Unlocking Hidden Communication and Cognitive Potential

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Multiply Involved Children

- Are cochlear implant candidates
- Our role is to help these children to achieve their full potential
- Expanded resources and expertise needed to serve these children well
- Improvement in language, cognition & QOL are important outcomes
- Outcomes research and new measures are needed
Intrauterine drug & alcohol exposure
Intra-ventricular bleed at birth
Congenital heart disease
Sensory integration, fine and gross motor delays
Oral motor dysfunction
Under-fit amplification
Habilitation – sign only
Alex Age 9 Years, 6 years post CI (implanted age 2 years, 9 months)

- Video not yet available for website
- Austin was developed open-set word recognition after 18 months of implant use
- Development of spoken language was slow and articulation ability complicated by his oral motor issues
- He is enrolled in a total communication program
- His main mode of communication at home is spoken language
## Ethan: CHARGE Syndrome
### Implanted Age 36 Months

- **Tracheotomy**
- **Developmental Delay**
- **Visually impaired**
- **Receptive language**
  - Exposure to sign and augmentative communication
- **Expressive language**
  - Natural gesture

<table>
<thead>
<tr>
<th>Pre-implant</th>
<th>Post-implant</th>
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<tr>
<td><strong>Word recognition</strong></td>
<td><strong>Receptive language</strong></td>
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<tr>
<td>◦ Closed-set: 24 months</td>
<td>◦ Oral with sign support</td>
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<tr>
<td>◦ Open-set: 36 months</td>
<td><strong>Expressive language</strong></td>
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<td><strong>Expressive language</strong></td>
<td>◦ Sign</td>
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<tr>
<td>◦ Augmentative communication</td>
<td>◦ Spoken language (post decannulation)</td>
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Ethan: Age 8, 5 Years Post CI (implanted age 36 months)

- Video no available yet for the web
- Ethan uses an augmentative communication device – he types a word on a touch screen and then activates the device to voice the word
- Ethan main mode of receptive communication is spoken language
- He is currently enrolled in a special education classroom rather than a TC program and has an aid that signs.

Open-set Speech Perception: LNT 96%; PBK–50 Word 52%; HINT –C, Quiet 33%
Estimates of additional disabilities among deaf children range from 20 to 50% (Gallaudet Research Institute; www.gallaudet.edu)
Evaluation of Children’s Cognition & Learning

- Pre-school intelligence testing has low reliability in typically developing hearing children.
- Deaf children are often language malnourished and therefore their language ability may not reflect their cognitive potential.
- Additional disabilities of vision and motor function may limit or preclude standard tests of reasoning.
Evaluation of Cognition & Learning in Young Deaf Children

- Language, attention, memory, social responsivity, motor skills, visual spatial skills
- Snap shot of todays skills & what skills are needed for progress
- Does not predict progress beyond a year or after intervention with CI
Early History of Controversy
- “Stars” were implanted to prove CI was effective
- Achieving age appropriate speech, language & mainstreaming defined success
What is the Meaning of Success?

- Spoken language?
- Mainstreaming and academic success?
- Improved language, spoken or sign?
- Quality of life?
  - Increased quality and variety of engagement with others
Why Are These Children Excluded?

- Professional lack of knowledge & discomfort
- Resource and time intensive:
  - Audiologic evaluation and programming
  - Care coordination
  - Difficulties identifying therapists & school based services appropriate for CI candidate/recipient
- Concerns regarding cost & resource allocation
  - family, CI clinic, society
- Full term, fetal distress
- Cerebral palsy (spastic diplegia) – guarded prognosis for independent ambulation
- MR: diffuse brain damage
- Family pursued auditory verbal therapy
- Age at first CI: 11 months
- Age at second CI: 4 years
John: Age 11, 10 Years Post CI (implanted age 11 months)

- Video not available for website yet
- John rapidly developed open-set speech discrimination and spoken language
- He has always been mainstreamed at grade level
- He walks independently and plays many sports

Open-set Speech Perception: CNC 88%
HINT Quiet 96%, S/N +5 73%
Jack

- Micro preemie born at 25 weeks
- Severe cerebral palsy
- G– tube
- Dedicated parents
- Multiple therapists including AVT
- 1st CI age 14 months
Jack: 7 Years Post–CI

- Post implantation diagnoses:
  - Quadriplegia/no motor memory
  - Cortical blindness
- Detection: 20 – 25dB
- MAIS 38/40
- Unable to use augmentative communication systems
- Word recognition not measurable
- Social responsivity present
- Parents report understanding of spoken language and enjoyment of music
- Hope for future: brain computer interface for mind control of devices

- Video not yet available for website
No accurate way to determine which infants and young children will be able to develop significant receptive and expressive language.

Challenged children may benefit and experience improved quality of life in ways not currently measured in our clinics.

Without CI these children’s potential for language and cognition may not be fulfilled.
Rosie

- Multiple congenital medical problems
  - Hypoparathyroidism, renal tubular acidosis, choanal atresia, developmental delay, cerebral palsy
- Aided by 12 months of age
- AVT and sign language
Rosie: Age 8, 6.5 Years Post CI (implanted age 2 years)

- Videos not available yet for website
- Rosie has open-set word recognition and spoken language
- Her primary mode of communication is spoken language
- Mainstreamed in school with sign interpreter for support

Open-set Speech Perception: PBK–50 Word 84%; HINT–C Quiet 83%, S/N+10 77%
Life is not measured by the number of breaths we take, but by the moments that take our breath away

Anonymous