UNC's Hearing and Development Clinic: Supporting DH/H+ Patients and Families through Multidisciplinary Care

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Disclosures

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- Financial:
  - Salary from University of North Carolina at Chapel Hill
  - LEND Audiology Supplement Director at UNC
- Non-Financial:
  - None

Learning Objectives

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- Describe the benefits of multidisciplinary care teams to patients, families, student training, and professional development
- Identify the key infrastructure for successful multidisciplinary teams
- Associate the WHO-ICF model to effective inter professional practice

Deaf/Hard of Hearing Children with Complex Needs

Deaf/HH Plus Complex Needs

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- "Deaf/Hard of Hearing (DHH) plus" or "DHH with added disability": any type of hearing loss co-occurring with other developmental or learning challenges or disabilities
  - ADHD
  - Developmental delays
  - Learning disabilities
  - Language impairments
  - Autism
  - Genetic conditions
  - Vision impairments
  - Fine or gross motor impairments
- About 40% of children with permanent hearing loss have other conditions or challenges impacting their development
- About 20% of those have *more than 2 disabilities*

Núnez-Batalla, et al, 2022; Gallaudet Research Institute, 2014

What are Developmental Disabilities (DD)?

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Developmental Disabilities

- Cognitive, physical, or both
- Onset before the age of 22
- Likely to be lifelong
- 16.7% of children in the US

Common types of DD

- Intellectual disability
- Autism spectrum disorder
- Cerebral palsy
- Fetal alcohol spectrum disorder
- Attention deficit hyperactivity disorder (ADHD)
- CHARGE syndrome & other genetic syndromes

Genetic Conditions

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- Connexin 26 & 30 mutations
- Usher syndrome
- CHARGE syndrome
- Waardenburg syndrome
- Treacher Collins syndrome
- Down syndrome
- Warsaw Breakage syndrome
- Pendred syndrome
- Beckwith-Wiedemann syndrome

- *Over 400 syndromes have been identified with atypical hearing thresholds (Van Camp & Smith, 2016)*

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Other Complications

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- Cytomegalovirus (CMV)
- Low Vision/ Cortical Visual impairment (CVI)/Blindness
- Epilepsy
- Traumatic brain injury (TBI)
- Dysgenesis (or agenesis) of the corpus collosum
- Craniofacial anomalies
- Prematurity
- Complex medical needs

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2013-2014 REGIONAL AND NATIONAL SUMMARY
Deaf/Hard of Hearing Children & Youth (N = 6,979)

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Type of Disability	Rates for DHH
Deafness with No Other Disabilities	59
Low vision and legal blindness	4.4
Developmental delay	6.1
Learning disability*	7.3
Orthopedic impairment	3.7
ADD/ADHD	4.8
Traumatic brain injury	0.6
Intellectual Disability	9.2
Emotional disturbance	1.9
Autism	3.0
Speech-Lang Impairment	7.3
Usher syndrome	0.3
Other health impairment(s)	7.8
Other conditions	8.0

Gallaudet Research Institute, 2014

2013-2014 REGIONAL AND NATIONAL SUMMARY
Deaf/Hard of Hearing Children & Youth (N = 6,979)

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Disability	% of DHH Population	% of General Population*	% of Students in US Schools
No disability	59	87	85
Intellectual disability	9.2	1.1	6
Specific learning disability	7.3	7.7	32*
Speech/language impairment	7.3	--	19
Low vision and legal blindness	4.4	0.16	--
Autism	3	1.74	13
Cerebral palsy	--	0.31	--
ADHD	--	9.04	--

**Note: Percent total is >100 because multiple responses were permitted*

Gallaudet Research Institute, 2014

Zablotsky, 2019

NCES, 2024

Rates of Conditions Among Children who are D/HOH

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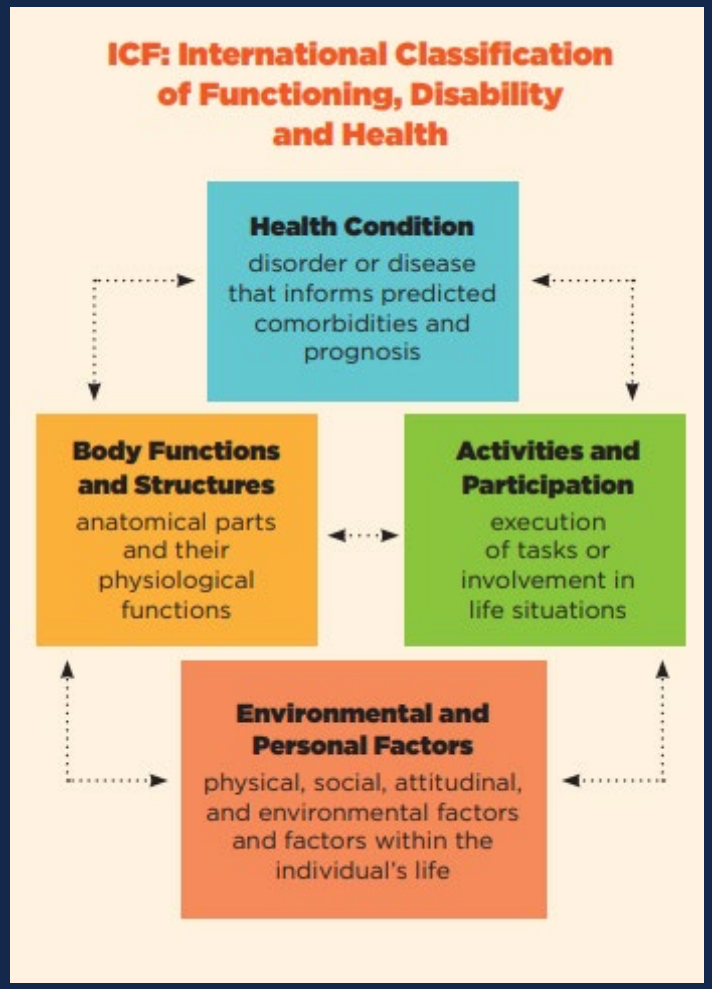
Type of Disability	Rates Among Children Who Are D/HH	Rates in the General Population
No disabilities	60%	86%
Cognitive (intellectual disability)	8.3%	0.71%
Cerebral palsy	--	0.3%
Blindness and vision impairment	5.5%	0.13%
ADHD	5.4%	5-10%
Specific learning disability*	8%	5-10%
Autism spectrum disorder	7%	1%

*The Individuals with Disability Education Act of 2004 [34 CFR 300.8(c)(10)] indicates children cannot be identified with a specific learning disability (SLD) if the child's performance is the result of a "hearing disability" (U.S. Department of Education, 2004). However, many educators recognize the possibility of SLD presenting in children who are D/HH.

Wiley, et al, 2022

International Classification of Functioning, Disability and Health (ICF)

- Developed by the World Health Organization (WHO)—a framework to address functioning and disability related to a health condition within the context of the individual's activities and participation in everyday life.



https://www.asha.org/siteassets/uploadedfiles/icf-childhood-hearing-loss.pdf

ICF Model

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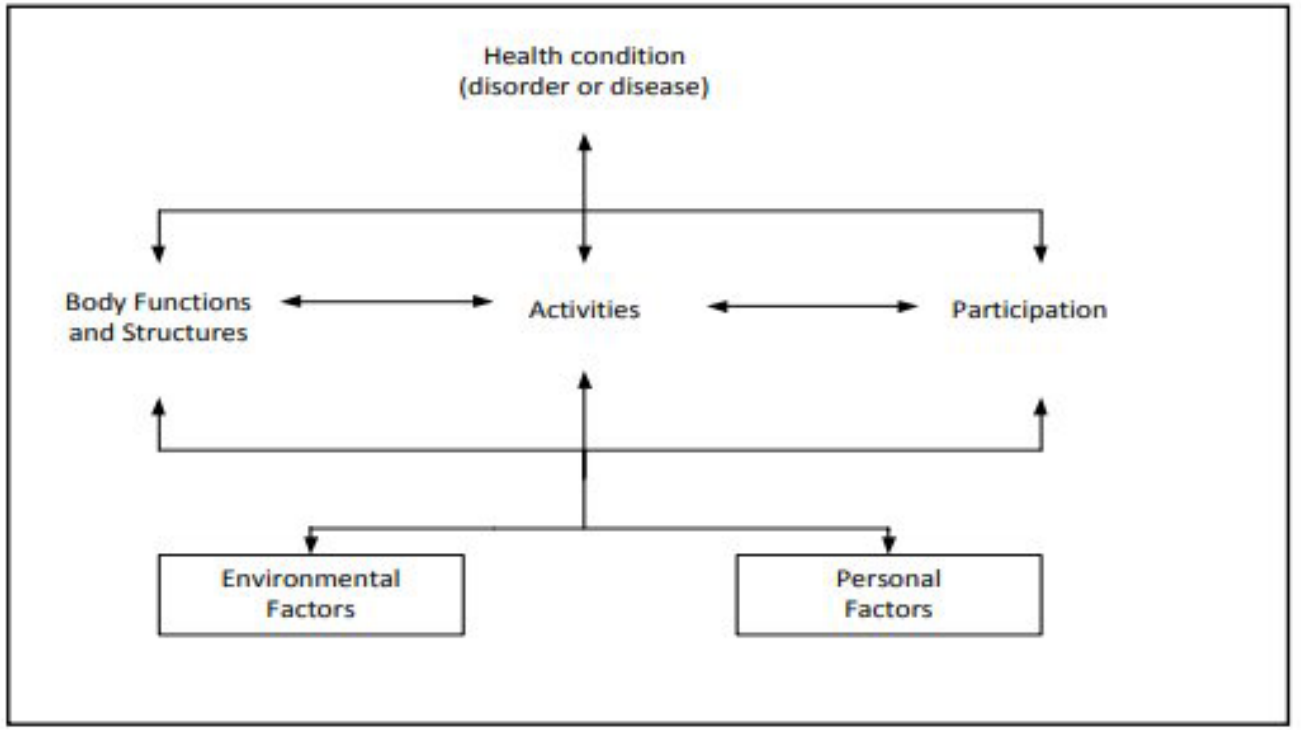
Box 1: The ICF Model: Interaction between ICF components



WHO 2001, 18

https://cdn.who.int/media/docs/default-source/classification/icf/drafticfpracticalmanual2.pdf?sfvrsn=8a214b01_4&download=true

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UNC Carolina Institute for Developmental Disabilities Hearing and Development Clinic

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Why the need for a Hearing and Development Clinic?

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- Our local pediatric audiologists, SLPs, and EI providers had concerns about some of the children followed in our clinical programs
- Parents often had concerns or wanted a second opinion
- The Committee for the Early Detection of Deafness (CODEPEH) and Joint Committee on Infant Hearing (JCIH) recommend all DHH children younger than 3 years complete assessments of speech, language, and cognitive skills every six months to help identify children with additional delays in expected milestones or atypical development.

Núnez-Batalla, et al, 2022

UNC Carolina Institute for Developmental Disabilities (CIDD)

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Three federally funded programs supported by the Association of University Centers on Disabilities (AUCD):

- University Center of Excellence in Developmental Disabilities (UCEDD)
- Intellectual and Developmental Disabilities Research Center (IDDRC)
- Leadership Education in Neurodevelopmental Disorders (LEND)

The Hearing and Development Clinic (HDC) at CIDD

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HDC team members:

- Audiologist
- Speech-language pathologists
- Psychologist
- Education specialist
- Occupational therapist
- Other specialists as needed
- Graduate and postgraduate trainees from each discipline
- Parents/Caregivers/Family

Referrals available to other teams e.g., Behavioral Medicine Clinic, Neurology, Genetics

Format for HDC Evaluations

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- Prior to assessment day (Family Advisor)
  - Detailed case history
  - Chart review / pre-evaluation staffing
- On the day of the assessment
  - Parent/s meet with family advisor
  - Morning assessments (arena style if applicable)
  - Lunch meeting/discussion
  - Afternoon assessments
  - Team meeting
  - Family feedback interpretive
- Following the assessment
  - Full written report provided to the family

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Assessment Batteries May Include

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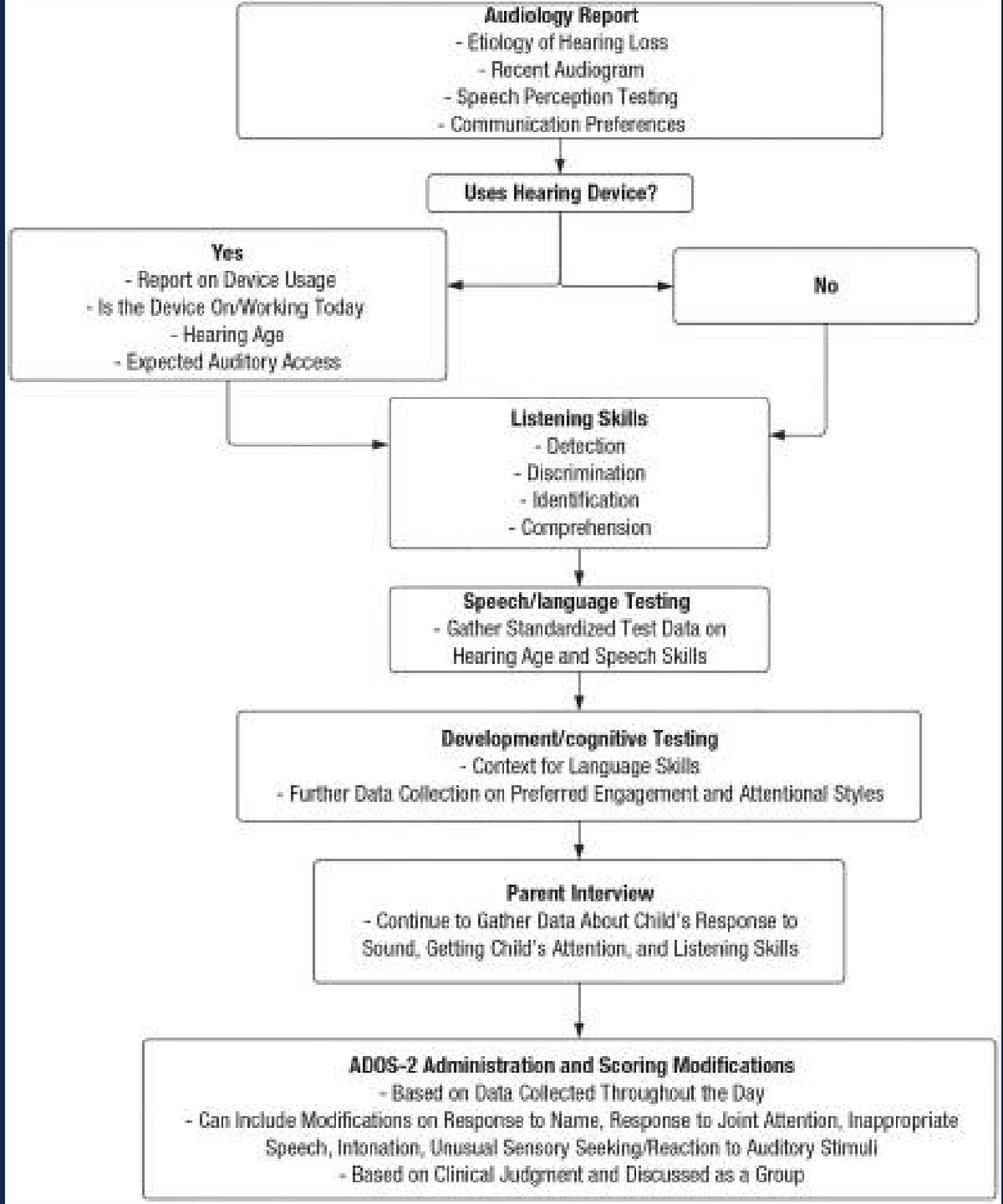
Hearing and Listening Screening	Developmental Assessment	Cognitive/IQ Assessment or Nonverbal IQ	Academic Achievement Assessment	Speech and Language Assessment
Motor Assessment	Sensory Assessment	Adaptive Assessment	Behavioral Consultation	Augmentative/ Alternative Communication Consultation
Autism Evaluation	Social/ Emotional Assessment	Parent Interview	Rating Scales (Parent/ Teacher/Self)	IEP Review



McFayden, et al, 2023

Common Outcomes of HDC Evaluations

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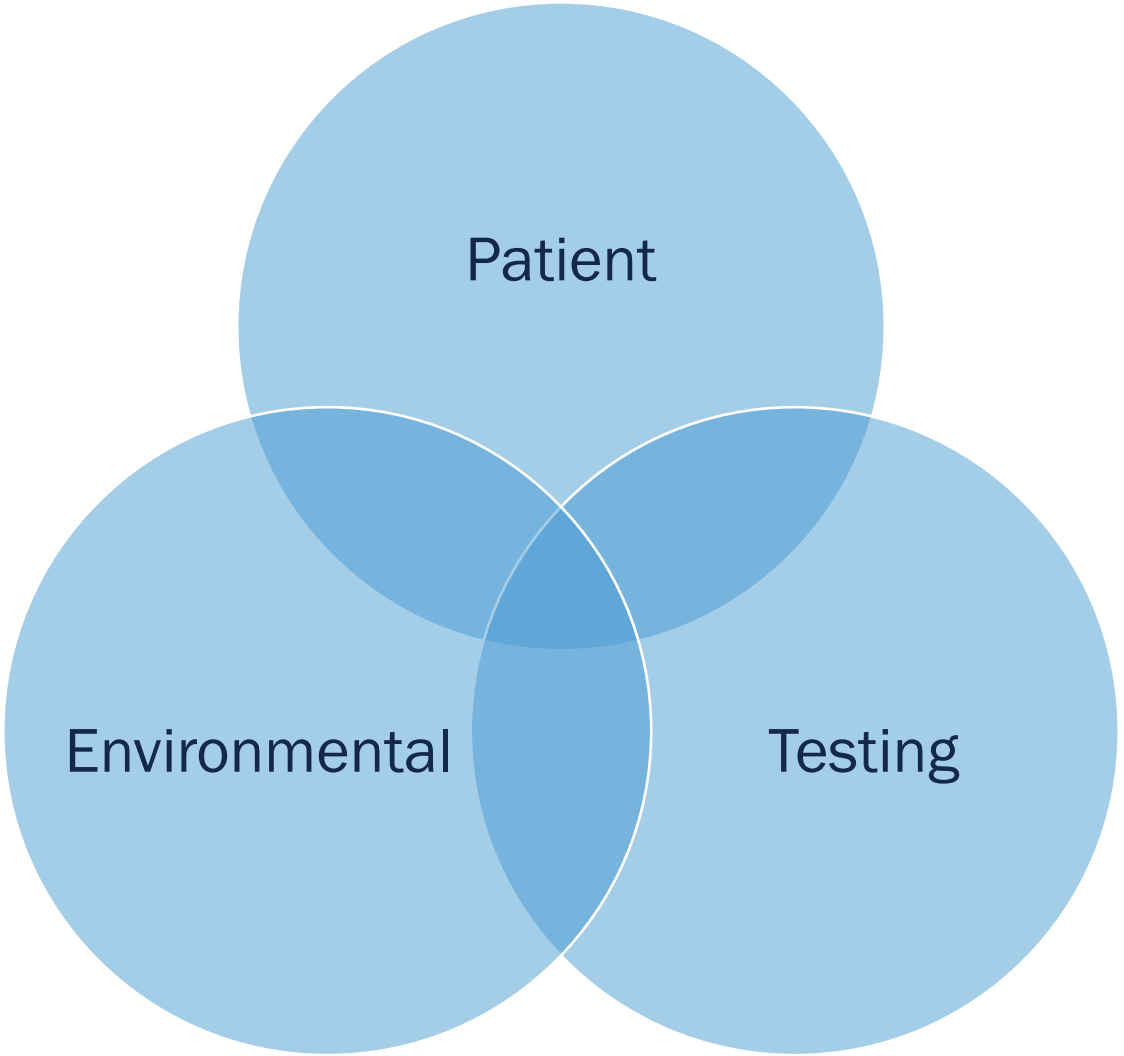
Differential diagnosis or rule out of

- global developmental delay or intellectual disability
- learning disability
- speech sound disorders (e.g., apraxia) &/or language delays
- autism spectrum disorder (ASD)

Recommendation for more in-depth AAC evaluation

Considerations



Considering Autism Diagnosis in Individuals who are Deaf or Hard of Hearing

Diagnostic Criteria for ASD

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Social Communication & Social Interaction

Deficits in:

- Social emotional reciprocity
- Nonverbal communicative behaviors
- Developing/Maintaining relationships

Restricted, Repetitive Patterns of Behavior and Interests

- Stereotyped or repetitive motor movements
- Insistence on sameness; ritualized behaviors
- Highly restricted Interests
- Hypo/Hyper reactive to sensory input

Skills expected for children who are D/HOH

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- Use of nonverbal communication means, such as eye contact, gesture use, direction of facial expressions
- Shared enjoyment and joint attention
- Social initiations, vocalizations/signs directed toward others
- Functional and imaginative play skills

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Signs of ASD in a young child who is DH/H

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Reduced pre-linguistic communication skills

- Joint attention
- Eye contact
- Requesting
- Showing/Giving
- Turn-taking
- Choice making
- Pointing/Gestures
- Posturing body for social communication
- Social smile
- Imitation

Does not progress in language skills despite consistent language exposure or optimized hearing technology

Signs of ASD in a young child who is Deaf/HOH (cont.)

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Reduced Social Communication/Interaction

- May not understand "function" of language
- Few to no strategies to clarify wants/needs
- Often misunderstands others
- Limited to no question-asking skills
- Gaps in social understanding
- Not initiating with peers
- Not tuning into faces of others
- Flat/Stilted facial expressions (not directed)
- Not "enjoying" experiences with others

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Distinctions in Sign Language Learners

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Children who are D/HOH may exhibit

- Jargon
- Echolalia
- Pronoun avoidance / use of names
- Reduced expressive language
- Idiosyncratic language
- Pragmatic delays

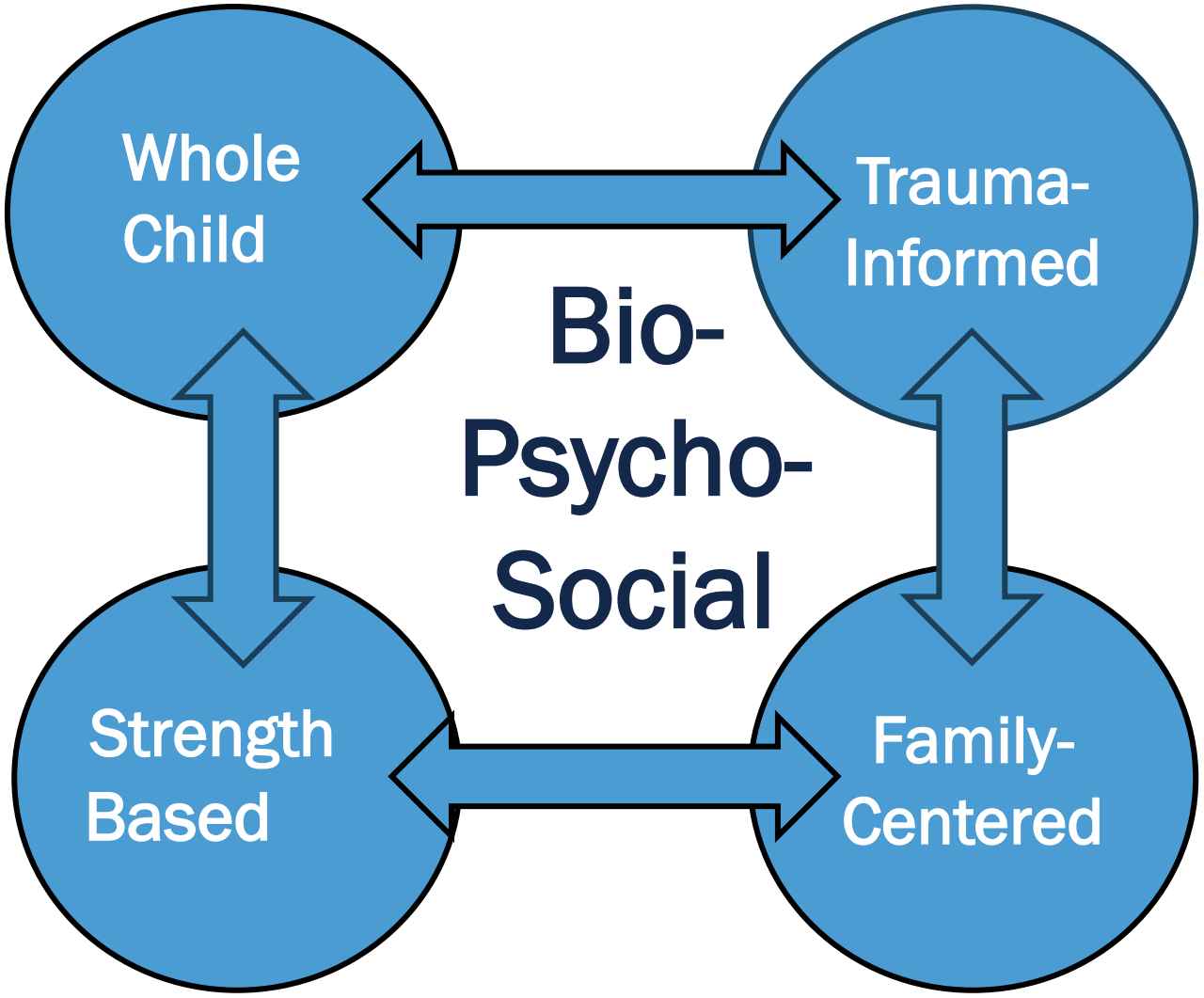
NOT expected in children who are D/HOH

- Pronoun reversal
- Palm reversals
- Facial Grammar
- Spatial Grammar
  - classifiers
  - agreement verbs
- Odd sign space
- Insistence of finger spelling when sign exists

Why do children who are Deaf or Hard of Hearing often receive a late diagnosis of ASD?

- Diagnostic overshadowing
- Focus on early medical needs
- Providers tell families it is not ASD or that they cannot co-occur
- Few providers are comfortable diagnosing ASD in the context of D/HH

Overarching Theoretical Approaches



Key Points of HDC

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- A hearing and development team requires core expertise in several professionals; at least one member of the team must have expertise in deafness
- Experienced professionals can become highly effective even if they do not have a background in deafness
- The most important findings are not the test scores; each child is more than the sum of his/her individual assessment components
- Recommendations should focus on functional outcomes; goals/progress are most important; for many children with complex needs, even modest gains can be highly rewarding for the family and for the professionals who work with them

Challenges

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Child/Family Related Challenges

- Logistics / travel
- Unfamiliar environment for child
- Fatigue
- Selection of appropriate measures
- Complexity of diagnosis and treatment planning
- Access to services and limited resources (AAC evaluations)

Institutional

- Need:
  - There are more children needing HDC assessment than we can accommodate
- Cost
  - Interdisciplinary team assessments are costly; reimbursement does not cover costs

Challenges (cont.)

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Institutional (cont.)

- Time
  - Many of the team members are engaged for a full day
  - Reports are lengthy and require multiple authors
  - Follow-up is time consuming; impact is not easy to measure
- Professional expertise
  - There's a need for professionals with expertise in multiple areas (e.g., ASD, ANSD +HL)
- Space
  - Requires facilities that permit "arena assessment"
  - Capability of direct and indirect observation; video/one-way mirrors

Benefits

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- For Families
  - Several professional disciplines seen in one day; families leave with a consensus on impressions/recommendations vs multiple diagnoses/recommendations
- For Graduate Students
  - Opportunity to participate directly in assessments involving interesting and challenging children under the supervision of experienced clinicians
- For Clinicians
  - The satisfaction (and challenge) of providing much-needed specialized services
  - A more holistic picture of the child is obtained through the collaboration of multiple disciplines
- For CIDD and UNC
  - Addressing an urgent need in our state

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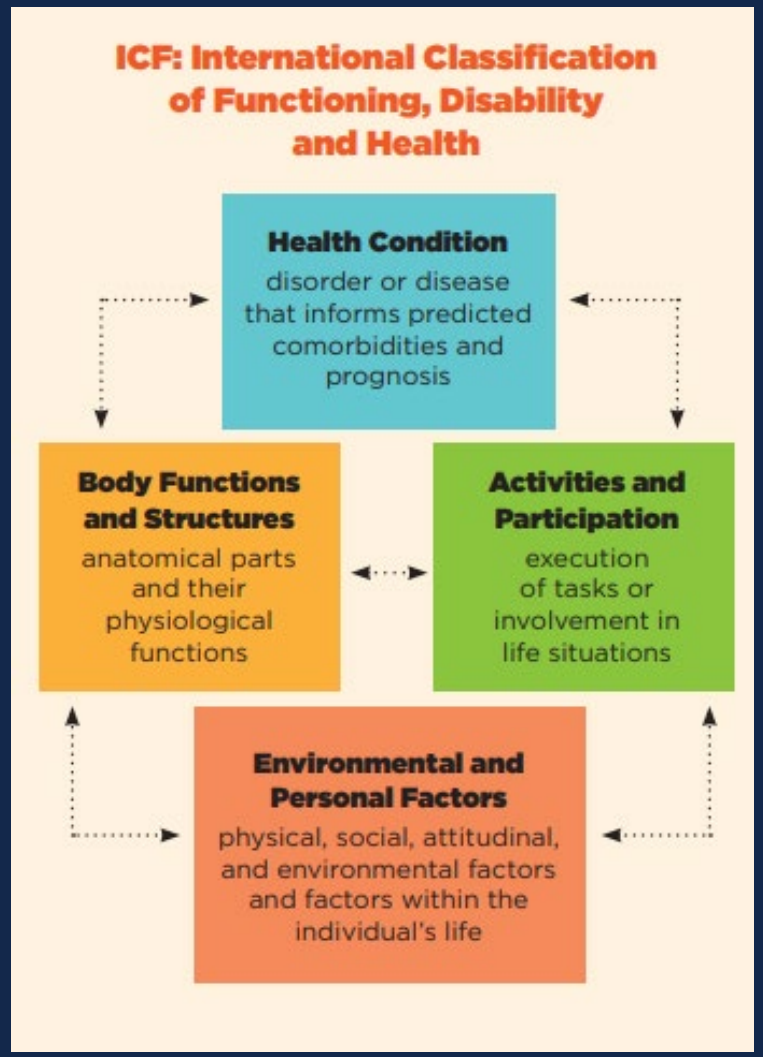

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