Teenagers and cochlear implants: opportunities and challenges

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Adolescence……

• A time of change … For all teenagers……

• For deaf teenagers… a time of great change……

• Over the past few years even greater changes for them……

• Educational systems, political systems……

• And…. The technology bringing different expectations……
Young people with cochlear implants: a growing group?

• Growing numbers of teenagers with cochlear implants….

• Three groups:
  ◆ Those implanted young, and now teenagers….
  ◆ Those implanted later and now teenagers…
  ◆ Those implanted as teenagers

• Increasingly those implanted as young adults..

• And a lot we don’t know about them…..

• Let’s think about adolescence
Adolescence: Time of transition

• Human beings need: (Schultz (from Luterman)
  ▶ Affiliation
  ▶ Affection
  ▶ Control

• What relevance has this to deaf young people? And those with implants?
Affiliation/Connection

• Peer group becomes more important than family
• What is the peer group? Peers have more influence than parents… or teachers!
• Parents fear “losing” their child..what about the child with an implant?

• Who is the peer group… if mainstreamed….  
• Who is the peer group … if born deaf and implanted as young adult…
Affiliation/Connection

- The deaf young person becomes aware of difference
- They question their deafness: and the implant
Affection

- Linked with self-esteem: what about the implant?

- Young person may feel they carry parents’ aspirations and parents’ success achieved by young person

- Parents’ choices visited on deaf young person – choice of education, of cochlear implantation
Control

- Young person needs to develop control
- When do parents relinquish control?
- Young person needs to learn how to deal with failure... do we let them?
- Overprotection leads to passivity – they need to take responsibility for own decisions and behaviour

- What about those with implants...
Listening to deaf young people

- We interviewed 29 young people with implants......
- All wearing their implants, all would want another...available as a booklet from us..
Issues from young people

- Knowledge - Variable and often limited understanding of cochlear implantation
  - “I get hit – it kill me…..”

- Decision-Making: all were happy with the decision made by their parents on their behalf:
  - “It’s my decision now…”

- Concerns….. 34% worry about their implant…..
Young people concerns..

• “The fact that it can break down and the fact that some time in your life have to have another operation to replace it.”

• I’m fine with being deaf – it’s just the actual breaking down. It’s like having some of your organs failing.”
Family and Social Relationships

- **Family**
  - Positive about communication

- **Friends**
  - Mostly a mix of hearing or deaf
  - Flexible communication skills, speech and/or sign depending on need.

- **Social gatherings**
  - Wanted groups for meeting other implanted Teenagers
Are you deaf or hearing?

- “I’m deaf but I can hear with my implant....”

- For the first time it is possible to be both...

- “ I can embrace the deaf and hearing worlds.....”
Young people talking…

“I know I’m deaf..without your cochlear implant you are always going to be deaf, it’s hard to cope with, I always want to be normal”

“I’m a bit of both – when I’m at the airport and there’s all these announcements I think I’m deaf and weird! I do! When I’m at the deaf club I think I’m deaf but here with my family I’m in the middle”

“To be honest inside me I’d say I’m hearing because I can hear what everyone else is saying.”
RUTH talking...

- “They say (my mainstream friends) I’m not deaf, because I can hear…….”

- “I HATE it when they say that…..”

- Discuss…..
At secondary or high school:

- Child may have done well at primary stage
- At high school it’s different:
  - Demanding curriculum
  - Demanding language
  - Poor acoustics
  - Change of teachers and listening conditions
  - Great deal of group work and conversation…
What about teenagers with implants at high school?

• Implants may appear to work too well!
• Why?
• Speech intelligibility is NOT the same as linguistic ability
• When they go to mainstream schools because they talk normally it may be assumed that all is well……
• “The mainstream teachers don’t know – because she sounds OK and doesn’t cause a problem…..”
The teenagers still have a hearing loss….

• ... we know the effect of moderate, unilateral hearing loss on education (eg Most, 2005)

• And the issues are subtle.............they mishear, and misunderstand... and the language may remain delayed
Teenagers talking….life in school (The Ear Foundation educational study with RNID)

• “I need one person at a time, just one person at a time not all the same time, whoo, over my head, I lose control. It is quite hard to work…other people talk too fast, then walk off”

• *Mainstream student (14)*
“Group work is the biggest pain you could ever possibly imagine. Small group is all right but big group or class discussions they are the worst.” Mainstream student, 14
Why? ….. this relates to the work of Seeber and team….

- Even bilaterally implanted adults, doing well with implants, have difficulty in localisation in reverberant surroundings...

- What about in noisy classrooms… the effect on teenagers…. With an imperfect signal…with busy, demanding conversations going on.. And they miss it……. 
What do they want?

- In classroom:
  - 76% ci helps in class
  - 7% sign support is as helpful
- They need visual clues – but not the same as profoundly deaf before
- Note-taker
- Electronic captioning
- Pre-class preparation
- Acoustics
- Teaching styles..
What do they want……

• Strategies to become independent learners… good teaching techniques…
• Information about their deafness, about managing the technology and acoustics
• Pre-class preparation
• Flexible support and communication …….. changing over time..
• Peer group support
• The same opportunities as other teenagers…. Some “street cred!”
European wide study – the strongest issue for parents… long-term educational support

- Training for local professionals was by far the most common issue to be raised by parents and professionals –

- Especially in mainstream, for teachers and classroom assistants, the need for long-term management – the early support was not continuing as children grew into adolescence and they needed support into adulthood –

- Supported by Cochlear Europe
But...do we know....

- How best to support deaf young people in high school with the latest hearing technologies?
- Their needs are more subtle than before.....when they were obvious....
- “new developments ensure that their educational needs are even more diverse and complex” Leigh, 2008
- They are functioning neither as profoundly deaf as in the past, but nor as hearing young people.. Therefore...
Cochlear implants for teenagers…

• We haven’t cured deafness, but we have changed it..

• More in mainstream schools…

• More using spoken language

• Improved educational attainments

• Improved psycho - social adjustments…. no evidence of greater mental health problems in the group
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- Our survey of young people…
How well do you understand people: (%)

- Not at all
- A little
- Well
- Very well

- In quiet
- In noise
- With one person
- In a group
Can other people understand what you say?
How helpful was your implant at...(%)

- school
- college
- university
- work

- no help
- a little help
- helpful
- very helpful
Did you get extra support or help for your implant at:

- School
- College
- University
- Work

- a lot of help
- some help
- no help

[Graph showing percentages of help at different locations]
What would you like:

• 57 free responses – 33 happy:
  ▪ “I am happy with support i have had....”

• Technical updates:
  ▪ Advice on what the new technologies are
  ▪ Regular updates

• Ideas:
  ▪ Would prefer technicians to be able to sign..
    ▪ Video conference for mapping
    ▪ Don’t change the map!
They should seriously listen to implant users and requests instead of ASSUMING that the new technology is better than the old!
Comments at university and work

• “My University is not deaf aware enough. They think because I speak I can understand everything. If I was a signer my needs would be obvious”

• “More information on related devices made available to employers and deaf awareness courses to be made available for a wider range of jobs.”

• “My boss doesn’t have time to talk about what I need.”
It’s a new world.....being deaf differently

- Communication has changed....
- Teenagers want to take control of technology
- Professionals can no longer stay in the clinic.....
- We have the technology...
- For them to be independent
- Into the world of work..
- “I thought FM was just for school”
What do they want and need…..

• And what can we do…(assuming the technology is fine……!)

• Address psycho social issues which are part of adolescence….for this group…self esteem is the most important thing you can give them and it affects learning……

• Address the long-term educational needs… in the UK and elsewhere anecdotal evidence that teenagers going back to special schools at high school level…

• Deaf educators – can they keep up with the pace set by surgeons?!
What can we do? Many initiatives…

• Programmes for teenagers…Teenzunited…
• Termly curriculum days for teens – 60% in mainstream do not see other teens with implant
• Euro Teens Friendship week
• Downloadable info; Apps
• Into the world of work…………
• Deaf Awareness in a Technological era
• Virtual conference – Dec 2013

www.earfoundation.org.uk