Promoting Earlier Hearing Related Diagnosis and Improved Intervention for Children with Developmental Disabilities through Interdisciplinary Collaboration

Meghan Breheney, MD

Angela Yarnell Bonino, PhD

Deborah Mood, PhD

Emily E. Nightengale, AuD

Susan Wiley, MD

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Bonino: Employed by Vanderbilt University Medical Center
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Wiley: Employed by Cincinnati Children's Hospital Medical Center- nothing to disclose

Objectives

- Recognize the prevalence and co-occurrence rates of reduced hearing and developmental disabilities in children
- Identify 3 barriers to audiological evaluation and management for children who are deaf and hard of hearing with co-occurring developmental disabilities, including systemic challenges, communication barriers, and access limitations
- Describe 2 practical strategies to improve care for children with co-occurring reduced hearing and developmental disabilities

Terminology: Developmental Status

Domains:

- Communication
- Cognition
- Motor
- Social Emotional
- Sensory

Developmental disability

Onset in early childhood; expected to continue through the lifespan
(e.g., autism, intellectual disability, cerebral palsy)

Developmental delay

Onset in early childhood; may resolve with intervention or time
(e.g., articulation concerns)

Neurodiversity

Broad umbrella term reflecting natural variation in how brains receive and process information or interact with others. Includes a wide range of neurological differences.

Prevalence of Developmental Disabilities

- 1:6 (17%) of children in the U.S. have a developmental disability (Zablotsky et al, 2019)
- Approximately 40% of children who are D/HH have a secondary disability (GRI, 2011)
- High rates of unrecognized hearing and vision concerns among those with intellectual/developmental disabilities (Hey et al., 2014; Russ et al., 2013)
- Children with co-occurring conditions likely need tailored and interdisciplinary intervention approaches
- Determining a child's hearing status promptly is critical to ensure access to appropriate interventions for maximizing developmental outcomes (Cupples et al., 2018; Moeller, 2000).

Increased rates of reduced hearing and developmental disabilities

Developmental Disability	Rate of reduced hearing	
Down Syndrome	60-80% conductive hearing loss 15-20% sensorineural hearing loss 10-20% mixed hearing loss	Bull et al., 2022; Kreicher et al, 2018; DeSchrijver et al., 2019
Intellectual Disability	24-93% (depending on whether DS is included)	Hild et al, 2008; Erickson & Quick, 2017; Hey et al, 2014
Cerebral Palsy	12-30% (higher risk of ANSD or neural hearing loss)	Reid et al, 2011; Weir et al, 2018
Autism Spectrum Disorder	2-7%	Syzmanski et al, 2012; Kancherla et al., 2013
Blind/VI	5.8% (can range up to 40% depending on classification)	Kancherla et al., 2013

Overlapping Risk Factors for Deafness and Developmental Disabilities

- Genetic
- Prematurity
- Low birth weight
- Congenital infection (e.g., cCMV)
- Birth complications
- Hyperbilirubinemia requiring exchange transfusion
- Exposure to environmental toxins or drugs during pregnancy

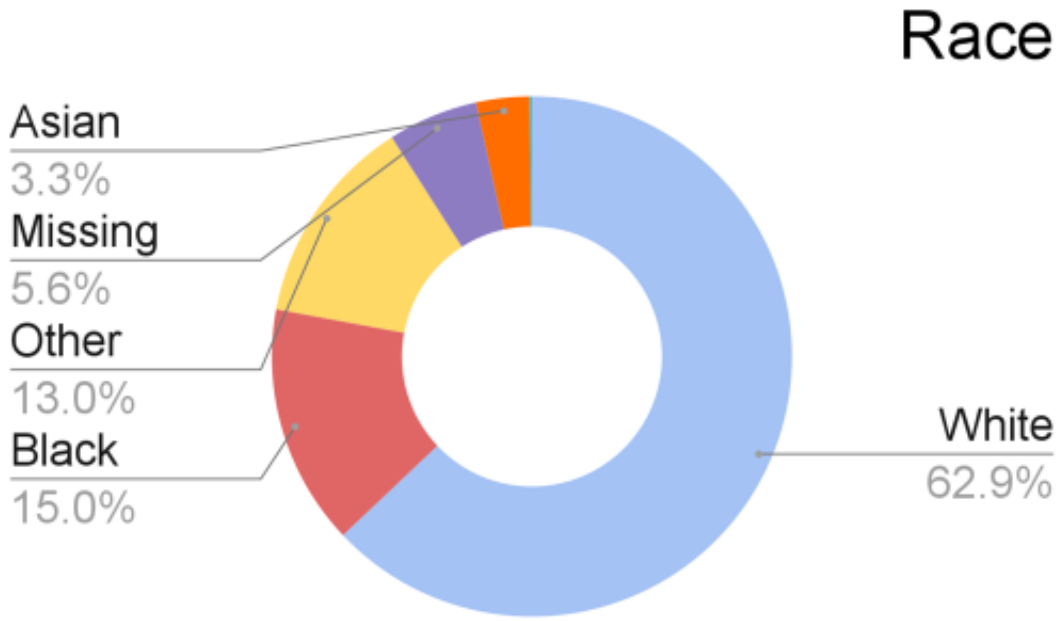
Overview of AudGenDB

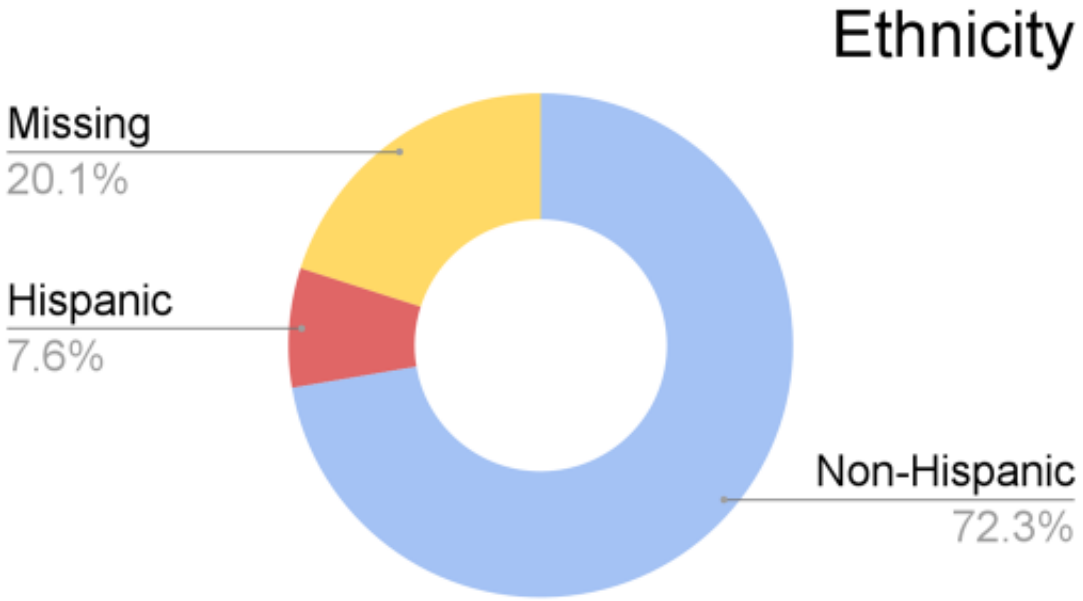
https://audgendb.chop.edu

NIH-NIDCD award number R24DC012207

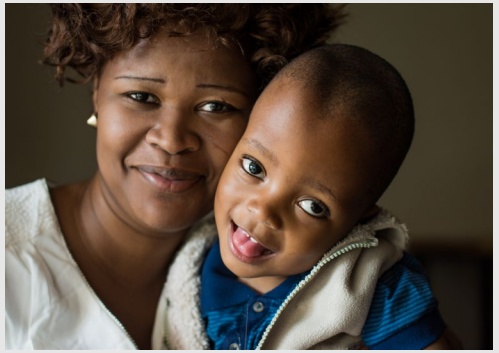
Participants

- Restricted to patients (<19 yr) with:
  - Clinical hearing data
  - ICD-9/10 diagnosis codes
- After filtering:
  - 131,783 patients were identified
  - 383,237 encounters
- 74% are from CHOP
- 59% are boys





Prevalence of Developmental Disabilities in Audiology Clinics



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Bonino, Goodwich, & Mood (2025). Prevalence and characteristics of developmental disabilities among children who receive hearing health care. *American Journal of Audiology*.

Prevalence in Audiology Clinics (N=131,709)

Developmental Disability	n (%)
None	99,500 (75.5)
Any Diagnosis	32,209 (24.5)
1	19,497 (14.8)
2	8,043 (6.1)
3	3,190 (2.4)
4 or More	1,479 (1.1)
Specific Disability	
ADHD	8,650 (6.6)
Autism	8,146 (6.2)
Cerebral Palsy	2,089 (1.6)
Chromosomal Abnormalities	3,144 (2.4)
Delayed Milestones	14,883 (11.3)
Down Syndrome	2,658 (2.0)
Intellectual Disability	2,212 (1.7)
Vision Differences	9,750 (7.4)

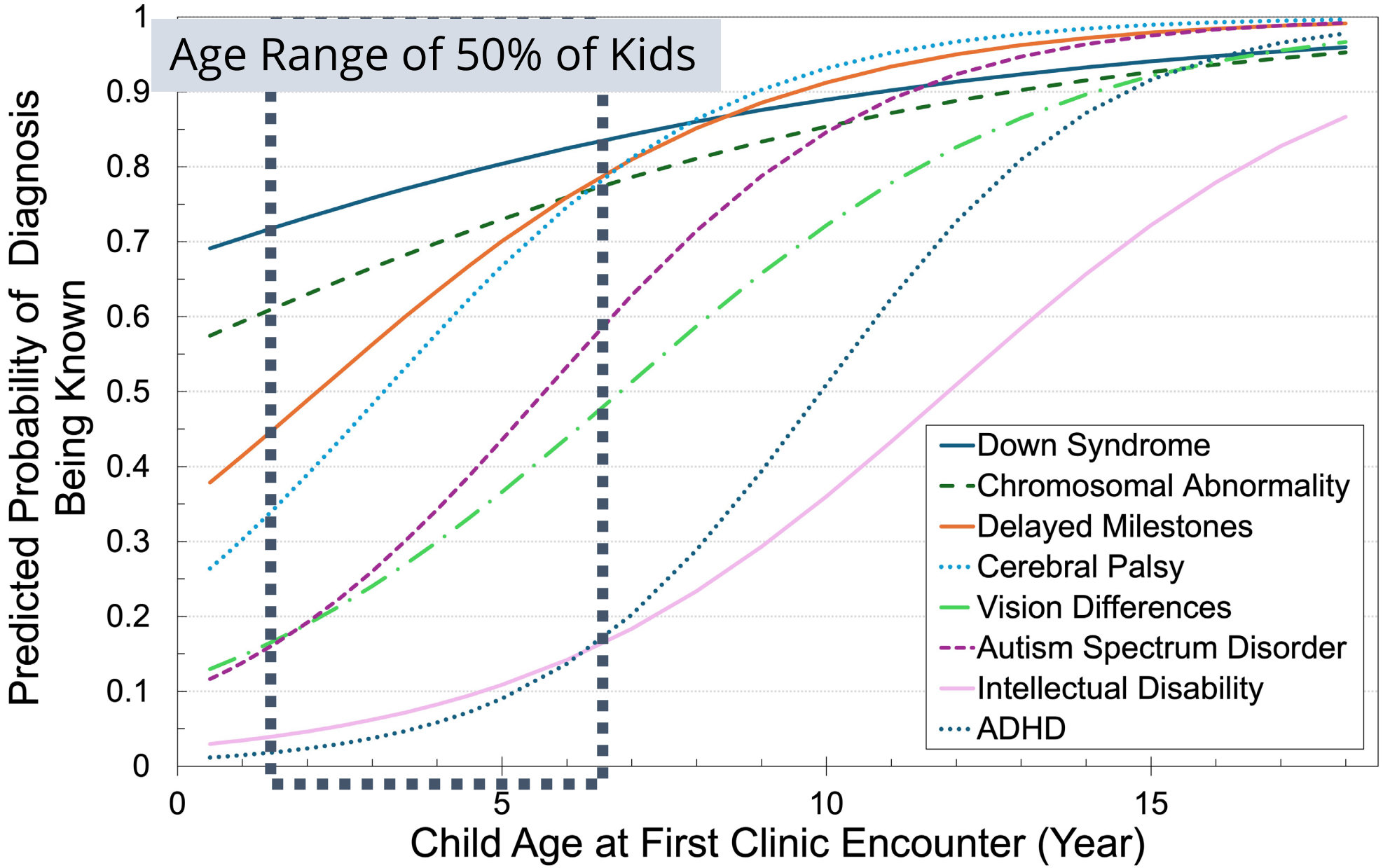
- **25% have at least 1 diagnosis**
- **10% have 2 or more diagnoses**

Prevalence of ASD, CP, DS and ID

Diagnosis		General US Population	Our Dataset
Down syndrome		1:700	1:50 (2.0%)
Cerebral palsy		2-3:1,000	1:63 (1.6%)
Autism		1:36	1:16 (6.2%)
Intellectual disability		2-3:100	1:59 (1.7%)

10% of the sample had one of these disabilities

Is the Diagnosis Known?



Earlier:

- DS
- Chromosomal

(sort of)

- Delayed Milestones
- CP

Later:

- Autism
- Vision
- ADHD
- ID

Accessing Gold-Standard Hearing Assessments

© istock

Bonino, Mood, & Dietrich (2024). Rethinking the accessibility of hearing assessments for children with developmental disabilities. *Journal of Autism and Developmental Disorders*.

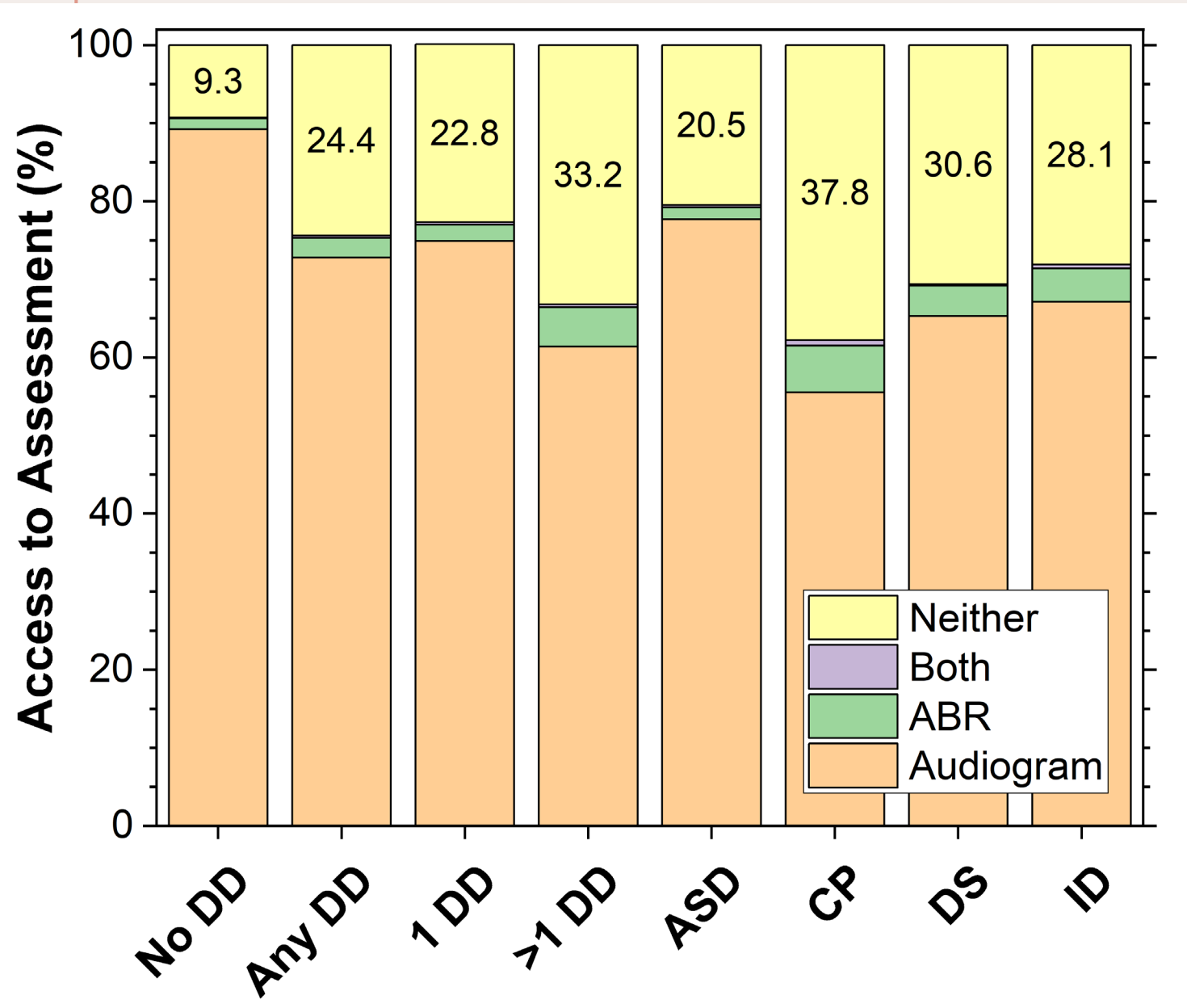
1-3-6 EHDI Framework

1. Receive a hearing screening no later than 1 month of age
3. Receive a diagnostic evaluation no later than 3 months of age
6. Receive early intervention services no later than 6 months of age

Access to Gold-Standard Assessment?

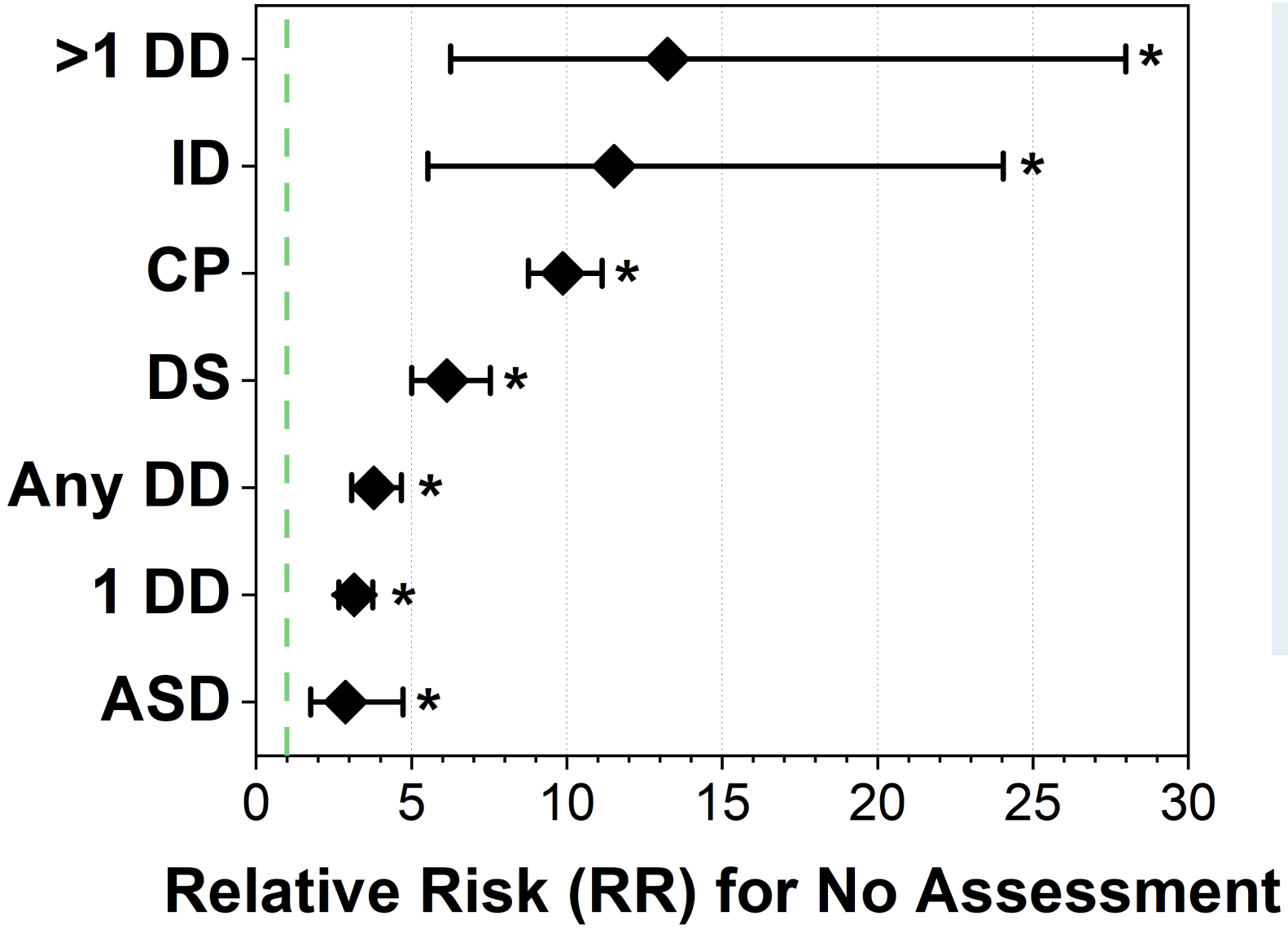
- In the first three months of hearing health care do children get access to:
  - Audiogram testing
  - ABR testing
- Access means that 1 or more thresholds had to be recorded
- Access to a gold-standard assessment is required to:
  - Fit hearing technology
  - Determine eligibility for hearing-related intervention services

Assessment Type By Group



During the initial 3 months of care **24.4%** of children with developmental disabilities did not receive a gold-standard assessment

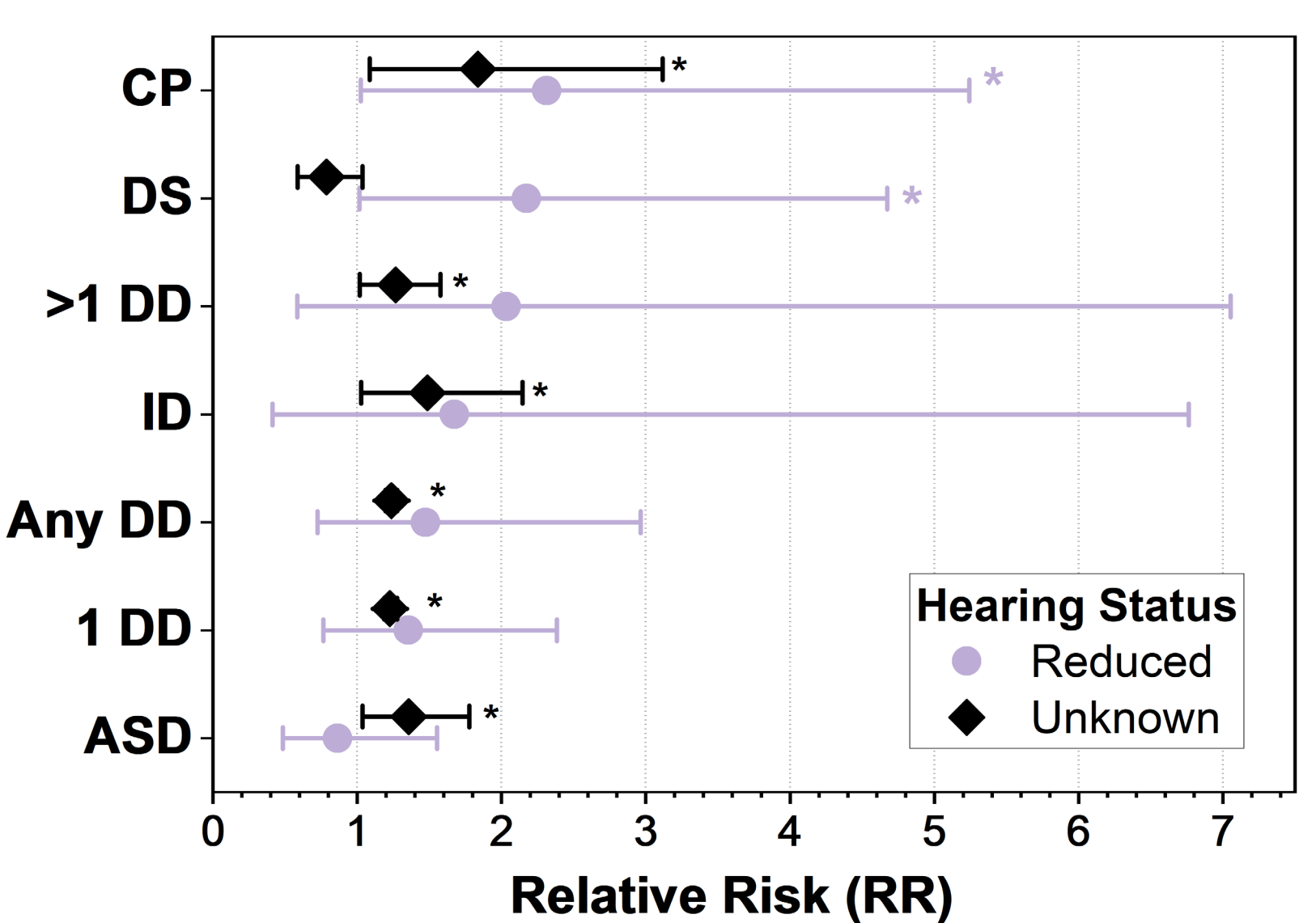
Risk for Not Accessing Assessment



All developmental disability groups were at higher risk than the comparison group for not receiving a gold-standard assessment.

The highest risk was seen for children with 2 or more diagnoses, ID, or CP.

Hearing Status



Children with developmental disabilities (except for DS) were more likely to have unknown hearing status.

Children with CP or DS had a higher risk of reduced hearing.

How are we doing?

- The most common reason for a delayed diagnosis following newborn hearing screening was a developmental or medical concern (Fitzpatrick et al., 2017)
- Children with developmental disabilities not identified with reduced hearing during newborn hearing screening, later dx with HL by age 7, encounter greater delays from referral to intervention (Mackey et al., 2024)
- Children with DD, not able to complete behavioral audiogram, encounter long delays in accessing ABR (Trudeau et al., 2021)
- Many studies regarding outcomes of children who are DHH exclude or fail to define children with developmental disabilities.

Children with developmental differences have a right to equitable access to:

- High-quality hearing healthcare
- Interventions to support language acquisition

TIMELY diagnosis of hearing and developmental concerns is critical

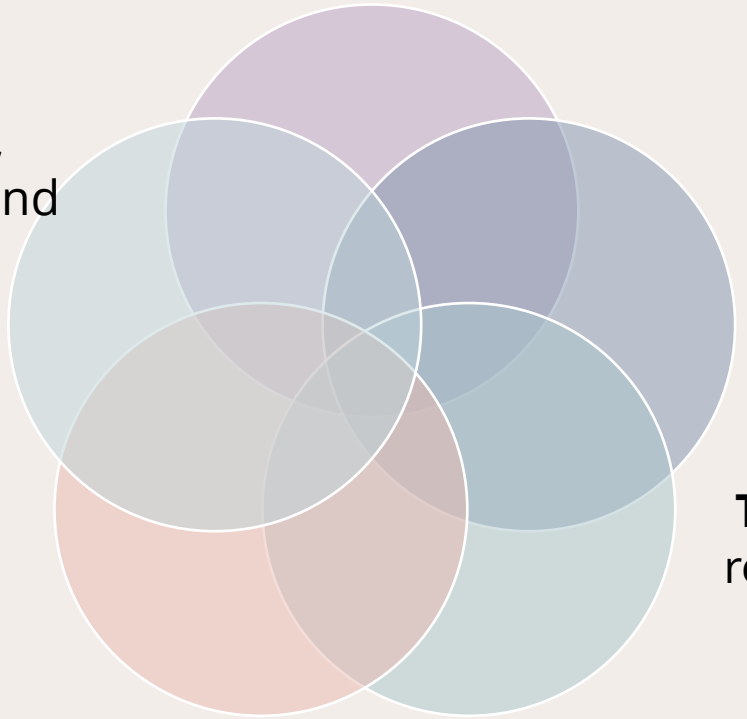
Interdisciplinary Strategies

Promoting earlier diagnosis and teaming to improve intervention

Potential Factors

Provider: comfort and experience testing children; biases and assumptions

Systems: commitment to addressing health disparities through investments in training, research, infrastructure, and policies



Child: developmental profile; sensory sensitivities; ability to transition; perception of environment; and anxiety

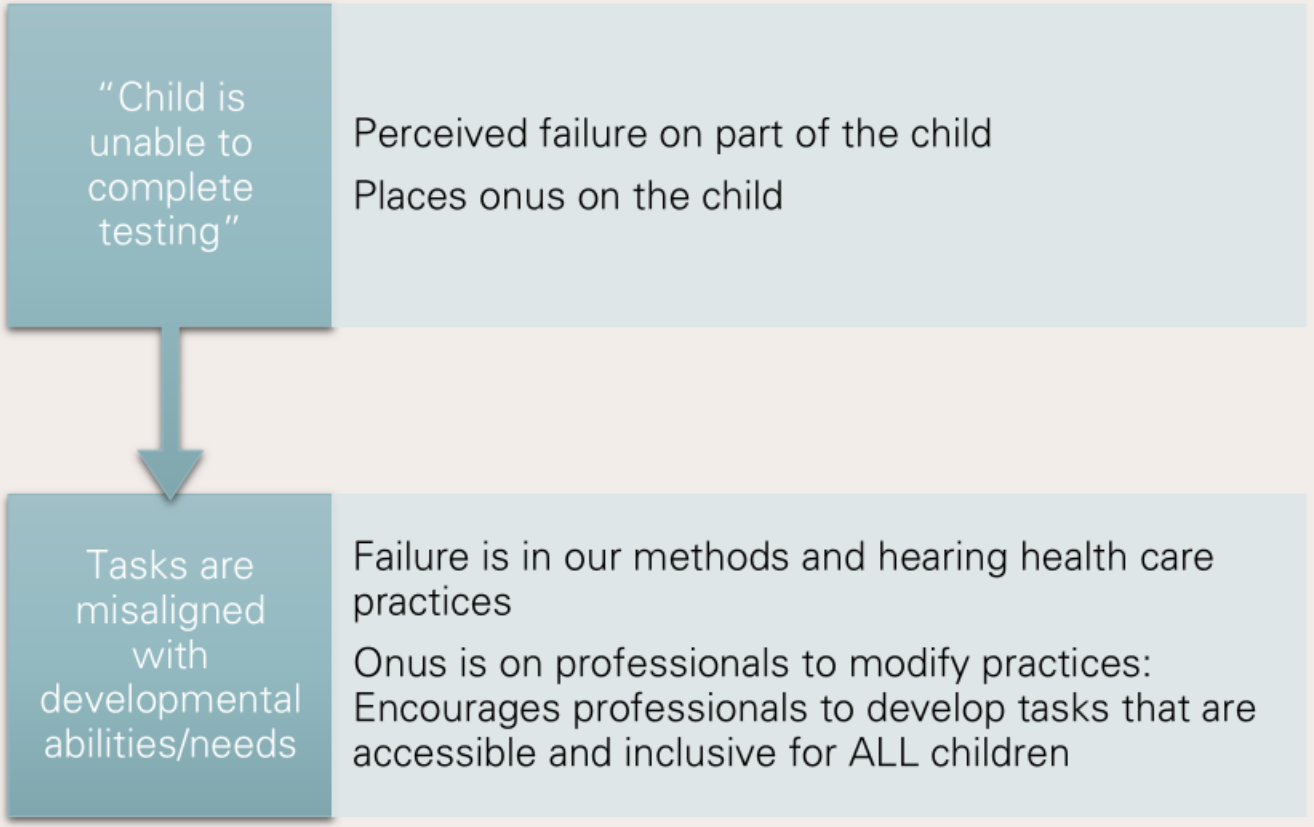
Clinic: clear protocols; scheduling practices; design of environment; use of supports

Testing Method: rigorous and reliable methods for measuring hearing in 1-2 visits

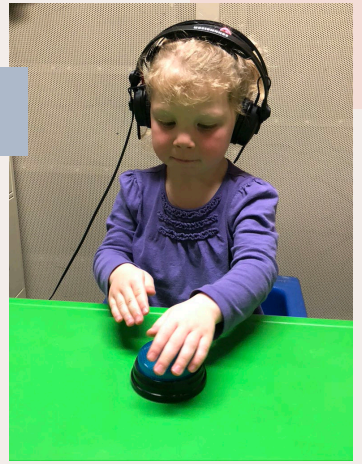
Child and clinic related factors

Traditional practice	Developmentally informed practice
Test selected based on child's chronological age	*Pre-screen to understand child's developmental stage, modify tasks based on child's developmental needs
Reinforcement based on social praise, aspects of the task itself	Reinforcement is accessible, meaningful, and aligned with interests
Implicit task demands are assumed to be within the child's repertoire	Reduce transitions, address sensory sensitivities, attend to language used to explain tasks
Follow up schedule recommended several weeks later	*Serial appointments scheduled to allow for gradual desensitization and benefit of repeated learning trials
Multiple follow up behavioral measures	Developmentally informed protocols specifying when to move to another procedure or sedated ABR, clear guidelines for establishing timely dx of hearing status

Flipping the script



Selection of Task



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Developmental Milestone Levels

Bonino Lab -- Adapted from Malley et al. (2019)

doi:10.17605/OSF.IO/59G8C

EASIER

	COGNITION	MOTOR	SOCIAL/ LANGUAGE
0	INTERESTED IN TOYS	CAN PUSH A LARGE BUTTON	EXPLORES ALONE BUT WITH FAMILIAR ADULT NEAR
	EXPRESSES WANTS WITH WORDS OR BY POINTING	CAN SIT IN CHAIR INDEPENDENTLY	SAYS FEW SIMPLE WORDS
	FOLLOWS 1-STEP INSTRUCTIONS		STRANGER ANXIETY IN NEW SITUATIONS
1	CAN STAY ON TASK ADULT DIRECTED - FOR AT LEAST 5 MINUTES	CAN MOVE OBJECTS ACROSS A TABLE	INTERESTED IN INTERACTING WITH ADULTS
	MATCHES PICTURES TO OBJECTS	EATS WITH SPOON	SAYS 2-3 WORD PHRASES
	SORTS BY CATEGORY	TURNS KNOB/HANDLE	ENJOYS ACCOMPLISHING TASK
	LISTENS TO INSTRUCTONS	STACKS 4 BLOCKS	IMITATES SIMPLE ACTIONS

→ Cause-and-effect Task

→ Traditional CPA (Drop-and-release Task)

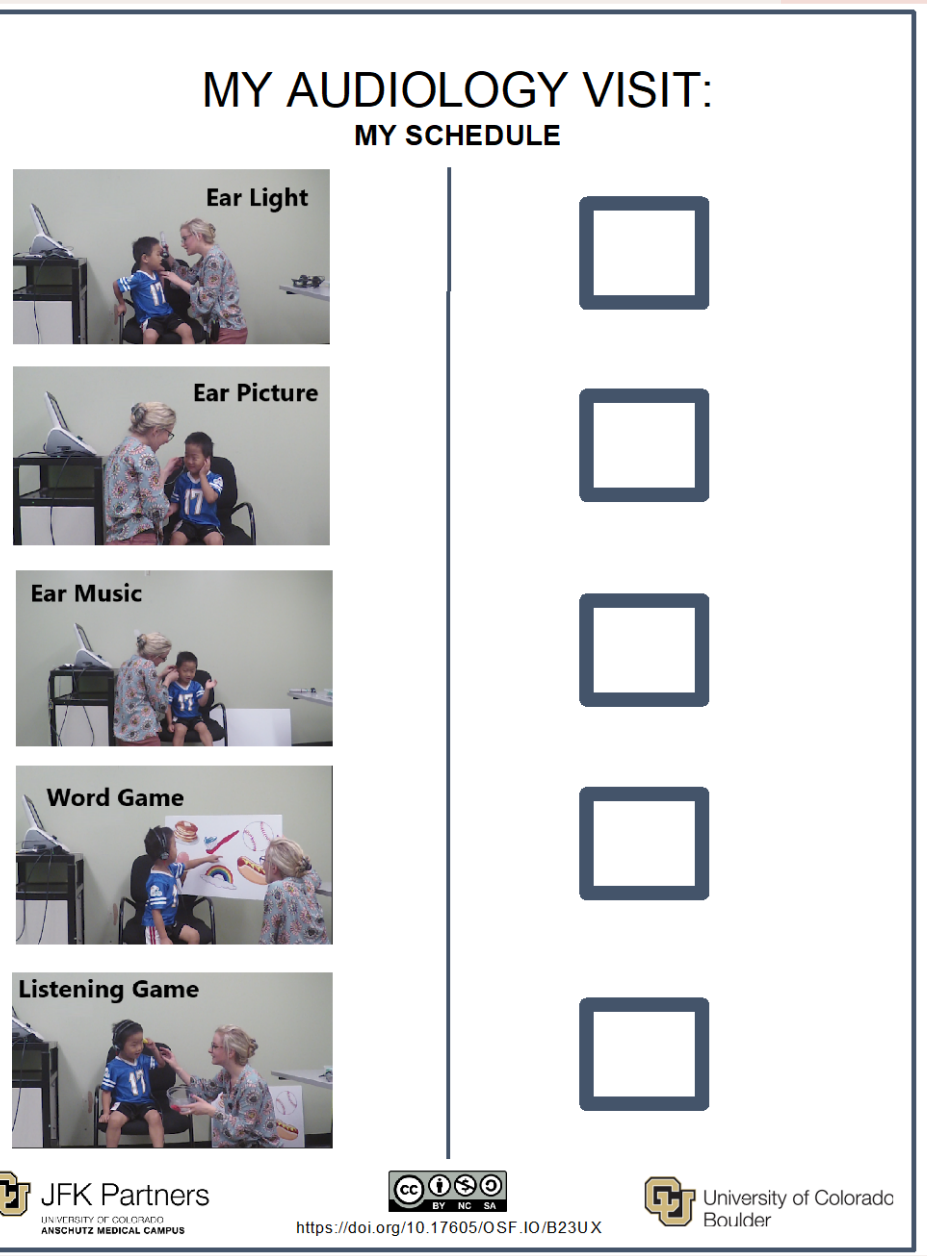
Visual Supports

- Help children transition and generalize desirable behavior(s) to new activities

- Visual schedules
- Video models

Paper:

Open Access Materials:



Library of Visual Reinforcement Materials

Activities	Animals	Sensory	Transportation and Equipment
- Cleaning - Cooking - Shopping - Sports	- African Safari - Big Cats - Birds - Birds of Prey - Bugs - Butterflies and Moths - Cats - Dinosaurs - Dogs - Farm Animals - Forest Animals - Frog and Toads - Reptiles - Sea Creatures - Snakes - Zoo Animals	- Bubbles - Clocks, Timers and Counters - Fans and Windmills Spinning - Items Moving and Spinning - People in Motion - Rainbows and Colorful Images - Reflections - Rides at Amusement Parks - Water spinning	- Airplanes - Boats - Emergency Vehicles - Farm Equipment - General Transportation Vehicles - Race Cars - Semi-Trucks and Heavy Construction Equipment - Trains
People			
- Babies - Faces			
Science and Letters			
- Alphabet - Space - Waterfalls - Weather			

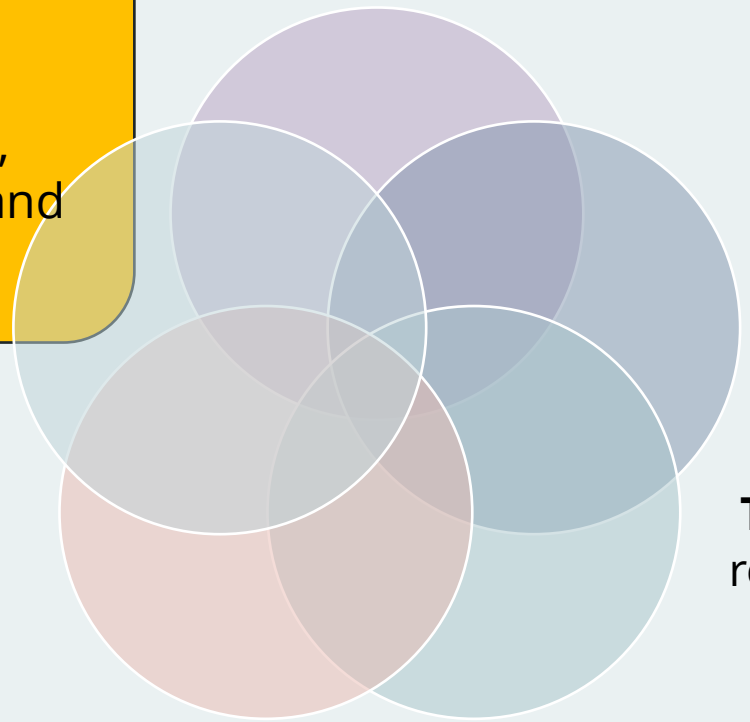
Open Access Materials:

Paper:

System Level Factors

Provider: comfort and experience testing children; biases and assumptions

Systems: commitment to addressing health disparities through investments in training, research, infrastructure, and policies



Child: developmental profile; sensory sensitivities; ability to transition; perception of environment; and anxiety

Clinic: clear protocols; scheduling practices; design of environment; use of supports

Testing Method: rigorous and reliable methods for measuring hearing in 1-2 visits

JCIH guidance: limited in regards to DD

Guidance has been broadly focused on identifying hearing thresholds based on **newborn** screening programs across all children.

Risk factors for **late onset** hearing differences includes conditions that are associated with developmental disabilities, though does not address hearing evaluation among children with Intellectual and Developmental Disabilities (IDD).

Guidance from the Early Intervention Supplement addresses therapeutic needs of children who are DHH with disabilities.

Medically informed strategies to support children with DD

Follow condition specific guidance when available

The AAP policy on otitis media with effusion that encourages watchful waiting for middle ear fluid is explicitly not appropriate for children with disabilities and high risk conditions for hearing differences (speech delay, cleft lip/palate, Trisomy 21 as examples).

- For MD's, definitively manage middle ear fluid (look, if can't see, send to ENT for microscope evaluation) Treat with antibiotics and re-evaluate middle ear status.

- For audiologists, even if there is fluid or abnormal tymps, please still evaluate hearing thresholds. If they are impacted, we manage this more robustly than when fluid without a hearing impact is occurring.

In children who have difficulty participating in hearing evaluations and are not getting results to reassure you that hearing is sufficient to support spoken language development, it is medically appropriate/necessary to pursue a sedated ABR.

It is helpful to coordinate with other sedated procedures, though consider the impact of scheduling benefits to the risk of delayed confirmation of hearing status.

Medically informed strategies to support children with DD

Medical work-up related to hearing within children with disabilities who are DHH should follow the same guidance as for those without disabilities (imaging, genetic evaluations). Workup can further be informed by what we may know about a specific condition.

On the flip side, children who are DHH and subsequently are identified with a disability should receive the appropriate work-up for individuals with IDD (genetic testing standards for IDD, additional medical work-up per condition and exam, i.e. CNS imaging in those with cerebral palsy).

Coordination of care is very important among children with disabilities who are DHH.

Partnering with Medical Providers

INSTEAD OF....
(child has) "normal hearing in at least the better hearing ear"
CONSIDER.....
"We cannot rule out all types of hearing loss at this time, therefore, an appointment to complete hearing testing is scheduled on (date)"

- While awaiting further hearing evaluation, appropriate to move on with developmental evaluation and intervention

- Primary care providers have varying levels of experience interpreting audiograms/audiology reports
- Helpful to have consistent and clear documentation of hearing status and need for follow-up

Tailored Assessment Protocols

Need to develop protocols for specific developmental disability profiles

Update protocols to address:

Aggressive assessment and intervention for middle ear pathology in children with developmental differences (Rosenfeld et al., 2016)	How soon to return to the clinic when incomplete hearing data are obtained	How soon to refer for ABR when behavioral testing is not successful

Audiological assessment in children with DS

Table 4. Age versus inconclusive behavioral test results.

Age	Inconclusive results *n* (%)
Up to 1 year	26/38 (68.4)
1 year	22/60 (36.7)
2–3 years	17/93 (18.3)
4–5 years	3/58 (5.2)
6–10 years	3/88 (3.4)
11–15 years	5/44 (11.4)
16–21 years	0/17 (0.0)

Table 5. Sound field versus ear-specific results at 500–4000 Hz by age and behavioral test technique.

Test type	No results *n* (%)	Sound field only *n* (%)	1 ear or sound field + 1 ear *n* (%)	2 ears *n* (%)	Total *n* (%)
Age					
Up to 1 year	23 (62.2)	14 (37.8)	0 (0.0)	0 (0.0)	37
1 year	23 (38.3)	34 (56.7)	1 (1.7)	2 (3.3)	60
2–3 years	22 (23.9)	53 (56.7)	3 (3.3)	14 (15.2)	92
4–5 years	8 (13.8)	20 (34.5)	3 (5.2)	27 (46.4)	58
6–10 years	12 (13.6)	7 (8.0)	2 (2.3)	67 (76.1)	88
11–15 years	5 (11.4)	4 (9.1)	0 (0.0)	35 (79.5)	44
16–21 years	0 (0.0)	2 (11.8)	0 (0.0)	15 (88.2)	17
Test type					
BO	6 (60.0)	4 (40.0)	0 (0.0)	0 (0.0)	10
BO and VRA	13 (81.3)	3 (18.8)	0 (0.0)	0 (0.0)	16
VRA	53 (28.0)	110 (58.2)	4 (2.1)	22 (11.6)	189
VRA and CPA	7 (35.0)	7 (35.0)	0 (0.0)	6 (30.0)	20
VRA and standard	0 (0.0)	1 (100.0)	0 (0.0)	0 (0.0)	1
CPA	14 (10.0)	10 (7.1)	5 (3.6)	111 (79.3)	140
Standard	0 (0.0)	0 (0.0)	0 (0.0)	22 (100.0)	22
Standard and CPA	0 (0.0)	0 (0.0)	0 (0.0)	1 (100.0)	1

Note. BO = behavioral observation; VRA = visual reinforcement audiology; CPA = conditioned play audiometry.

Retrospective chart review of 273 children with DS who received hearing evaluation in 2013

145 boys, 128 girls; average age at evaluation = 5.92 ± 4.74 years

Average age to reliably complete behavioral testing in children with DS was delayed by up to 30 months compared to typically developing children.

Majority of children with DS attained good-to-fair reliability for audiologic results in soundfield starting 16 months (85.7%) and ear specific (two ear) results at 6–10 years (76.1%).

Nightengale et al., 2020

Example of Down Syndrome protocol

Current AAP guidelines	Research based suggestions
0-1 months: evaluate for congenital hearing loss with objective testing such as BAER or OAE. If don't pass NBHS refer to ENT familiar with stenotic external canals Tympanometry if TM poorly visualized	0-1 months evaluate for HL with ABR
If pass NBHS, rescreen at 6 months of age; middle ear disease should be treated immediately when dx	Basonbul et al, 2020- N=131 Of those who pass NBHS, only 22% had ABR in first 12 months; 71% of those ABRs were abnormal Taking into consideration risks of anesthesia (not given in their cohort before 10 months) and greater unlikelihood of unreliable behavioral testing in this population at young ages in this population, rx natural sleep ABR by 3 months
Behavioral audiogram at age 1 but many unable to complete: BAER if not able to complete; consider vestibular	Porter et al, 2022 85% of participants (ages 5-17) had moderate or greater HL above 8KHx 50% had abnormal middle ear function when wideband acoustic immitence (WAI) or tympanometry were successfully measured
If pass early BAER, behavioral audiogram and tympanometry rx every 6 months until normal hearing levels are established bilaterally via ear specific testing (usually after 4 yo);	
Behavioral tests annually; if normal hearing not established via behavioral, additional screen via OAE or dx BAER with sedation of necessary	

Starting Place

- Recommended that all babies with DS, craniofacial differences, or known syndromes to access diagnostic ABR before 3 months of age, regardless of newborn hearing screening results
  - https://doi.org/10.1016/j.ijporl.2020.110017
  - https://doi.org/10.1044/2021_JSLHR-20-00699
- Quality improvement project on assessment for children with cleft lip/palate: https://doi.org/10.1177/1055665621029526
- Need to consider high frequencies and wideband acoustic immittance (WAI) for children with DS: https://doi.org/10.1044/2022_JSLHR-22-00023
- General health assessment guidance for DS: https://doi.org/10.1542/peds.2022-057010
- Systematic review for CP: https://doi.org/10.1177/08830738211004519

- Benefits of diagnostic ABR access prior to NICU discharge: https://doi.org/10.1044/2024_AJA-24-00178

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Thank you