• Cochlear implants have opened up a world of sound and communication opportunities to profoundly deaf children.

• But what about the small, but growing number of children with cochlear implants who have additional and significant other disabilities?
• Autistic spectrum disorders

• Cognitive difficulties, which are likely to prevent normal progress

• Physical difficulties

• Visual impairment
Previous studies; measurable benefits and the professional experience

- Implanting children with Down’s syndrome; [England et al 2010]
- Language development [Fukuda 2003]
- Speech production and listening [Hamzavi 2000; Waltzman 2000; Nikolopoulos 2008]
What about the Parent or Family Experience?

• Wiley et al [2005] interviewed parents of children with implants and complex needs with the focus being on communication outcomes

• McCracken [2012] in a major study for the NDCS interviewed 51 parents of children with complex needs, 12 of whom had implants

• this wide reaching report focussed on the role of professionals, and educational and audiological management
Our Study

• We wanted to focus on the parents’ perspective exclusively, and look in detail at their experiences and opinions concerning cochlear implantation – from pre-referral, through the assessment phase, surgery, tuning and follow up
10 families took part in the study

<table>
<thead>
<tr>
<th>Child</th>
<th>Age</th>
<th>Age at CI</th>
<th>Years implant use</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. boy</td>
<td>8.5 years</td>
<td>2.10 years</td>
<td>5.6 years</td>
</tr>
<tr>
<td>2. boy</td>
<td>8.4 years</td>
<td>3.10 years</td>
<td>4.0 years</td>
</tr>
<tr>
<td>3. boy</td>
<td>11 years</td>
<td>5.9 years</td>
<td>5.0 years</td>
</tr>
<tr>
<td>4. boy</td>
<td>2.6 years</td>
<td>1.4 years</td>
<td>1.2 years</td>
</tr>
<tr>
<td>5. girl</td>
<td>3.6 years</td>
<td>1.5 years</td>
<td>2.0 years</td>
</tr>
<tr>
<td>6. boy</td>
<td>10.5 years</td>
<td>5.3 years</td>
<td>5.0 years</td>
</tr>
<tr>
<td>7. girl</td>
<td>2.11 years</td>
<td>1.11 years</td>
<td>1.0 year</td>
</tr>
<tr>
<td>8. boy</td>
<td>9.0 years</td>
<td>1.10 years</td>
<td>7.0 years</td>
</tr>
<tr>
<td>9. boy</td>
<td>8.6 years</td>
<td>5.5 years</td>
<td>3.0 years</td>
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<tr>
<td>10. girl</td>
<td>10.0 years</td>
<td>4.0 years</td>
<td>6.4 years</td>
</tr>
</tbody>
</table>
Data Collection

- Each of the families were interviewed using a semi structured format.
- Participants were interviewed at home and lasted around 1 hour.
- All interviews were audio recorded and transcribed.
5 main themes were identified:

- Impact of cochlear implantation
- Assessment process
- Educational issues
- Management of technology
- Overall perceptions
Theme 1; assessment phase

- 6 of the 10 families had experienced significant delays during the assessment phase.
- 2 families felt the delays were necessary due to their child’s frail health.
- 4 families felt the delay was due to a reticence to implant their complex child.
Assessment phase

- The 4 families whose children had been implanted more expediently were all the most recently implanted.
- Still, 1 family felt that the implant team would have delayed implantation without her intervention.
- “I wouldn’t say they advised against it - I would say I pushed for it more than they would have liked - they would have definitely waited longer if I hadn’t pushed.”
## Theme 2; the benefits of cochlear implantation

<table>
<thead>
<tr>
<th>Impact of CI</th>
<th>Number</th>
<th>Typical comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase in quantity and quality of vocalisations</td>
<td>6/10</td>
<td>“he’s a lot more vocal and changes his vocalisations- he’s changed from quiet to loud cos he can hear himself more”</td>
</tr>
<tr>
<td>Perceived improvements in listening</td>
<td>6/10</td>
<td>“he does seem to be listening to you, turning his head to see what you are saying”</td>
</tr>
<tr>
<td>Better communication</td>
<td>7/10</td>
<td>“he is trying to say more, recently he’s been more proactive in initiating speech than before”</td>
</tr>
</tbody>
</table>
### Theme 2; the benefits of cochlear implantation

<table>
<thead>
<tr>
<th>Impact of CI</th>
<th>number</th>
<th>Typical comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improved inclusion in family life</td>
<td>8/10</td>
<td>“she is more included in the running of the house, people coming, kids running around”</td>
</tr>
<tr>
<td>Improved responsiveness to the environment</td>
<td>7/10</td>
<td>“he’s a lot more aware of what’s going on around him and more settled in himself”</td>
</tr>
</tbody>
</table>
Theme 2 ; benefits of cochlear implantation

• All 10 families said they had been pleased with the implant overall; 5 expressed that feeling very forcibly

• “I swear by that implant- for me it’s crucial, she wouldn’t be her without it”

• Whereas the other 5 were more measured

• “when he’s actually able to concentrate even for a few minutes, at least he’s getting a chance to respond, it’s not a lot, but it’s something!”
Theme 2; benefits of cochlear implantation

- the better communication reported by 7 out of the 10 families ranged from small increases in pre-verbal communication skills to a dramatic increase in 1 child’s comprehension and expression of spoken language.
Theme 3: Educational issues

- 7 out of the 10 children whose families were interviewed attended schools for children with severe learning difficulties. 3 children were not yet old enough to attend school.

- 1 child attended a resource base for deaf children located within a mainstream school.

- 4 of the 7 families expressed concerns about their child’s educational placement.
Theme 3: Educational Issues - concerns

- The school was unable to meet the child’s learning and listening needs

- Special schools are not good listening environments
  - “it’s a really noisy class- I went to pick him up one afternoon & I thought this is not the right environment to learn to keep your implant on- if I had a choice I’d take mine off!”

- The lack of input from teachers of the deaf

- The lack of communication between home and school
Theme 4; practical management of the implant system

- Out of 10 families, 7 had chosen the device they wanted for their child.
- All 7 families chose the implant system which best suited their child’s physical needs, with 6 choosing as little as possible to be worn on the ear, and 1 opting for the smallest device possible.
Theme 4; practical management of the implant system

- Wearing the speech processor all day is a significant challenge
- 4 families felt their child wore the processor all their waking hours
- 6 described their children as intermittent users - with issues such as medical complications, and head control impeding the wearability
- 2 families expressed the necessity for their child to have periods of quiet during the day, particularly in noisy environments, where they became distressed
Conclusions

- This study starts to explore the outcomes and benefits of cochlear implantation for this special group of children by listening to those best placed to comment on it; the parents themselves
Conclusions

• Research now needs to find ways to measure changes systematically and appropriately.

• We also need to consider:
  
  • *The pathways to assessment*
  
  • *Educational support and resources, particularly for those working in special school settings*
  
  • *Long term management at home and school*
  
  • *Outcomes for special groups such as implanted children with autism*
• Thanks for listening!

• And I would like to thank Advanced Bionics for supporting this project