Unlocking Hidden Communication and Cognitive Potential

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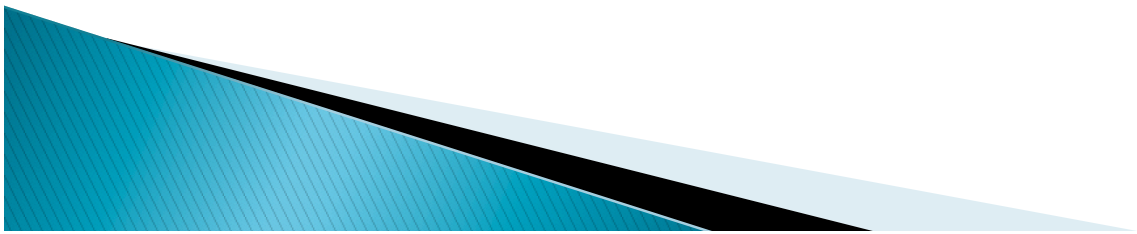
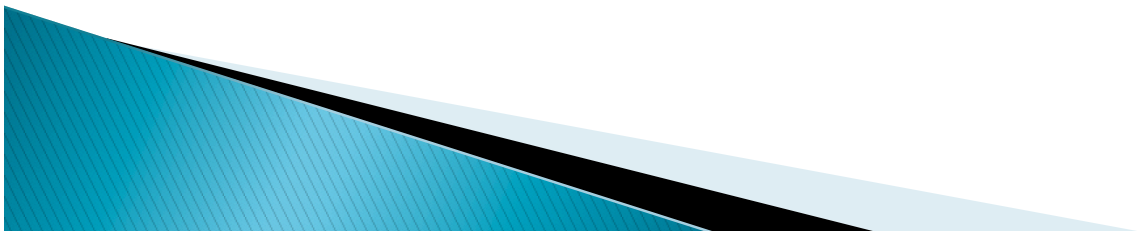
Multiply Involved Children

- 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



Alex

- 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 progrom
- 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

Pre-implant

- Word recognition
  - Closed-set: 24 months
  - Open-set: 36 months
- Receptive language
  - Oral with sign support
- Expressive language
  - Sign
  - Augmentative communication
  - Spoken language (post decannulation)

Post-implant

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

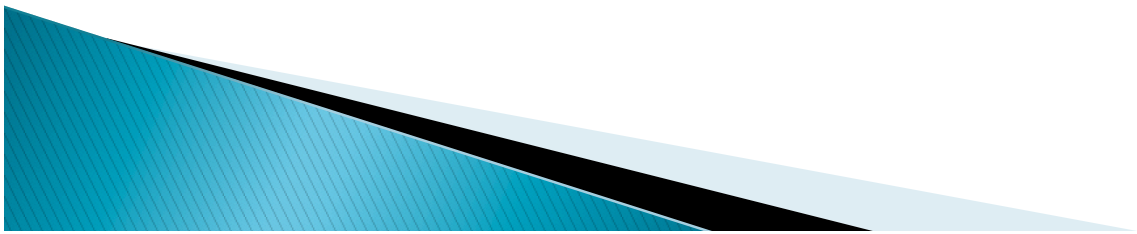
Video

- 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.

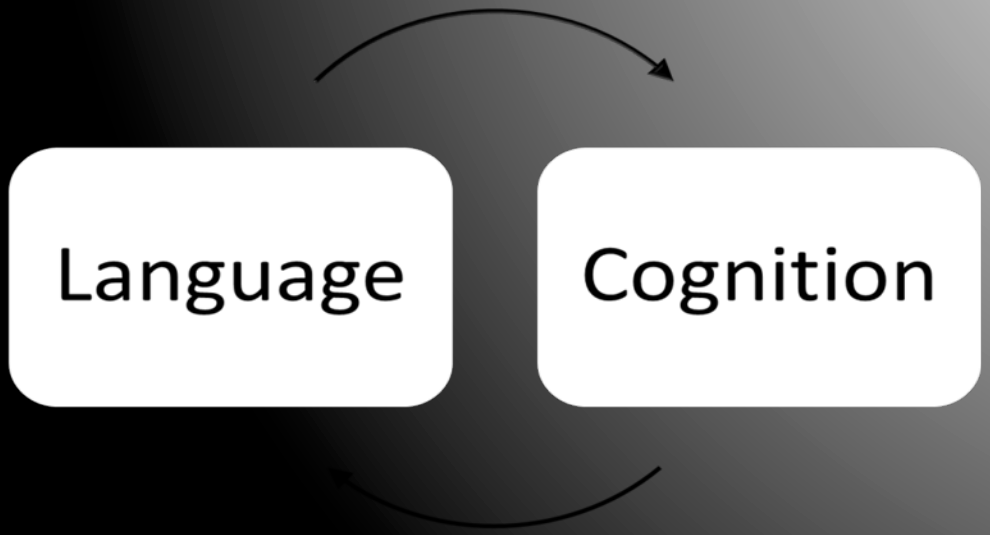
Open-set Speech Perception: LNT 96%; PBK-50 Word 52%; HINT –C, Quiet 33%

Deaf "Plus"

- Estimates of additional disabilities among deaf children range from 20 to 50% (Gallaudet Research Institute; www.gallaudet.edu)



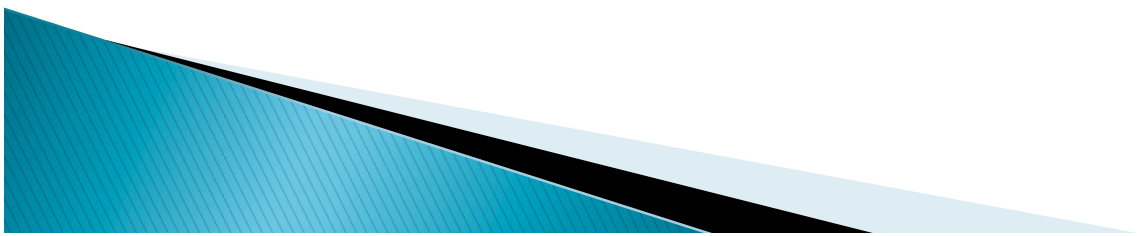
The Relationship Between Language & Cognition



- **Children with implants can speak, but can they communicate**? Robbins AM, Svirsky M, Kirk KI.; Otolaryngol Head Neck Surg. 1997 Sep;117(3 Pt. 1):155-60.

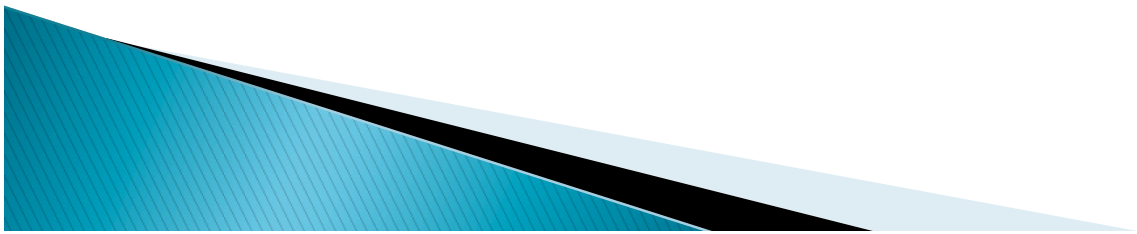
Evaluation of Children's Cognition & Learning

- 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



Why Are These Children Excluded?

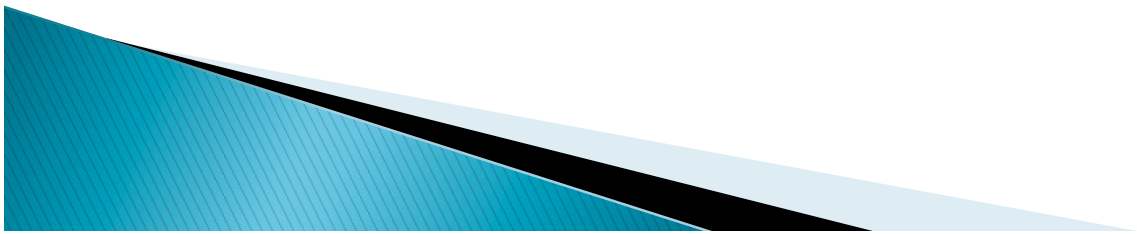
- Early History of Controversy
  - "Stars" were implanted to prove CI was effective
  - Achieving age appropriate speech, language & mainstreaming defined success

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

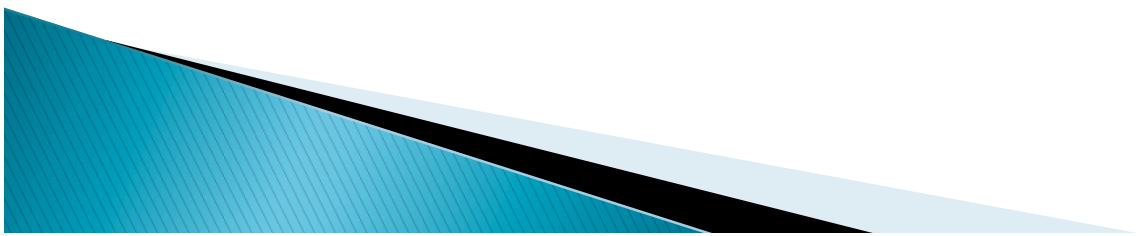
Jack: 7 Years Post-CI

- 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

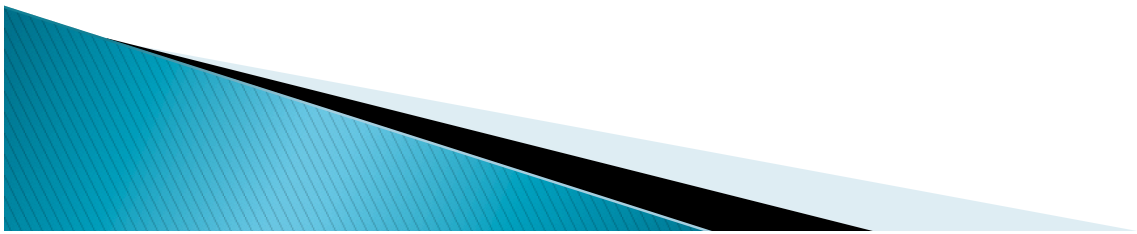
Conundrum

- 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

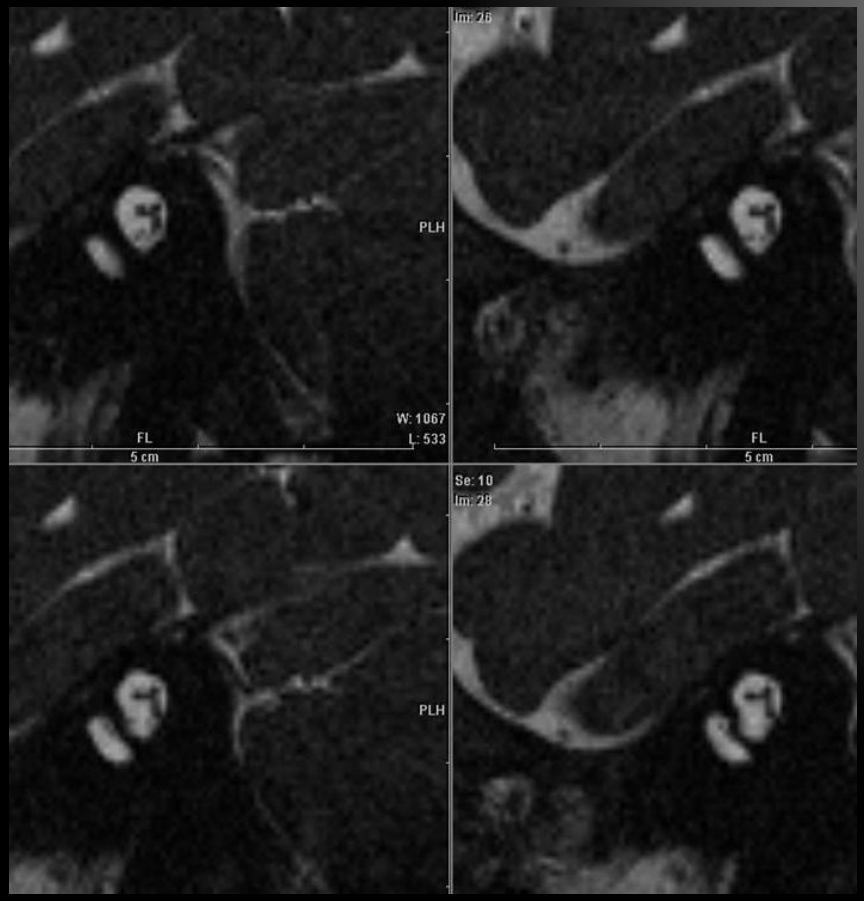


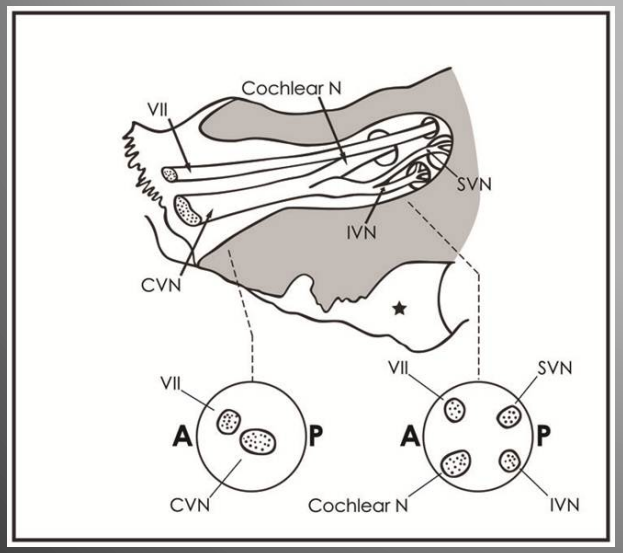
Rosie

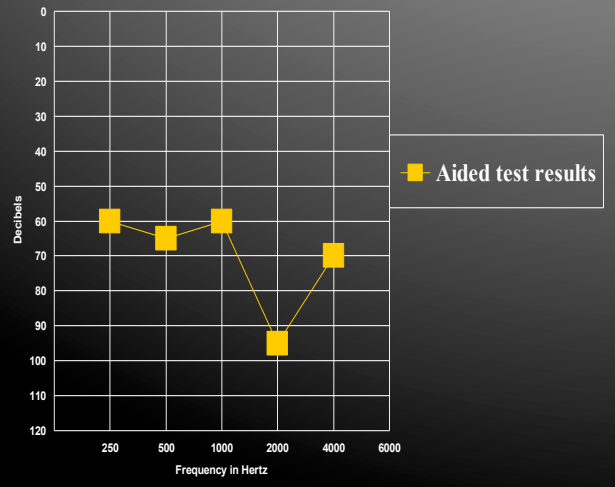
- Multiple congenital medical problems
  - Hypoparathyroidism, renal tubular acidosis, choanal atresia, developmental delay, cerebral palsy
- Aided by 12 months of age
- AVT and sign language



Rosie: Cochlear Nerve Deficiency







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

Anonomyous