly deaf adults and children. Bilateral cochlear implantation is now considered accepted medical practice”. We realise that the question of the appraisal is not whether bilateral cochlear implantation is acceptable but rather the cost effectiveness. Our concern is that there are children whose maximal benefit of binaural hearing via implantation will miss their window of opportunity because a decision is taken without considering the most recent evidence. We already know that hearing children need a more advantageous signal to noise ratio to discriminate speech in background noise compared to adults. The same is true for hearing impaired children but to an even greater extent. There is already evidence to suggest that simultaneous bilateral cochlear implantation allows children more effective access to speech when listening in background noise (Papsin and Gordon “Bilateral cochlear implants should be the standard for children with bilateral sensorineural deafness.” 2008 Curr Opin Otolaryngol Head Neck Surg. 16(1):69-74)

It is of major concern to us as Auditory Verbal practitioners in the habilitation of children with hearing impairment that each child is fitted with their most appropriate technology to give him or her the access to the sounds that would be of most benefit to each individual child. We agree for the need for a highly considered opinion as to what might be in each child’s best interest. We do however have increasing experience of offering habilitation to children with bilateral implants and observe distinct localising behaviours that are not seen amongst our...
unilaterally implanted children. We currently offer pre-school habilitation programmes to approximately 50 families per year: 17 children have bilateral implants (34%), 16 children have unilateral implants and the remainder are hearing aid users. The comments below are made given our intensive experience of working with children who have severe to profound loss of hearing and with their parents.

Section no:

1.2 Whilst we appreciate that the recommendations in the previous ACD did not constitute the Institute’s formal guidance, it is disappointing to see that simultaneous bilateral cochlear implantation is not an option for prelingual children in the current recommendations. Please see comments above.

In addition to the two categories of patients defined (and the potential re-instatement of prelingual children), the following categories of patient should be considered:

Children with additional difficulties (including a fluctuating, conductive hearing loss) in whom the better hearing ear is only marginally better (ie 5-10 dBHL) than the stated 90 dBHL at frequencies of 2 and 4 kHz in the absence of any conductive overlay and without acoustic hearing aids.

1.4 Within the UK, the expectation of many professionals for a child with severe hearing loss using acoustic hearing aids is that the speech, language and listening skills will inevitably be delayed. This does not necessarily have to be the case. The UK practices of offering monitoring and support following diagnosis rather than intervention and remediation often leads to a child with severe hearing loss lagging behind his/her hearing peers. This is not necessarily as a result of inadequate technology but instead can be due to insufficient training of family and carers in promoting the development of listening and speaking.

If ‘adequate benefit’ is applied in its current form, it is possible that children with severe deafness may receive implants when other habilitation strategies may be of better service to them.

1.5 See also section 4.3.4. Who will be the arbiter of the ‘valid trial’ of a hearing aid? If the Implant Team recommend that local audiology services improve the hearing aid fitting who will judge whether a desired outcome has been reached, or indeed could be improved upon?

1.7 Although it is agreed that “Assessment of cost should take into account acquisition costs, long term reliability and the support package offered.”, it is potentially worrying since the support package described on paper can be somewhat diluted in practice.

4.3.9 Our experience with working with children with bilateral implants is in accord with the comments of this section. We believe that the evidence reviewed within this Appraisal does not fully reflect the outcomes of bilateral cochlear implantation.

4.3.12 In addition for the need to review more recent evidence pertaining to the cost-effectiveness of bilateral implantation, mention should also be made of the special
category of candidate paediatric implant users who have a diagnosis of Auditory Dysynchrony/Auditory Neuropathy. Children with this diagnosis may present with functional hearing akin to that of a severe to profoundly deaf child although their audiological thresholds may indicate a lesser degree of loss of hearing sensitivity. Further research to determine the circumstances under which implantation should be recommended for this sub-population is required.

Finally, in the Executive Summary (section 1.6.2) and in the Overall Summary of Effectiveness in children (section 5.7) of the Effectiveness and Cost effectiveness of Cochlear Implants - Final report, no consideration is given to the following points:

The urgent need to consider the impact of early, intensive habilitation such as Auditory Verbal Therapy programmes for children with cochlear implants on the following:

- Competancy in spoken language
- Competency in literacy
- Do children receiving implants prior to school entry whose spoken language competency is equal to their peers at 5 years of age, maintain parity with their hearing peers throughout school?
- Does early, intensive habilitation (pre and) post-implantation reduce the need for educational support in later childhood while still enabling the child with an implant to fulfil their potential? (That is, would measures of verbal and non-verbal IQ (or similar), be equivalent?)