

North Carolina Council for the Deaf and Hard of Hearing

Quarterly Meeting Minutes

November 5, 2022

9:00 am – 12:30 pm

Virtual Meeting

Members Present:

Christina Armfield
Greta Knigga-Daugherty
Meredith DeNaples
Kevin Earp
Michael Evola
Rebecca Freeman
Dr. Erika Gagnon
Pattie Griffin
Randal Lee Hartline
Betty Kelly
Mike Lupo
Dr. Robert Nutt
Dr. Claudia Pagliaro
Daphne Peacock
Laurie Ann Rook
David Rosenthal
Donald Tinsley Sr.
Hope Turpin

Ex Officio:

Jan Withers (Present)

Liaison:

Kimberly Harrell (Present)

Members Absent:

Antwan Campbell
Rep. Carla Cunningham
Dr. Kathy Dowd
Megan Pender
Senator Bill Rabon
Elizabeth Strachan
Rep. Diane Wheatley

Current Vacant Council Seat(s)

Senate Appointees (2)- President Pro Tempore
Governor Appointees -Parent of a Deaf or HOH Pre-school
child

Call to Order: The meeting was called to order at 9:00 a.m. by David Rosenthal, Chair

Welcome; Introductions; Ethics Reminder; Approve Minutes from August 5, 2022

Motion: Donald Tinsley (Dr. Robert Nutt) moved to approve the minutes from August 5, 2022, Council meeting. **Motion passed.**

None of the members acknowledged having a conflict of interest or appearance thereof on matters listed on this agenda

Disclosure: Dr. Kevin Brown (presenter) noted he is a consultant and on advisory boards for all three cochlear implant companies

David Rosenthal, Chair

Announced Linda Amato, Council Vice-Chair has stepped down. Nominations were asked at the August's Council meeting. One nomination was received for Michael Evola. Floor was opened for any additional nominations. No other nominations were noted. Members were polled, unanimous approval of Michael Evola as Council vice-chair.

Motion: Kevin Earp (Donald Tinsley) moved to approve Michael Evola as vice-chair
Motion passed

The Cochlear Implant Process: Initial ENT Exam

Keven Brown, M.D., Ph.D., Otolologist, UNC School of Medicine

Initial Meeting

- Surgeon Goals
 - Determine severity of hearing loss
 - Determine cause of hearing loss
 - Discuss options for treatment and if surgery is an option safety of this option
- Parent Goals
 - Why does my child have a hearing loss?
 - What are options to help them communicate?
 - How effective are options and what are the risks
 - How can I be sure I am making the correct decision?
 - Can I trust you with my child?

Workup

- History of hearing loss, especially the timeline of hearing loss, is it one side or both? Does child benefit from hearing aids? Family history of hearing loss?
- Exam: external ear, otoscopic exam, neck (any masses), cardiac
- Genetics
- Ancillary consults
- Imaging – MRI scan, if abnormalities found a CT scan would be required

Secondary Meeting

- Provide parents with information needed to make decision on treatment options
- Severity of hearing loss, genetics, imaging results
- Provide reasonable expectations of outcomes of CI in child's unique situation
- Respect autonomy of parents to make decision, however it is not an option not to make a decision, must decide to proceed with either visual or spoken language

Parent Counseling

- With counseling reasonable expectations are set for outcome, depending on cause of hearing loss
- Open Set- which is communicating verbally with another person
- Closed Set- which means that if you have cues for what information is being discussed, that you can understand enough of what's being said to make that out
- Sound recognition-can use for cued speech
- Establish Expectation on how parents participate in the rehabilitation process (*important component of what determines whether a child does well with the CI or not is the rehabilitation that happens afterwards*).

Surgery

- Greatest concern to parents
- Typically, 1.5-to-2-hour surgery if the anatomy is not complicated, both ears simultaneously take about 3 hours
- Devices can malfunction, if that happens it is replaced, about 1% of cases over the lifetime of the patients
- A thumbnail-size opening over the mastoid cavity. Cavity is air filled
- Pocket created behind and above ear for receiver to be tucked in
- Dissect bone away until reach space between facial nerve and eardrum- facial recess
- Open facial recess and look into the natural opening and identify round window of cochlea
- Remove bone surrounding that window and slowly insert electrode

Device Selection

- Both company and electrode must be chosen, unless anatomy dictates otherwise, Parents typically choose device and surgeon selects the electrode

Consideration of Cochlear Implant in Single Sided Deafness

- Children that have a hearing loss on one side, can have a cochlear implant to restore that hearing. It improves their ability to determine the direction the sound is coming from and improves their ability to understand speech in a background of noise and makes it far less cognitively effortful for them to understand speech

Final Points

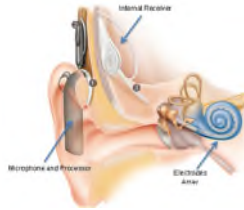
- Parents are counseled for all options for their child to communicate, visual versus verbal communication and, counseled for considerations for hybrid and complex cases, where they may do both visual as well as oral language.
- Children that are candidates for cochlear implants and parents that prefer verbal communication may ultimately elect to receive a cochlear implant

The Cochlear Implant Process: Audiology

Erika Gagnon, Au. D., Pediatric Audiologist, UNC School of Medicine

What is a Cochlear Implant?

- A cochlear implant is a tool which is designed to detect, convert, code, and transmit the salient features of acoustic signals into electrical signals that are delivered to the cochlea, the end organ of hearing
- Cochlear Implants is a two-part device
 - **Internal:** electrode array, receiver/stimulator (a chip), retention magnet
 - **External:** microphone, transmitting cables, speech processor, transmitting coil, power supply, user controls



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- How a cochlear implant works
 - <https://www.youtube.com/watch?v=Vm0nZH9RahE>

NC Medicaid Cochlear Implant Candidacy

- Children aged 12 months and older
- Confirmed diagnosis of severe to profound sensorineural hearing loss in the ear to be implanted
 - Exception for cases of auditory neuropathy when speech understanding is very poor
 - No middle ear infection
- Limited benefit from hearing aid trial
 - 40% or less on age-appropriate speech perception testing

How do Cochlear Implants and Hearing Aids Differ?

- **Hearing Aids:**
 - Acoustically amplify sound through outer and middle ear to stimulate traveling wave in cochlea
 - Outcomes rely on the responsiveness of surviving hair cells
- **Cochlear Implants:**
 - Bypass damaged hair cells and electrically stimulate the nerve directly
 - Convert the acoustic input signal into an electrical pattern that is transmitted by FM signal through skin to internal device and delivered to electrodes in Scala tympani
 - Rely on surviving neural elements to be stimulated by direct delivery of current pulses

Pediatric Cochlear Implant Evaluation

- **Diagnostic Testing**
 - Tympanometry
 - OAE/ABR (age/developmental ability)
 - Unaided thresholds
 - Aided speech perception

- **Counseling**
 - Did they meet candidacy criteria?
 - Discuss surgery
 - Discuss device options
 - Language goals? Discuss potential outcomes based on goals
 - Aural (re)habilitation

Cochlear Implant Programming

- The child returns for device “activation” about 2-3 weeks after surgery
 - Very conservative settings are created for the child to adjust to the new electric hearing
 - Technology has different programs to turn up between visits
- There are several visits in the first year to optimize the settings
 - Based on parent/child report, hearing testing and speech understanding with the cochlear implant continued setting changes are made
- Settings are not one size fits all or even the same across ears
 - Settings are impacted by time, hormonal changes, general body changes
 - For young children bi-annual visits are needed
 - For young adults visits are annual

Critical Period for Spoken Language Acquisition

- Theory that there is a limited period of opportunity for an infant to process acoustic input, learn to discriminate the sounds and understand meaningful language
 - Spoken language outcomes for children with cochlear implants are improved with younger age at implantation

The Cochlear Implant Process: Early Intervention

Beth Whitfield, Teacher of the Deaf and Hard of Hearing, NC Department of Public Instruction

Diane E. Doak, Executive Director, Beginnings

Johanna Lynch, Parent Educator, Beginnings

The Early Learning Sensory Support Program for Children with Hearing Impairments (ELSSP)

- Is Legislative appropriation
- Approved direct service provider for Part-C
- Serve children from age birth to three years of age and their families
- Services provided across North Carolina by licensed staff who have specialized training to meet the unique needs of children who are deaf or hard of hearing

Referral Avenues

- Audiologist/ EHDI Newborn Screenings
- Direct referral to quality assurance intake coordinator
- Children must be enrolled in the NC Infant Toddler Program with CDSA to received Part-C services from ELSSP-HI providers

Services

- Frequency and Location are decided based on individual need and can change as needs change

- Coaching- based on Model of Early Intervention-helps parents develop their abilities to interact with their child in ways that support their child's communication
 - Coaching is used to promote the learning of language and vocabulary in all routines and environments in the communication modality of the family and the child
 - Supports parent/caregivers as the primary teacher of their child
 - Supports families as they advocate for themselves and for their child
 - Supports and promote the social and emotional development of children including opportunities to connect with other children and families
- Assessments- annually until the child turns three
- Teaming- team with other professionals to support the whole child in and the family

Johanna Lynch, Parent Educator, Beginnings

- Beginnings is a private agency, and we collaborate with state agencies
- We have 10 parent educators across the state that work with parents/caretakers, not children
- Receive referrals from audiologists, families, and schools
- Work with families from identification to age 22
- Collaborate with professionals
- Provide resources and instruction to preschools/schools and districts

Empowering Parents/Caregivers- teaching parents:

- How to read their child's audiological report/audiogram
- Language and communication-know all language and communication options that are used within the Deaf and Hard of Hearing community
 - Choices they *may* have to make for their child's language development
- How hearing relates to language development/literacy
- Technology, as appropriate and recommended by audiologist
- Early intervention/school-age services and transition to adulthood
- Advocacy and child self-advocacy

The Role of the Parent Educator

- The goal is to teach parents the skills they need to advocate effectively for their child's needs medically and educationally

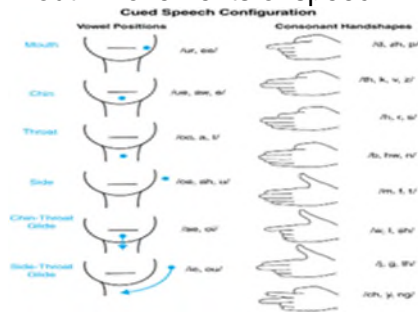
Teaching Parents and Caregivers: Language vs Communication vs Mode

- Language, a system of conventional spoken, manual (signed), or written symbols by means of which human beings, as members of a social group and participant
- Communication is a simply the act of transferring information from one place, person, or group to another. Every communication involves one, sender, a message, and a recipient. Can be verbal, nonverbal, images or written
- Mode, or system, is the method by which communication is conveyed

The Choices-when parents have to make a choice:

- Visual communication methods
 - American Sign Language (child and family must learn)
 - Visual language
 - A grammar structure different than English
 - If taught as a child's primary language, the child will learn English as a second language to learn to read and write

- Used within the Deaf community
- Considered when a child has bilateral profound hearing
- Recognized as a world language by many states for high school graduation requirements
- **Not a universal language**
- American Sign Language Recommendations
 - At least one family member become fluent
 - Full-time use of the language at home
 - Use rich language and provide environmental information
 - All family members use ASL, ideally fluent in ASL
 - Involvement in the Deaf community
 - Learn Deaf culture
 - Learn necessary accommodations
 - Learn rights that protect language access
- Auditory-Verbal. Listening and Spoken language
- Auditory Oral
 - 'Traditional' auditory training approach
 - Conducted with the child in individual therapy
 - Emphasis is to teach the child to use residual hearing with the aid of amplification and speech reading and contextual/visual cues to receive auditory information
 - Focus on developing communication skills to allow for mainstreaming
 - Excludes sign language
 - Homework for carryover of treatment objectives
- Cued Speech (Child and family must learn)
 - A visual communication system using 8 handshapes in four different locations around the chin and cheek (cues) in combination with the natural mouth movements of speech



- Each cue makes the sounds of spoken language look different
- Hand shapes help the child distinguish sounds that look the same on the lips, such as 'p' and 'b'
- Cues are used simultaneously with speaking
- A system for a child who may not be able to learn entirely through amplified hearing
- Simultaneous Communication/Signed Exact English
 - An Educational philosophy that uses spoken language and sign language simultaneously

- Uses an English-based sign language system, which can include speech, speechreading, fingerspelling, natural gestures, and the use of residual hearing
- Total Communication
 - A philosophy more than a communication method, it uses a combination of methods to teach a child, including a formal sign-language system, fingerspelling, body language, speech reading, oral speech, and amplification
 - The sign language used in total communication is not a language in and of itself like ASL, but closer to manually coded English (SEE, Pidgin, SE)
 - **School districts define “Total Communication” to include augmentative communication, something most of our population does not use**

Best Practices

- Use listening devices, when appropriate
- Get the child’s attention before communicating
- Reduce background noise and/or visual clutter
- Get close
- Ensure access to facial expressions, when appropriate
- Meet other families, children, teens, and adults

The Cochlear Implant Process: Educational Support

Mark Patrick, Director, North Carolina Scholl for the Deaf Morganton

North Carolina School for the Deaf (NCSD) is duly accredited public separate school for students who are Deaf and Hard of Hearing. We serve students who are 3 years old through 22 years of age and who have a documented hearing loss. We do not provide therapeutic services 24 hours a day 7-days a week, we are a 24/5 school. Students go home every weekend and we do have a dormitory for students who live more than an hour away.

Amplification Philosophy

- NCSD maintains a supportive stance for each student individually in accordance with their Individualized Education Plan (IEP)
- Amplification including but not limited to, cochlear implants, hearing aids, bone anchored hearing aids, and assistive technology devices are considered tools and are not synonymous with identity
- Each student is provided with a positive academic and cultural environment regardless of amplification status

Data

- Amplification usage at NCSD among the total of 63 students consist of:
 - 8 students have cochlear implants, 5 of them have binaural CIs
 - 6 students with CI’s actively use Spoken Language in addition to ASL for expressive communication
 - 15 students have hearing aids
 - 1 student has a Bone Anchored Hearing Aid
 - 1 student uses bimodal amplification: CI and Hearing Aid

- 7 students with cochlear implants that are not in use. The most common reasons are internal device failure followed by lack of perceived benefit

Support Services

- The North Carolina school for the deaf has a full-time speech language pathologist and audiologist to provide services to our students
- Both clinicians are fluent in American Sign language and cognizant of Deaf and Hearing culture norms and values
- Services may be provided individually or in a group session with peers who are working towards similar audition and spoken language skills

Academic Performance

- Students who have enrolled with cochlear implant(s) and a strong successful foundation in spoken language continue to thrive at NCSD.
- The consistently identified common factors is full engagement and tireless work from the students' families to ensure that appropriate resources, services, and language foundation is obtained

Trends

- At NCSD, students who have implants binaurally tend to identify a preference for one processor over time. The favored processor statistically has been first one received.
- The 5 students who are binaurally implanted; 3 have stopped using their second processor due to lack of equally perceived benefit
- The student with bimodal; cochlear implant and hearing aid amplification, is successfully using both Spoken Language and ASL
- Students with Spoken Language skills tend to use their ability across both the home and school environment.
- All NCSD current students with cochlear implants are successfully acquiring and using American Sign Language

Parents and Young Adults with Cochlear Implant Panel

Erika Gagnon, Facilitator for Panel Discussion

John and Melinda Lanier, Deaf Parents of Deaf Children

Holly Shoun, Hearing Parent of a Deaf Child

Craig Lewis, Hearing Parent of a Deaf Child

Mary Margaret Lewis, Deaf Young Adult with CI

Questions Posed to Parent Panel:

What was the implant decision-making process like and what helped convince you to move forward with surgery?

Craig Lewis: It was a difficult decision for us. We are a home school family and received lots of good advice in many ways. The advice we received suggested that she would be much more successful with us in our family environment with CI's. She received her first implant at 18 months old and second 10 months later after lots of discussions with NC Attorney General and our insurance company.

Holly Shoun: Our process was exactly as described in Dr. Browns presentation. We went to several doctors to make sure there were no other medical problems that could be causing our son's hearing loss. The biggest thing I remember from the process is the expectation or the

pressure on the parents, that it is up to the parents to decide, and parents need to meet the expectation of teaching language.

John and Melinda Lanier: It was disappointing to learn our son couldn't hear anything with hearing aids. We wanted the best for our son, and we made the decision for him to have the CI surgery when he was 2 years of age, and he did so much better with the implant. When our daughter was born, we decided to do the same - she was implanted at the age of 1, overall, the process was a good experience

Early days of the device what support was helpful or was not helpful as you navigated CI journey?

Craig Lewis: We had a lot of great support around us. Right after the implant Mary Margaret worked with a Speech-Pathologist for the first 3 months. We did the IEP process through local school system for additional service but decided we were getting much better service from elsewhere.

Holly Shoun: Parker was identified late, and he was implanted at 2.5 years of age. Parker had tremendous delays in speech and language. At 3 years of age, he attended Cassel Pre-School. He had speech therapy daily. They supported me and taught me things on how to advocate and how to teach him. We received a lot of support from polished professionals.

John and Melinda Lanier: It took 5 different doctors to tell us he failed his hearing screening. Chapel Hill is where they told us he was Deaf. When we had our daughter, we knew we had to go to Chapel Hill first.

What advice would you give other parents out there moving through the cochlear implant process?

Craig Lewis: Take advantage of all resources and encourage your child to do the same.

Holly Shoun: Get connected to qualified professionals with lots of experience.

John and Melinda Lanier: Keep in touch with your support system and the professionals, especially Chapel Hill, they gave us good advice. Keep up with speech and language therapy, audiology appointments, they will guide you through process

Please share with us the impact Cochlear Implantation has made on your child(en)'s lives?

John and Melinda: It has been amazing to see how wonderful these devices have been. Our son is doing well he is socializing with friends and plays sports. Our daughter doesn't need an interpreter and one would assume she is hearing. Our children thank us for implanting them.

Holly Shoun: Opportunities have been so wide because he has cochlear implants. He's an athlete in college and plays lacrosse. I think he would have been the same with or without the CI's. It helps him get where he wants to go more easily.

Mary Margaret: I was implanted at a very young age. Being Deaf didn't slow my progress academically or socially. CIs has given me lots of opportunities. I have an option for the rest of my life if I want to be able to hear and communicate verbally or if eventually learn sign language and go without CIs, and for this option I am very grateful.

Council Feedback and Wrap Up

David Rosenthal, Chair

- The next Council meeting scheduled for February 3, 2023; will be an in-person meeting

There being no further business and announcements, the Council meeting was adjourned at 12:00pm

2023 Meetings: February 3rd, May 5th, August 4th, November 3rd

<https://www.ncdhhs.gov/divisions/dsdhh/councils-commissions>