Development of a Multidisciplinary Team to Provide Care to the “Whole Child” With Hearing Loss

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Overview

- Introduction of team structure
- Presentations from each specialty and role in providing holistic care for children with hearing loss
- Case examples
- Future directions
- Q&A
Team Members

- Physicians/surgeons
- Audiologists
- Speech and Language Pathologists
- Clinical Outcomes and Outreach Coordinator
- Psychologist
- Neuropsychologist
- Social Worker
- Others as needed (OT, PT)
Integrating Psychology and Audiology to Provide Well-Rounded Care
Michael Hoffman, PhD
Psychosocial Research

- Studies from Gallaudet estimate that 40-50% of children with hearing loss have a comorbid diagnosis
  - Increased rates of ADHD (20% vs. 6.9%)

- Children with hearing loss often experience difficulties academic performance, behavior, feelings of being different/teasing, increased rates of psychopathology, and social withdrawal

- Data from US national database:
  - 16.6% have seen a doctor for social emotional problems (vs 4.4%)
  - 11.5% have been medicated for emotional difficulties (vs 6.9%)
Rationale for Psychology and Audiology Integration

- Audiologists and SLPs are very well trained to assess issues of speech/language
- However, children with hearing loss are impacted in many ways
- Providing holistic services that address the “whole child” improves patient care and helps align with patient-centered collaborative care
- Psychologists are well positioned to help manage these things!!!
A Broad Integration Model

Cochlear Implant Team
- Serial developmental assessments
- Assess family readiness

Microtia Clinic
- Standardized screening and assessment of families
- Surgery prep

CAPD Patients
- Consult regarding psychoedu evals
- Discussing other diagnoses

Research
- Tracking outcomes and publishing data

Handouts
- Handouts on typical psychosocial experiences
- Child development handouts

General Audiology
- Standardized screening
- Outpatient therapy
- Meet w/ new ID families
- Device compliance
- Booth testing
- Warm handoffs

Sound Sensitivities
- Outpatient therapy involving biofeedback and CBT

Microtia Clinic
- Standardized screening and assessment of families
- Surgery prep
Cochlear Implant Team

- **Assessment of family readiness:**
  - Understanding of surgical/rehabilitation process and family perspectives of CIs/hearing loss
  - Concerns about appearance/surgery and potential barriers/psychosocial complicating factors
  - History of parental mental health and family stressors and relations
  - School/daycare setting

- **Developmental assessment (Bayley)**
  - Cognitive functioning, receptive/expressive language, and fine and gross motor
Microtia/Atresia Clinic

- Multidisciplinary clinic for children with conductive hearing loss/microtia/atresia
- Conduct psychosocial consultations

Assess:
- Family context/stressors
- Psychosocial history
- Appearance-related concerns
- Developmental history/EI services
- Academic functioning/IEP
- Psychosocial concerns impacting physical health
Screening Patients

- Screening of permanent hearing loss patients occurs:
  - At device selection OR fitting
  - 1 month follow-up OR 3 month follow-up
  - Every 6 month follow-up

- Patient experiences and challenges change, repeated screening helps us to serve needs at different times

- We can also track change over time
Screening Patients

- **3 age ranges:**
  - 0-5: Parent report
  - 6-12: Parent and self-report
  - 13+: self-report

- **Items:** 6-8 questions
Sample Questions

- How often is your child bothered by his/her hearing loss?
- How often does your child feel different from other children because of his/her hearing loss?
- How often does your child wear his/her hearing devices?
- How often does your child feel down, depressed, or bad about him/herself?
- How often does your child feel nervous, anxious, or on edge?
- How often does your child have difficulty falling or staying asleep?
- How often do you feel stressed or worried about your child’s development or behavior?
- How often do you feel stressed or worried about managing your child’s hearing loss?
What Can Psychology Do?

- The issues do NOT have to be specific to hearing loss, but can include:
  - Sleep, feeding, behavior problems, anxiety, depression
  - Device usage, parental stress, parental decision-making
  - Identity formation around hearing loss
  - Brief assessments for ADHD
  - Adjustment for parents and children following initial diagnosis
  - Transition periods – adolescence/college/young adulthood
  - Improving family communication around hearing related issues
  - Brief developmental assessments for children
  - Warm handoffs or complex booth testing assistance
  - …and many more!
Providing Neuropsychological Assessments to D/HH children
Greg Witkin, PhD
Who am I?

- **Completed Undergraduate Studies at the University of Rochester**
  - B.A. in Brain and Cognitive Sciences and American Sign Language

- **Earned M.A. and Ph.D. in Clinical Psychology from Gallaudet University**
  - Included specialized training in working with D/HH individuals, both in ASL and Spoken English
  - Included clinical training at several sites in the DC/Baltimore area
  - Pre-doctoral internship at the Mailman Center for Child Development in Miami, FL
  - 2-year postdoctoral fellowship in pediatric neuropsychology at the NYU Child Study center

- **Currently at Nemours / A.I. duPont Hospital for Children**
Why Evaluate?

- Answer referral questions
- Identify atypical behavior, conditions, or development
- Provide quantitative method of measurement of strengths and weaknesses
- Provide information used to develop individually tailored recommendations
Neuropsychology

- **What is neuropsychology?**
  - Subfield of clinical psychology that focuses on brain-behavior relationships
  - Goals:
    - Determine how the brain influences behavior, learning, attention, and social/emotional functioning
    - Utilizes various assessment techniques to evaluate cognitive strengths and weaknesses
    - Identify supports or recommendations to help the child at home, school, or in other settings
  - Work alongside other medical teams or treatment providers to maximize efficacy
Your Child May Benefit From an Evaluation If:

- There is a neurological or medical cause for difficulties
  - Hearing loss is *not* necessarily associated with language, learning, or cognitive difficulties.
  - But hearing loss can result from conditions with known cognitive effects, such as prematurity, some genetic disorders, meningitis, or tumors
- They are not making expected progress with language or academics
- They are not responding to provided interventions
- You need clarity regarding their diagnoses and/or educational needs
- You need documentation to support special education requests
What is a Neuropsychological Evaluation?

- Attention and concentration
- Learning
- Language Acquisition
- Emotional development and emotional regulation
- Motor development
- Executive Functions
- Memory
- Social development
- Visual spatial skills
Why Not Just Go Through the School District?

- Different goals
  - Academic classification versus diagnosis and treatment
- What tests are administered when the district conducts an evaluation?
- What areas are missed?
- What if testing was already done by the district?
Neuropsychological vs. Psychoeducational

- **More Comprehensive**
  - Includes measures of attention, executive functioning, memory

- **More easily compares results across domains**
  - How do these areas influence one another?

- **Can help explain the role of the brain, medical concerns, or hearing loss**

- **Can provide diagnostic clarity**
What Will An Evaluation Tell Us?

- How the child learns
- How to better teach the child
- How to utilize the child’s strengths to overcome weaknesses.
- What accommodations or interventions are needed
- Once we understand why a child is struggling, we can provide better and more appropriate interventions
- Helping the child understand why he or she is struggling can also help improve the child’s self concept and self esteem
Special Considerations for D/HH Children

- Age at hearing loss
- Type of hearing loss
- Language Access
- Educational environment
- Ability to communicate with evaluator
- Appropriate test selection
- Appropriate interpretation of test results, to obtain accurate recommendations and make good predictions for future functioning
Outcomes and Outreach Coordinator
of the Pediatric Communication Center

Melissa Stone, MSED, CCC-SLP

Email: mstone@nemours.org  Phone: (302) - 651 - 6555
Introduction

- Melissa has been working as a speech language pathologist for 15 years. She has worked at Nemours AI duPont Hospital for Children for over 8 of those 15 years prior to taking on this new role in October.

- This unique position was created to help bridge the gap of communication for families, education providers, early interventionists, and/or other medical teams/providers.
Family Related Services

- Contact for families/patients newly diagnosed with hearing loss
- Help guide them to psychology services
- Help in scheduling follow up appointments
- Provides initial referral to outside early intervention, statewide, or educational programs as necessary
Family Related Services

- Contact for families/patients moving through cochlear implant candidacy process
  - Hold initial family meeting to educate family on candidacy process
  - Coordinate candidacy appointments within an appropriate time frame
  - Contact families who have questions or concerns regarding candidacy process
  - Provide auditory verbal therapy home training to families that live far away and can’t receive follow up speech therapy support from our team
Outcomes

- Collect and analyze audiological, newborn hearing screening, and surgical data as it pertains to children with hearing loss
  - Protocol/Treatment Outcomes – PedAmp
Family Related Services

- **1-3-6 Data**
  - Screening of hearing by 1 month of age;
  - Diagnosis of hearing loss by 3 months of age;
  - Enrollment in appropriate audiological or early intervention program by 6 months of age.
Audiology Department

2018 IN REVIEW

June 2018—December 2018

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CHILDREN DIAGNOSED WITH SENSORINEURAL HEARING LOSS AND AUDITORY NEUROPATHY SPECTRUM DISORDER ACROSS 5 DIFFERENT STATES.

73%
OF FAMILIES CAME TO OUR HOSPITAL PRIOR TO 1 MONTH OF AGE FOLLOWING A FAILED NEWBORN HEARING SCREENING.

68%
OF THOSE PATIENTS WERE DIAGNOSED WITH SENSORINEURAL HEARING LOSS BY 3 MONTHS OF AGE.

50%
OF THOSE PATIENTS FIT FOR AMPLIFICATION PRIOR TO 6 MONTHS OF AGE.

5 DIFFERENT STATES PROVIDED REFERRALS TO OUR HOSPITAL FOLLOWING A FAILED NEWBORN HEARING SCREENING.

GEOGRAPHIC AREA
15 children received the gift of sound through cochlear implantation in 2018 with our help!

Cochlear Implants 2018

- Bilateral: 53%
- Unilateral: 47%

Cochlear Implants 2013-2018

- Patients
- Implants

We continue to help coordinate cochlear implant surgery and follow up services for patients across different states.

23 ears were implanted with the latest technology in 2018! Our hospital continues to work alongside all three of the major cochlear implant companies helping patients and families choose implants that best suit their lifestyle.

Geographic Area

- [Percentages and bars]

Implant Types 2018

- Advanced Bionic: 9%
- Cochlear: 58%
- MedEl: 32%
- Other: 40%
Outreach

- Works alongside early intervention programs, state programs, and educational programs for children with hearing loss within DE, PA, NJ, and MD.
  - Send referrals to appropriate programs
  - Help coordinate exchange of information
  - Supports families in gathering information regarding IEP supports and school programs
  - Receives intake referrals and helps families get scheduled with appropriate appointments
  - Travels to educational programs to observe patients, if requested by educational team or families, in order to provide support and unity of the family, educational team, and medical team
  - Provides support to programs via teleconferences, in-services, handouts
Outreach

- Coordinator for Nemours community events supporting our ENT and Audiology Departments.
  - Annual Hear We Go 5k and Family Fun Day
  - Yearly Better Speech and Hearing Month Awareness Event
  - Annual Fundraising Events to support Hear We Go Event
The Role of the SLP
Amy Powell M.S., CCC-SLP, LSLC Cert AVT
“The way a team plays as a whole determines its success. You may have the greatest bunch of individual stars in the world, but if they don’t play together, the club won’t be worth a dime.”

-Babe Ruth
What part does the SLP play?

- The SLPs participation will vary throughout the process.
- Assessment of current skills and determination of suitability for surgery.
- After candidacy, other professionals may be at the forefront of treatment.
- In the long term, the SLP will likely have the longest involvement with the patient.
Throughout candidacy and treatment the SLP may refer back to other professionals on the team for support.

For the SLP, the team often becomes larger after implantation, now requiring more frequent contact with school professionals and other support people outside of the medical facility.

The most important team members are the patient and the family!
Summary:

The overall success of the child is greatly determined by the communication and collaboration of the team.

Questions?
Multidisciplinary Programs
Audiology and ENT
Nemours Audiology

- 14 Audiologists across 5 sites in DE Valley
- Diverse backgrounds and areas of expertise
- Full service Diagnostic and (Re)Habilitation Services
  - Diagnostic evaluation (behavioral, electrophysiologic, and sedated services)
  - Cochlear Implants
  - Hearing aid/ALDs
  - Auditory Processing Program
  - Bone anchored/Osseointegrated Devices
Nemours Otolaryngology (ENT)

- 8 Fellowship trained, Pediatric Physicians (surgeons)
- 3 Advanced Practice Providers (APN, PA)
- Full spectrum of pediatric services
  - Aerodigestive and Airway
  - Middle Ear surgeries/treatments
  - Skull base
  - Rhynology
  - Complex ear cases
  - Cochlear implants
  - Etc.
Multidisciplinary Offerings

- Cochlear Implant (Otology, Audiology, SLP, Psychology, Social Work)
- Voice program (ENT, pulmonology, SLP, psychology)
- Ear Anomaly Clinic (Otology, Audiology, psychology, plastic surgery)
- Craniofacial Clinic (ENT, Audiology, Psychology, Plastic surgery, SLP, Ophthalmology, others as needed)
- Vestibular (Otology, Audiology, Orthopedics, Neurology, Physical Therapy)
General Changes in New Model of Care

- Audiologists have a psychosocial screener that they give to patients with hearing loss that help bridge referral to psychology
- Additional support when families are having behavioral concerns
- Resource on team when hearing and performance aren’t matching up, cognition in question.
- Assistance with parents who need more support
- Outcomes and Outreach being done by single point of contact who isn’t with patients all day.
Case Study #1

- 4 Y.O. referred from local university for evaluation.
- Hearing: unilateral mild to moderate HL in high frequencies.
- Warm hand-off conducted with psych same day to help with family coping and adjustment.
- Met with ENT to approve hearing aid.
- Audio/Psych joint appointment for hearing aid selection and fitting.
- One year later: Outreach coordinator discussed communicating with school about FM, DE Hands and Voices, and statewide services.
Case Study #2

- Current 20 Y.O. male
- Diagnosed with hearing loss at 4, wore bilateral HAs
- Attended School for the Deaf and bilingual
- Hearing worsened over time, implanted at 18 years of age
- Worked with Speech therapy, ENT, Audiology for CI eval
- More recently working with Psychology
Case Study #3

- Current 5 Y.O. female
- Medical history: premature, history of prolonged NICU stay, and short gut syndrome
- Diagnosed with ANSD at 1 month old, wore bilateral Has with little benefit
- Implanted at 15 months of age
- Worked with school district for early intervention and preschool, transferred to Clarke Schools for Hearing and Speech
- More recently working with Psychology for sensory processing
Future Directions

- Central Auditory Processing Disorder
- Sound Sensitivity Program (Audiology, Psychology, ENT, Occupational Therapy)
What Questions Do You Have?

THANK YOU!!!!