

CHILDREN WHO ARE DEAF AND HARD OF HEARING WITH AN AUTISM SPECTRUM DISORDER

Christie Yoshinaga-Itano, Ph.D.

Deborah Mood, Ph.D.

JFK-HCP Webinar

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Understanding the dual diagnosis

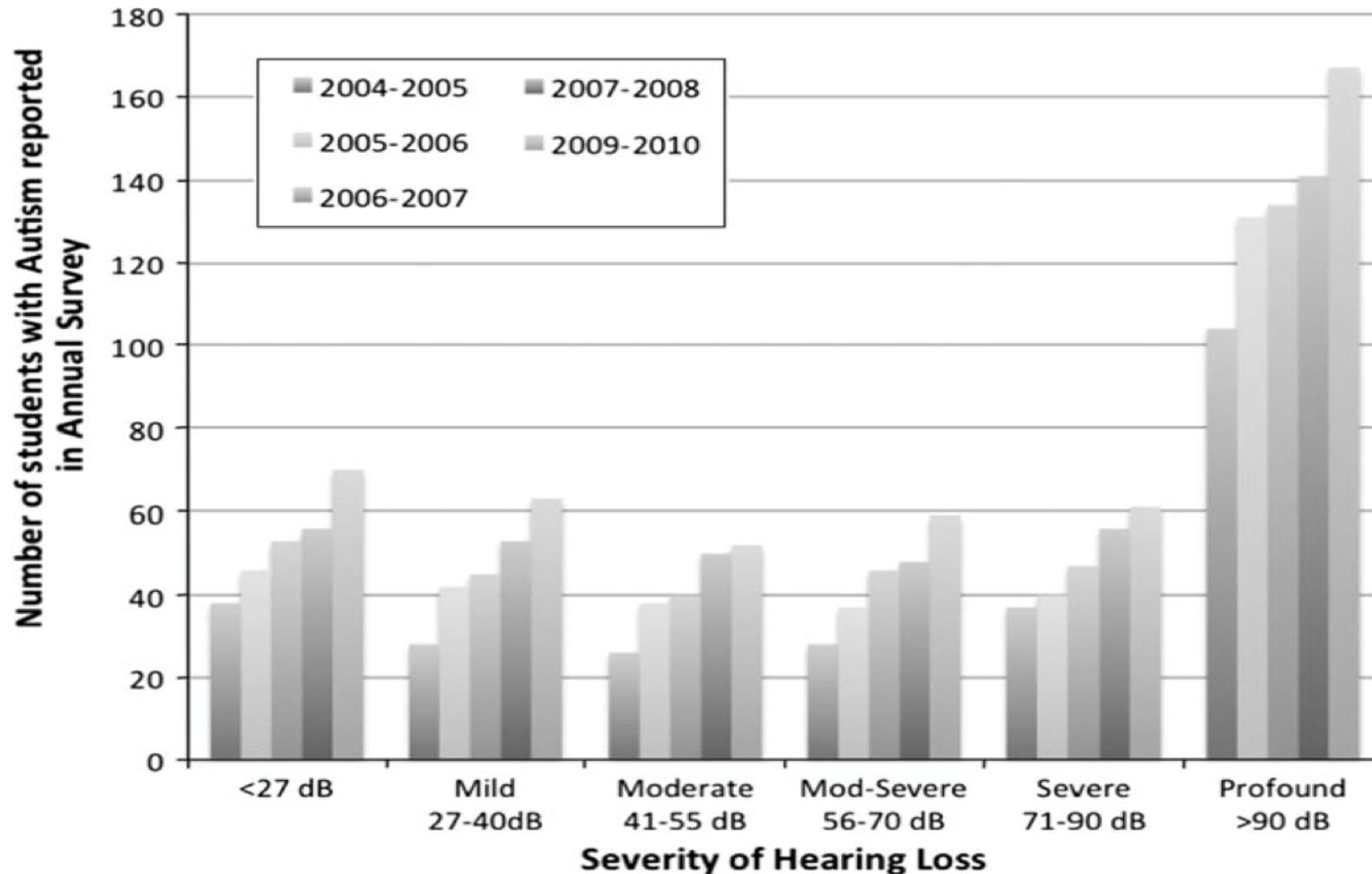
Higher ASD Rates in D/HH children

Severity of HL & ASD dx = Mixed results

D/HH children are later to be diagnosed (esp. mild HL)

Delayed dx → delayed intervention → poorer outcomes

Prevalence of Autism based on Severity of Hearing Loss

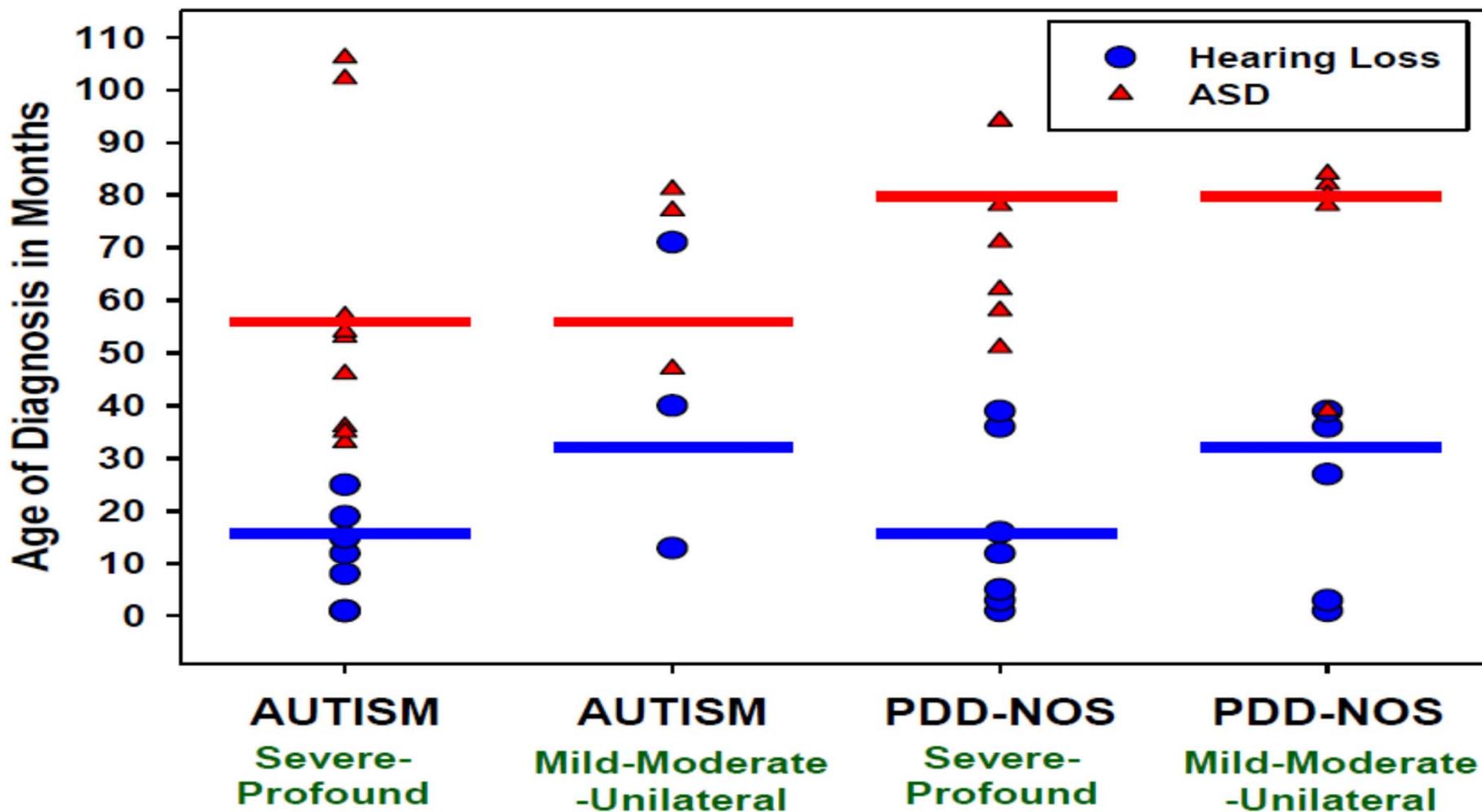


Data is provided here from the Annual Survey of Deaf and Hard of Hearing Children and Youth Conducted by the Gallaudet Research Institute
Published in Szymanski, Brice, Lam and Hotto, 2012

Age of Diagnosis for ASD and Hearing Loss

Median 53.5 months

Median 78 months



Meinzen-Derr, J et al "Autism Spectrum Disorders in Children who are Deaf or Hard of Hearing" International Journal of Pediatric Otorhinolaryngology 2014 Jan;78(1):112-8

At-risk

- **CHARGE Syndrome**
 - Reports of autistic behavior in CHARGE syndrome
 - Used Autism Behavior Checklist to assess features of 160 children with CHARGE as compared to deaf-blind children and children with ASD
 - Hartshorne, T, et al: Autistic-Like Behavior in CHARGE Syndrome. American Journal of Medical Genetics 2005: 133A:257–261.
 - Not all in agreement with this finding due to challenges in understanding the impact of dual sensory impairment on presentation
- **Symptomatic CMV: Case series of 7 children, 2 with ASD**
 - Yamashita, Y et al. Possible Association between Congenital Cytomegalovirus Infection and Autistic Disorder Journal of Autism and Developmental Disorders, 2003: 33 (4) 455-459.
- **Possibly Prematurity: Most studies on prematurity have only used screening tools, not confirmatory diagnostic evaluations**
 - Stephens, BE et al. Screening for ASD in extremely preterm infants. J Dev Behav Ped 2012 33(7): 535-541
- **Possibly Usher Syndrome: 1/26 with ASD**
 - Dammeyer, J. Children with Usher syndrome 1/26 with ASD Usher Syndrome: mental and behavioral disorders. Behavioral and Brain Functions 2012, 8:16.

Screening tools for Autism Spectrum Disorder: Earlier is Better

- Red Flags
- Checklist for Autism in Toddlers
- MCHAT: Modified Checklist for Autism in Toddlers
- Screening Tool for Autism in Toddlers (STAT)
- Infant-Toddler Checklist
- Parent's Observation of Social Interaction

Screening

No ASD screening tools have been validated for children who are Deaf/HH

Clinical experience of several providers suggests that some screening tools such as the MCHAT and SCQ can both over and under-identify children who are D/HH

Advisable to still refer a child who presents with red flags for ASD who “passes” these screening measures to be referred for a more comprehensive ASD diagnostic assessment.

The Baby and Infant Screen for Children with aUtism Traits (BISCUIT) was administered to children with conductive hearing loss (need for PE Tubes) and children in this category did not overlap with the results from the children with ASD (suggesting that children who are at risk for HL do not have autistic traits)

Worley, J et al 2011 Developmental Neurorehabilitation 14(3) 171-176

Screening

- Colorado has applied the LENA autism screening (LLAS) among 83 children birth to 72 months who are Deaf/HH of varying degrees of hearing loss
- The LENA ASD screening algorithm was applied to the data outputs to categorize likelihood of an ASD
- Minnesota CDI results (specifically social development domain) were also evaluated among children flagged as at risk on the LENA
- Children at risk require further evaluation

**LENA DATA COMPARING
CHILDREN WHO ARE HARD OF
HEARING WITH CHILDREN
WITH TYPICAL DEVELOPMENT,
ASD, AND LANGUAGE
DISORDERS**

Unique Acoustic Characteristics of Children with Autism and Their Caregivers:

Dongxin Xu ^{1,2}

Jill Gilkerson ^{1,2}, Jeffrey Richards ¹, Steve Rosenberg ³

¹ LENA Research Foundation, Boulder, Colorado, USA

² University of Colorado, Boulder, Colorado, USA

³ University of Colorado, Denver, Colorado, USA

www.lenafoundation.org

Different Technologies & Instruments in Autism Research:

- **Questionnaire & Human Observation**
- **Video, Eye Tracking, EEG, fMRI,
.....**
- **Audio Recording**

Advantage of Audio Recording:

- **Convenient Operation**
- **Large Sample Size**
- **Naturalistic Setting**
- **Automatic Processing**
- **Objective Measurement**

Cost Effective Way of Studying:

- Child
- Caregiver
- Their Interaction

In Natural Environment

Rich Information:

- **Not just Child Vocal Behavior**

AND

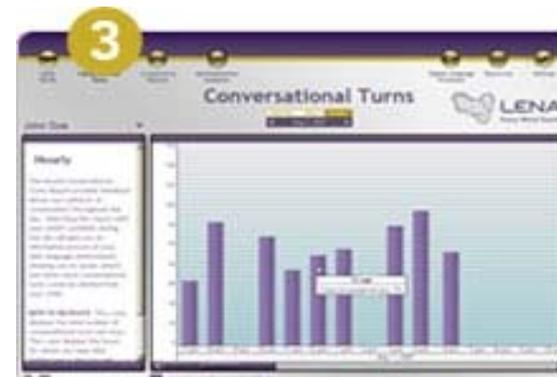
- **Child Social-Emotional Behavior**
- **Language and Communication Development**
- **Articulatory Motor & Stereo-type Behavior**

Demonstrate the Potential:

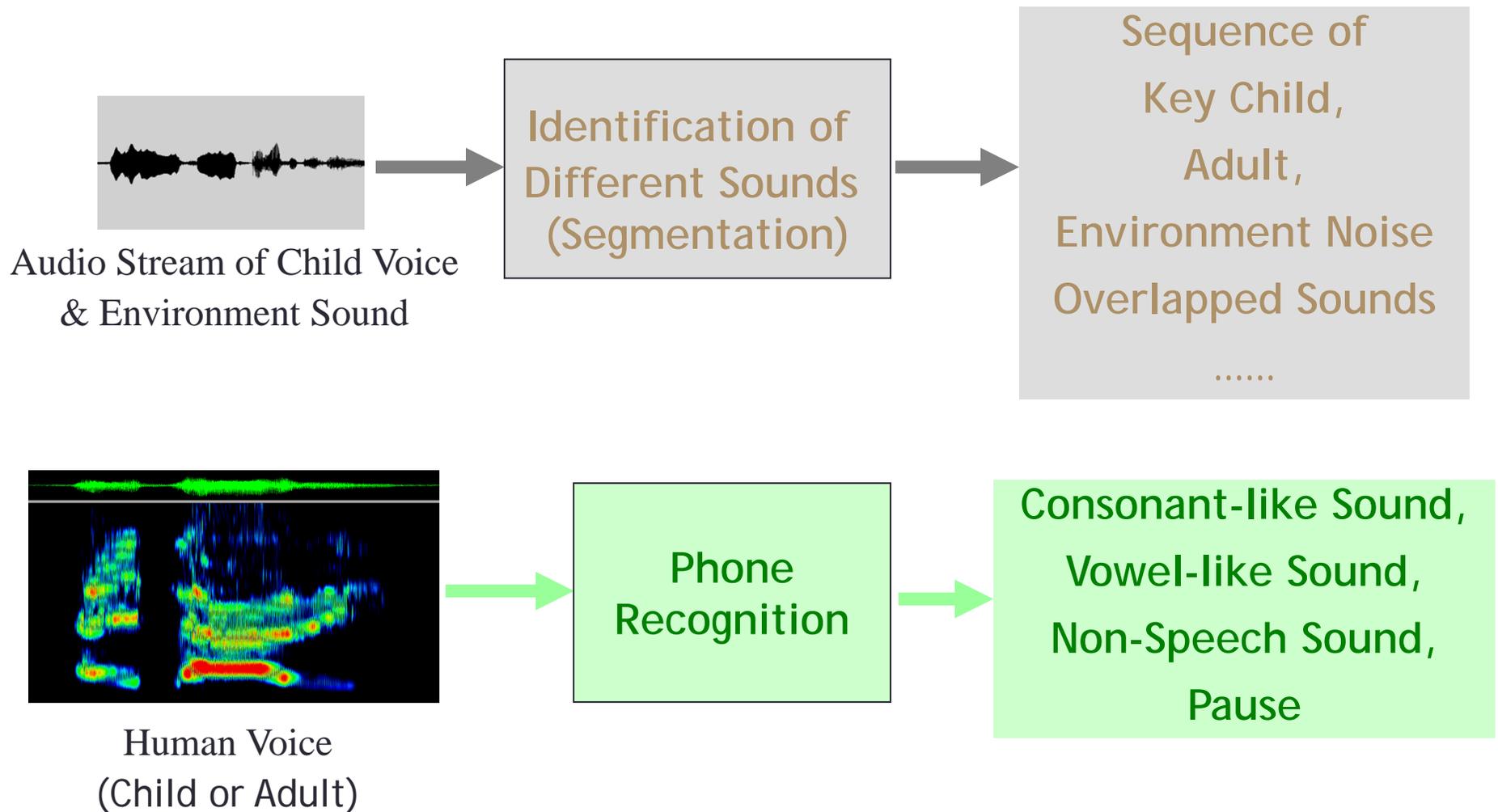
- **Naturalistic Audio Recording**
- **Automatic Processing**

- **Study Objective Features & Measurements:**
 - Child Interaction with Environment
 - Child Vocal & Phonetic Development
 - Developmental Trajectories
 - Unique Characteristics
 - **(compared with children of Typical Development & Language Delay)**
 - Caregivers of Children with Autism

LENA: Language Environment Analysis



Automatic Processing



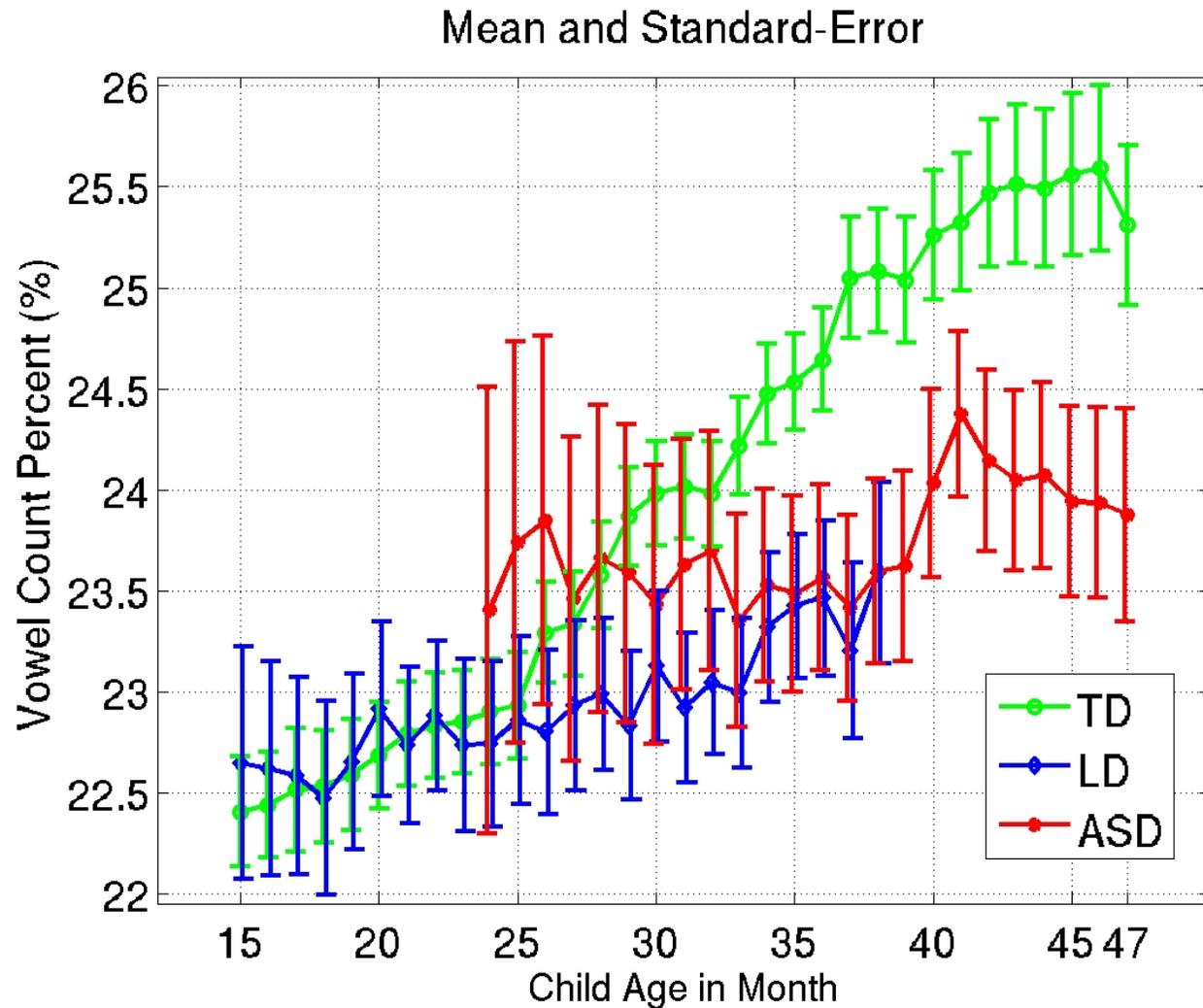
Data Set of the Study

Child Groups	Number of Children (N)	Number of Recordings	Child Segments (number in million)	Phoneme-like Units (number in million)
Typical Development (TD)	106	802	2.15 M	8.42 M
Language Delay but not ASD (LD)	49	333	0.75 M	2.65 M
Autism (ASD)	71	225	0.53 M	1.82 M
Total	226	1363	3.43 M	12.89 M

In the following slides of results of findings

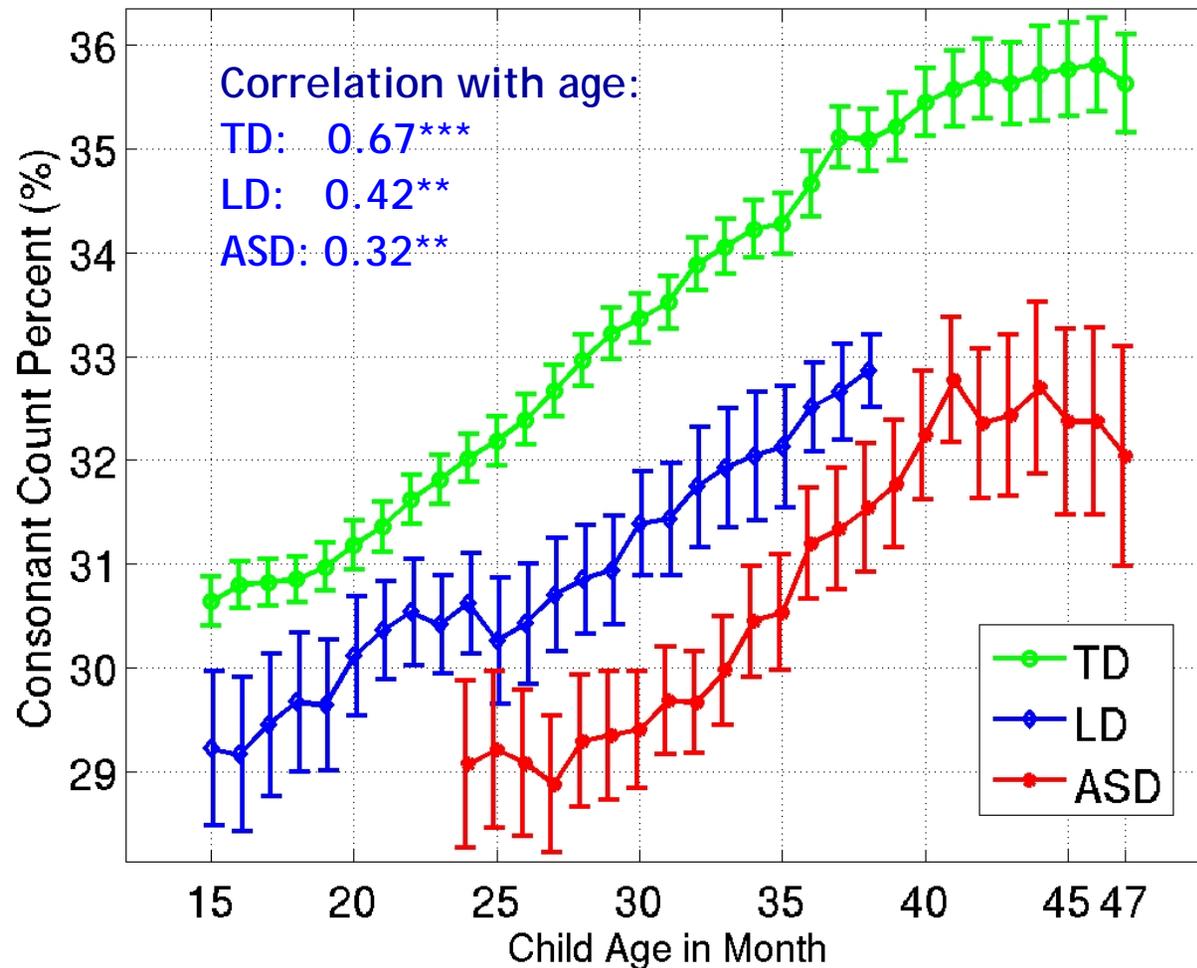
- **Green:** Typical Development (TD)
- **Blue:** Language Delay not Related to Autism (LD)
- **Red:** Autism (ASD)

Frequency of Vowel-like Sound



Frequency of Consonant-like Sound

Mean and Standard-Error



t-test

(Welch 2-sample 2-side)

TD versus ASD:
 $t(90) = 7.95^{***}$

TD versus LD:
 $t(68) = 5.52^{***}$

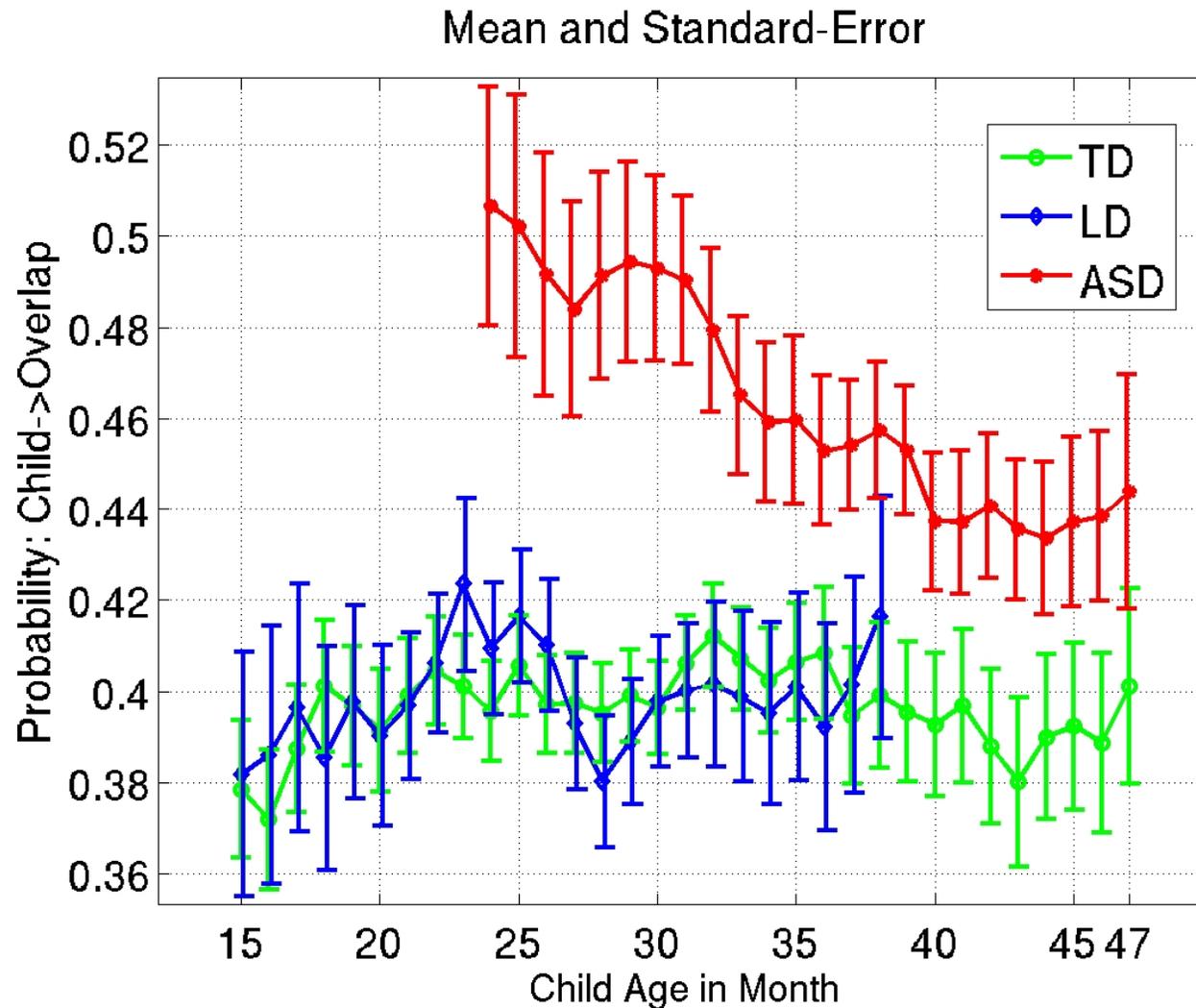
LD versus ASD:
 $t(118) = 2.62^{**}$

* $p < 0.05$

** $p < 0.01$

*** $p < 0.001$

Probability of Sound Collision



t-test

(Welch 2-sample 2-side)

ASD versus TD:
 $t(132) = 3.66^{***}$

ASD versus LD:
 $t(111) = 2.94^{**}$

TD versus LD:
 $t(90) = 0.13$

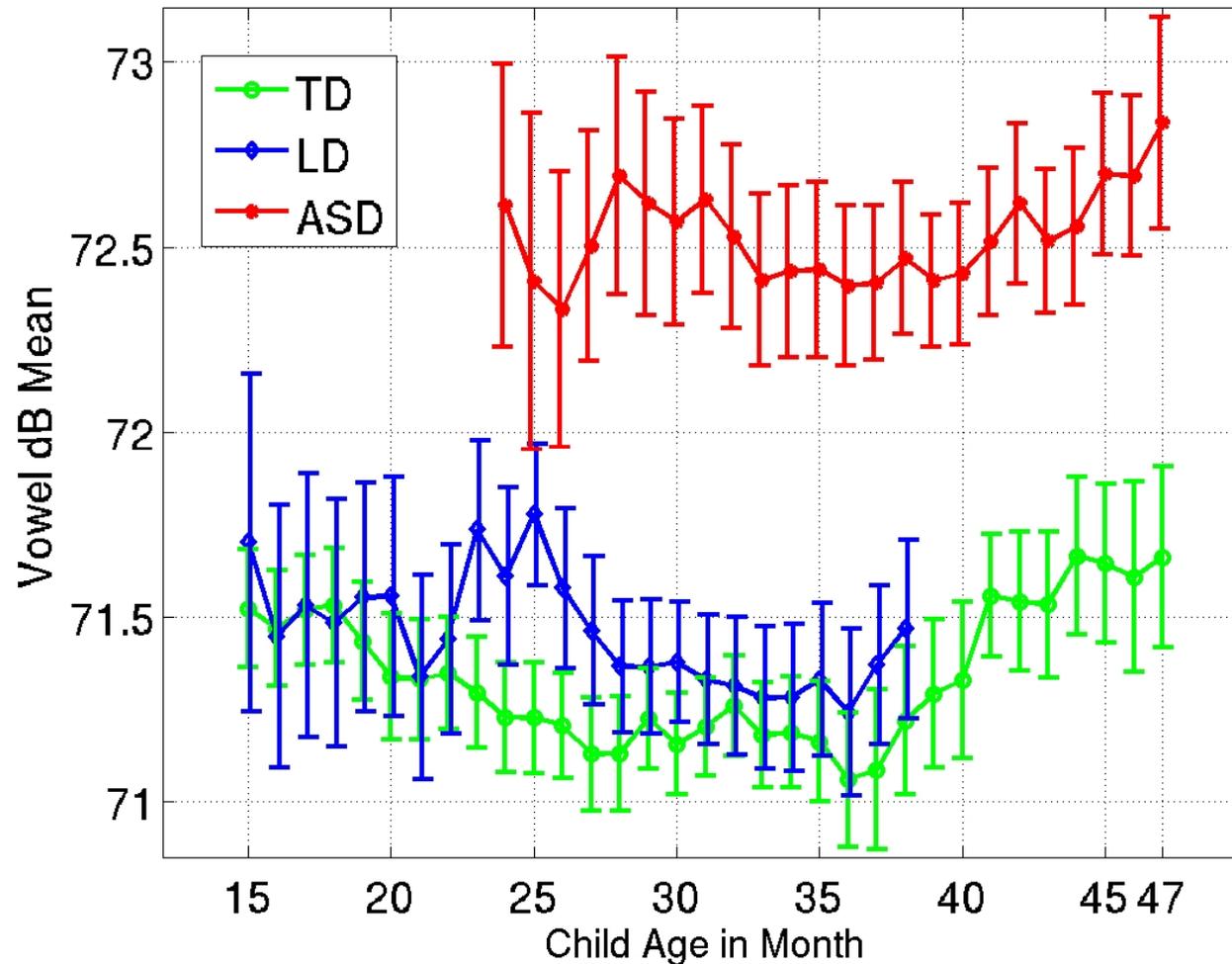
* $p < 0.05$

** $p < 0.01$

*** $p < 0.001$

Child Vowel Volume (dB)

Mean and Standard-Error



t-test

(Welch 2-sample 2-side)

ASD versus TD:
 $t(125) = 5.84^{***}$

ASD versus LD:
 $t(117) = 4.78^{***}$

TD versus LD:
 $t(97) = 0.45$

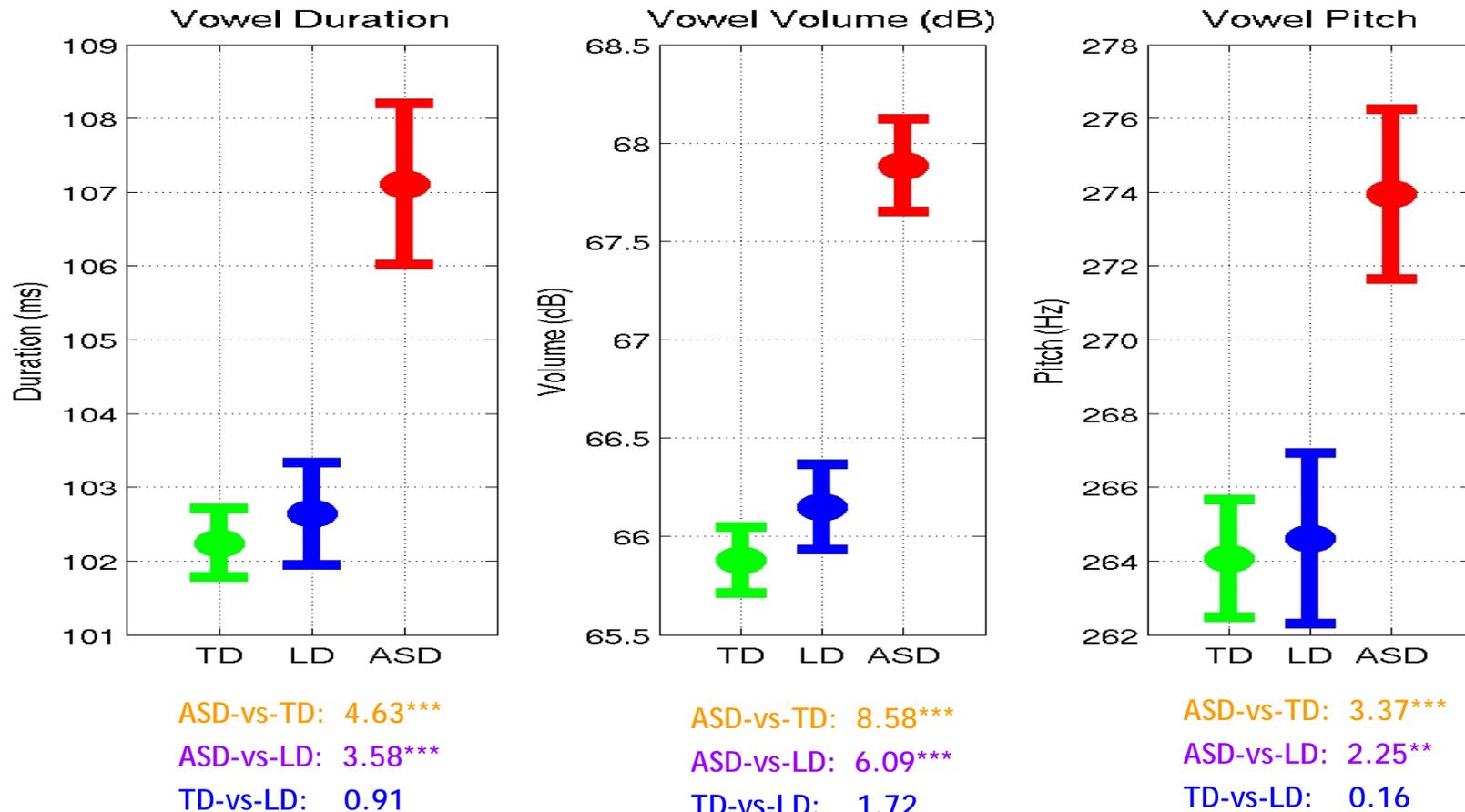
* $p < 0.05$

** $p < 0.01$

*** $p < 0.001$

Characteristics of Female Caregiver (Vowels inside “Child-directed” Voice)

Mean, Standard Error and t-Statistics

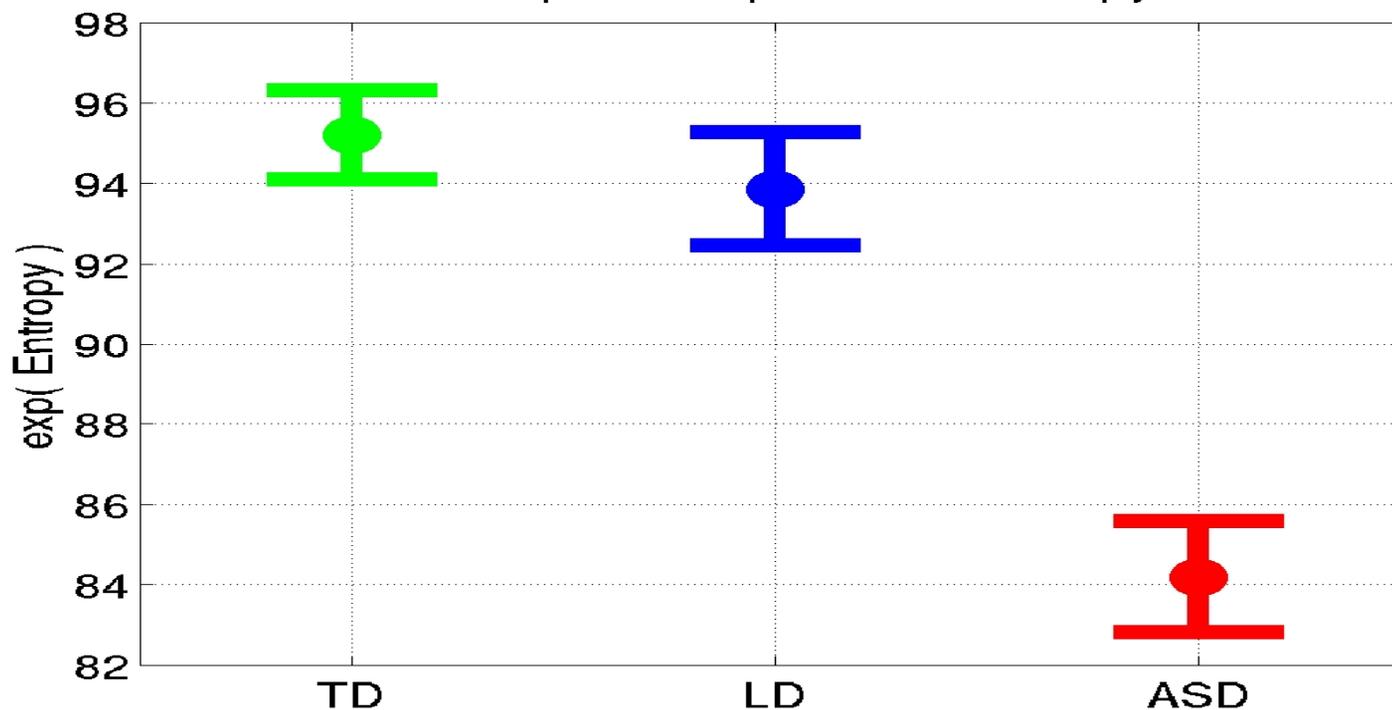


t-test: *p<0.05; **p<0.01; ***p<0.001

Characteristics of Female Caregiver ("Child-directed" Non-Speech Voice)

Mean, Standard Error and t-Statistics

Non-speech Spectrum Entropy



ASD-vs-TD: 7.02***; ASD-vs-LD: 5.44***; TD-vs-LD: 1.01

t-test: *p<0.05; **p<0.01; ***p<0.001

Conclusion: Unique Characteristics of Children with Autism:

- **Less Frequent Consonant-like Sounds**
- **Higher Chance of Sound Collision**
- **Louder Vowel-like Sounds**
- **Lower Spectrum Entropy of Unvoiced Consonant Sounds (how noise-like versus tone-like a sound is)**
- **Discriminant Analysis: 94% (6% Equal-Error-Rate)**

Conclusion: Female caregivers of children with autism

- **Unique Characteristics of “Child-directed” Voice of Female Caregivers of Children with Autism:**
 - **Longer Vowel Duration**
 - **Louder Vowel Volume (dB)**
 - **Higher Vowel Pitch**
 - **Lower Spectrum Entropy of Non-Speech Sounds**

PHONETIC DEVELOPMENT ANALYSIS USING AUTOMATED APPROACH

Dongxin Xu ^{1,3}, Mark VanDam ², Jill Gilkerson ^{1,3},
Sophie E. Ambrose ², Mary Pat Moeller ², Jeff Richard ¹

¹ LENA Research Foundation

² Boys Town National Research Hospital

³ University of Colorado, Boulder, Colorado

Prosodic Features:
Correlation with Phonetic Development Score (AVA)

Child Group	N	C-Dr-SD	N-Dr-M	V-dB-M	V-f0-M	V-f0-SD
TD	100	-0.44***	-0.64***	-0.53***	-0.54***	-0.58***
LD	46	-0.39**	-0.59***	-0.14	-0.13	-0.04
ASD	67	-0.43***	-0.47***	-0.09	-0.41***	-0.34**
HH	39	-0.62***	-0.77***	-0.55***	-0.34*	-0.78***

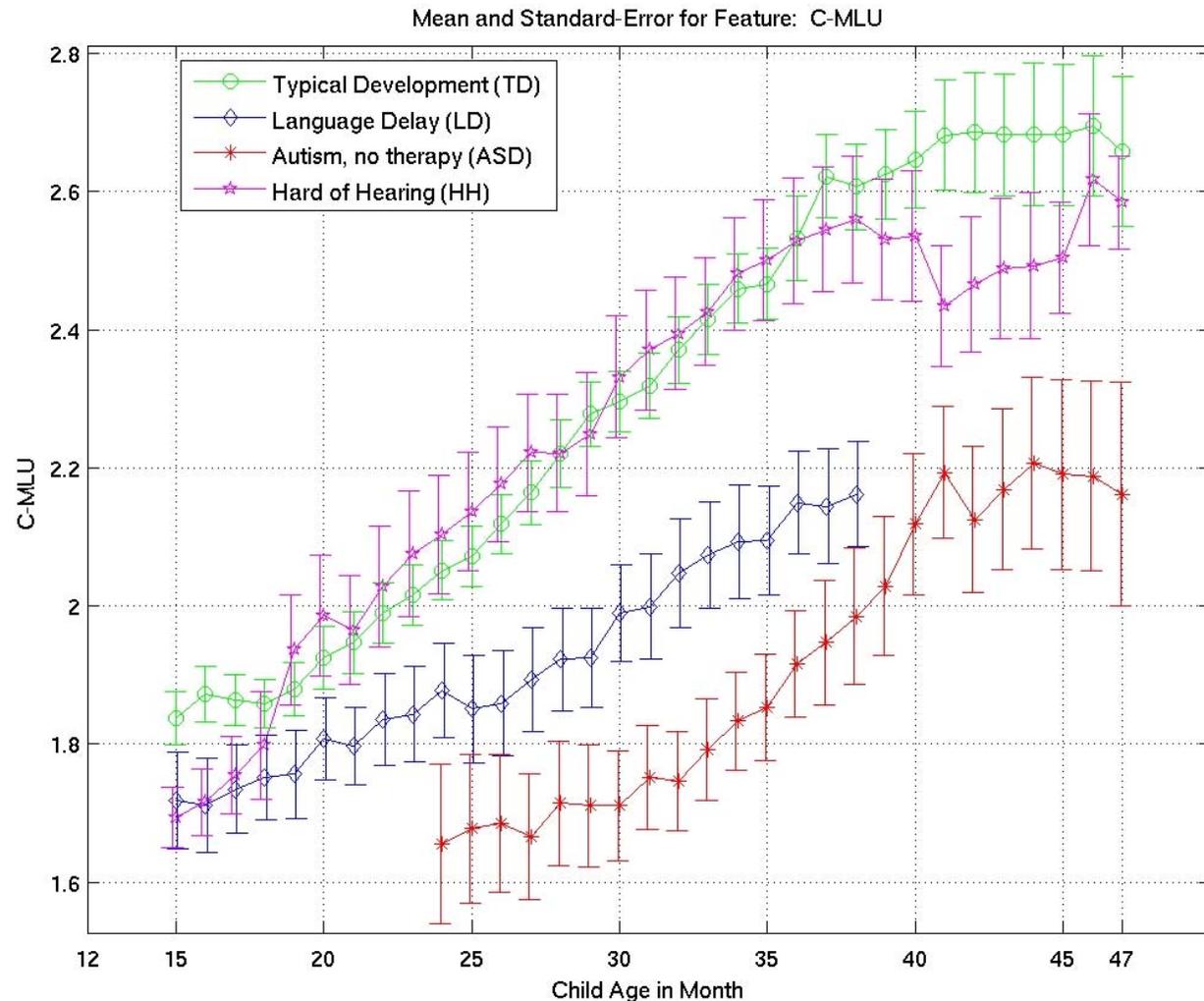
p-value: *: $p < 0.05$, **: $p < 0.01$, ***: $p < 0.001$

Result of C-MLU: Trajectories & Correlation with Chronological Age

Correlation with chronological-age:

HH: 0.51 ***
 TD: 0.63 ***
 LD: 0.32 *
 ASD: 0.32 *

*: $p < 0.05$
 **: $p < 0.01$
 ***: $p < 0.001$



LENA and all children who are deaf or hard of hearing

- Including severe-profound/profound hearing loss
- Children with additional disabilities
- Holds promise
- Needs additional research
- Over-refers of children with severe-profound/profound hearing loss, late-identified children and children with HL and additional disabilities other than autism

3 COLORADO CASE STUDIES FROM EHDI

Diagnosed with autism at different levels of severity
from mild to severe

Followed from age of identification in the first few
months of life

MACARTHUR-BATES CDI: WORDS AND GESTURES RESULTS FROM THREE YOUNG CHILDREN WITH HEARING LOSS AND ASD

Elizabeth Kellogg

Christine Yoshinaga-Itano

July 2013

MacArthur-Bates Communicative Development Inventories (CDI)

- Second edition: Fenson et al. (2007)
 - First edition: Fenson et al. (1993)
- Parent questionnaire
- Two inventories
 - Words and Gestures (WG)
 - For infants 0;8 to 1;4
 - Words and Sentences (WS)
 - For toddlers 1;4 to 2;6

CDI: WG

- Part I
 - *First Signs of Understanding*
 - *Phrases Understood*
 - *Starting to Talk*
 - *Vocabulary Checklist*
 - 396 items within 19 semantic categories
- Part II
 - *Actions and Gestures*
 - *Pretend Objects*

CDI: WG

Actions and Gestures

- Early Gestures (by 12 months*)
 - *First Communicative Gestures*
 - *Games and Routines*
- Late Gestures (by 16 months*)
 - *Actions with Objects*
 - *Pretending to be a Parent*
 - *Imitating other Adult Actions* (using real or toy implements)

CDI: WG

- Useful for assessing children with ASD
- Children with ASD are usually language delayed
- Vocab checklist is based on parent report
- Appropriate for children with limited comprehension and production
- Includes gestures and early non-verbal communication
 - But doesn't directly address joint attention

Current Case Study

- All children in Colorado Hearing Intervention Program (CHIP) receive intervention and regular assessments
 - Include modified MacArthur-Bates CDI to reflect children's production of signs and/or spoken words
- 13 children from CHIP program were later diagnosed with ASD
- 3 children chosen for case study
 - Had assessments from at least as early as 9 months old
 - Had consistency of assessment data approximately every 6 months until at least 32 months old
 - All from metro areas in Colorado

Sam

- Born in 2005
- Deaf, Caucasian parents
- Severe bilateral sensorineural hearing loss at birth
- Learned to sign
- Did not speak

Max

- Born in 2002
- Hearing, Caucasian parents
- Profound bilateral sensorineural hearing loss at birth
- Cochlear implants at 16 months
- Mostly speech, some signs by 26 months
- Diagnosed with ASD at 18 months
- Diagnosed with childhood apraxia of speech at 5 years

Allen

- Born in 1996
- Hearing, Caucasian parents
- Severe bilateral sensorineural hearing loss at birth
- Fitted with hearing aids at 2 months
- Total communication approach used
 - Signs the most of the three children

Age Quotients

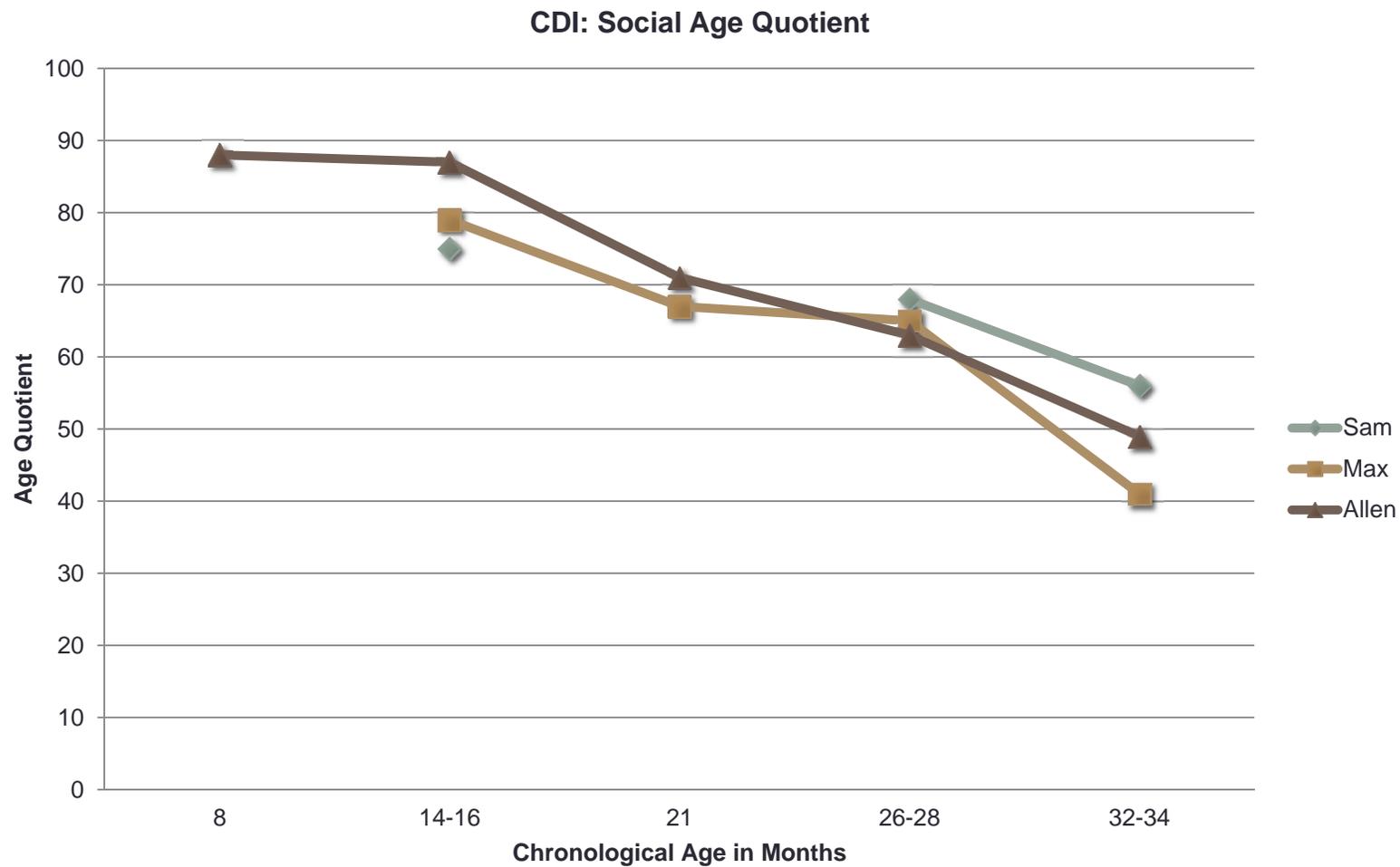
- Developmental age divided by chronological age times 100
- Expectation: maintain at 100
 - Year's growth in a year's time
- MacArthur-Bates: CDI: WG normed from 8 -16 mo
- Developmental age <8 mo is counted as 8 mo for age quotients
- $(\text{Developmental age } 8 \text{ mo} / \text{CA } 9 \text{ mo}) * 100 = 89$
 - 89 on graphs might be misleadingly high
 - Trajectory might be more appropriate from 14 mo on

CHILD DEVELOPMENT INVENTORY: SOCIAL QUOTIENT

Development Quotient

- $(\text{Development Age} / \text{Chronological Age}) \times 100$
- Decreases with time
- Both loss of skills and
- Failure to gain new skills – interaction with peers

Personal-Social Quotient: CDI



Results

- LLAS is a robust measure resulting in the most accurate need for referral.
- Using a double screen (LENA and CDI) the refer rate for the LLAS and M-CDI is 16.87%
 - Those that referred on LLAS but not the M-CDI was 24.10%
 - Those that referred on the MINN-CDI Social but not the LLAS were 7.23%
- Therefore, using a double screen relying on LLAS is the most appropriate for determining who warrants referral for further evaluation
- The sensitivity for referral is robust for all types of hearing loss, except for bilateral severe/profound hearing loss

Moving beyond screening to diagnosis

- “Gold standard” assessment tools commonly used with hearing children have not been validated with children who are D/HH
 - ADOS-2, ADI-R
 - Efforts underway in Great Britain to validate for use with D/HH
- Use of ADOS-2 with D/HH (Mood & Shield, 2014)
 - May under-identify ASD if used in a “standardized” manner
 - Failure to administer module that matches the child’s language functioning results in lack of ability to assess atypical language and social communication
 - Administration of “easier” module relies on tasks that are too developmentally easy and a missed opportunity to assess social/communication skills appropriate for the child’s developmental functioning
- Many tools may not reliably identify ASD among children who are D/HH
 - Use of ADOS-2 algorithms with D/HH is not advised
 - When used by a clinician familiar with ASD and deafness, ADOS-2 may reveal important clinical information
- Multiple sources of information and rule in/rule out process are necessary

“Red Flags” for a possible ASD in children who are Deaf/HH

Atypical preverbal communication

- poor eye contact, lack of pointing, poor orientation for communication, poor joint attention
- delays in language acquisition beyond what one could expect based on hearing loss/etiology/intervention history

Atypical language features

- echolalia, palm rotation errors, persistent gesture use despite instruction in formal sign and use of formal sign by others in the child’s environment (distinct from home signs)

Social difficulties

- failure to initiate/respond to peers when communication taken into consideration, failure to recognize Deaf cultural norms, etc

Repetitive behaviors/restricted interests

- **atypical in absence of comorbid ID**
- **may occur briefly while communication is being established**

“A lack of progress should never be assumed to be only due to a mismatch of chosen communication modality or insufficiencies in the language stimulation environment”
(Wiley & Innis, 2014)

Characteristics of ASD language features in sign and speech

Similarities	Differences
Echolalia	Pronoun reversal (speech only?)
Pronoun avoidance/Use of names	Palm reversals (sign only)
Lack of expressive language Deficits in receptive language	Facial grammar - impaired?
Idiosyncratic language	Spatial grammar - classifiers, agreement verbs
Pragmatic deficits	

SHIELD (2014), SEMINARS IN SPEECH & LANGUAGE

- Although not a “core symptom”, language deficits go hand-in-hand with ASD
 - True for deaf/HH as well as hearing
- Shield study of Deaf of Deaf children with ASD
 - About 1/3 had minimally expressive sign
 - On average, receptive ASL skills were significantly below peers
- Suggests that exposure to sign in and of itself is unlikely to be a “silver bullet” in the case of ASD even though often used as an intervention for hearing children with ASD
- May need alternative communication strategies such as AAC

Deficits in Social/Communication and social interaction	ASD	Typically developing D/HH
Deficits in social/emotional reciprocity	<ul style="list-style-type: none"> • Atypical social approach • Difficulty with reciprocal conversations • Reduced sharing of affect /interests/ enjoyment and limitations in social interaction 	<ul style="list-style-type: none"> • Appropriate social smile • Appropriate eye contact • Engages others in their environment with integrated eye contact, give/show behavior, gestures, vocalizations • Imitate motor/vocal/signs • Appropriate joint attention <p>33 34</p>

Deficits in Social/Communication and social interaction	D/HH + ASD
Deficits in social/emotional reciprocity	<ul style="list-style-type: none">● Reduced/absent social smile● Limited or inconsistent eye contact● Limited give/show behavior ²⁸● Reduced sharing of affect● Difficulties with joint attention ²⁸● Difficulty engaging in social conversation at one's language ability level● Does not readily respond to name or culturally appropriate attention getting measures● Difficulty understanding others' needs and feelings or processing facial/signed emotion cues³⁵

Deficits in Social/Communication and social interaction	ASD	Typically developing D/HH
Deficits in communicative behaviors for interaction	<ul style="list-style-type: none"> • Poorly integrated verbal/nonverbal behavior • Abnormalities in eye contact and body language • Limited facial expressions/gestures • Difficulties in understanding nonverbal cues 	<ul style="list-style-type: none"> • Appropriate eye contact • Well integrated gestures/eye contact/vocalizations • Wide range of facial expressions; use of ASL facial grammatical markers • Will learn incidentally with visual/auditory access, the sequence of learning language will follow typical developmental norms May have difficulties with vocabulary, grammar, word order, idiomatic expressions and other aspects of verbal communication ^{19 20 21 23}

Deficits in Social/Communication and social interaction	D/HH + ASD
Deficits in communicative behaviors for interaction	<ul style="list-style-type: none"> • Limited gestures • Lack of pointing for shared enjoyment • Difficulty with choice making (e.g. pointing to make choices) • Using others as objects for communication (e.g. hand as tool) • Abnormal prosody of speech/sign • May demonstrated poorly integrated sign and spoken language (if utilizing total communication approach) • Shifting of signing space below typical visual spatial space • Poor understanding/use of integrated ASL facial grammatical features³⁶ • Gaps in acquisition of language and delays beyond expected for hearing loss/intervention history/accessibility of language • Limited spontaneous language use of words within child's repertoire for social communication (e.g. to comment, share, request). • Limited range of facial expression or poorly coordinated • Difficulty grasping Deaf cultural norms (e.g. use of attention getting strategies, entering/exiting conversations)

Deficits in Social/Communication and social interaction	ASD	Typically developing D/HH
Deficits in developing and maintaining appropriate relationships	<ul style="list-style-type: none"> • Difficulties building relationships appropriate to developmental level • Difficulty adjusting behavior to context • Difficulty with imaginative play • Difficulty making friends or limited interest in people 	<ul style="list-style-type: none"> • Interested in people and able to develop age-appropriate relationships when communication is accessible • Imaginative play follows typical developmental course (commensurate with language and nonverbal IQ) • Flexible play • May prefer to control conversation or play if having troubles following changes in conversation based on language level or in challenging listening environments (when using an auditory/oral approach)

Deficits in Social/Communication and social interaction	D/HH + ASD
Deficits in developing and maintaining appropriate relationships	<ul style="list-style-type: none">● Reduced shared enjoyment● Delayed acquisition of symbolic play skills inconsistent with nonverbal IQ● Difficulty making and sustaining friendships even when communication is accessible● Unusual social overtures toward others (e.g. backing into parents, grunting at peers, hitting peers to initiate contact)● Play is rigid and unimaginative

Restricted/Repetitive Patterns of Behavior	ASD	Typically developing D/HH
Stereotyped or repetitive speech, motor movements, or use of objects	<ul style="list-style-type: none"> ● Stereotyped repetitive speech (i.e., echolalia, repetitive language use, idiosyncratic phrases) ● Repetitive motor movements ● Repetitive use of objects ● Difficulties with transitions 	<ul style="list-style-type: none"> ● Usually not demonstrated, particularly in children with well-established communication system and average nonverbal IQ ● Echolalia can occur as a typical developmental pattern, but should be for a brief period of time ● You/I pronoun reversals can occur as part of typical development for children with co-occurring visual impairments

Restricted/Repetitive Patterns of Behavior	D/HH + ASD
Stereotyped or repetitive speech, motor movements, or use of objects	<ul style="list-style-type: none"> ● Echolalia in sign or spoken language^{7 26-28} ● Idiosyncratic gestures (e.g. persistent use of made up gesture, distinct from home sign,²⁸ when formal sign taught/used) ● Palm rotation errors^{7 28 32} ● Difficulty with pronoun use (not using point gesture to indicate others, fingerspelling name instead of using pronoun/point, “you”/”I” confusion in auditory/verbal children)⁷ ● Rocking, twirling, flapping, spinning ● Highly repetitive play with objects (e.g. persistence in lining up toys with significant upset if disrupted)

Restricted/Repetitive Patterns of Behavior	ASD	Typically developing D/HH
Excessive adherence to routines	<ul style="list-style-type: none"> • Verbal rituals • Excessive resistance to change 	<ul style="list-style-type: none"> • Given an understanding/communication, child will change routines, activities • The resistance seen is typical for all children or due to comprehension issues • May struggle with transitions if language level doesn't yet support understanding first-then concept

Restricted/Repetitive Patterns of Behavior	D/HH + ASD
Excessive adherence to routines	<ul style="list-style-type: none">• May require parents/caretakers to say things in exactly the same way• Resistant to change, transitions are difficult (these difficulties are beyond that anticipated by language level)• Significant upset when routines are disrupted

Restricted/Repetitive Patterns of Behavior	ASD	Typically developing D/HH
Highly restricted, fixated interests that are abnormal in intensity or focus	<ul style="list-style-type: none"> • Preoccupation with a particular object or topic • Highly unusual interest for child's developmental age (i.e., ceiling fans) 	<ul style="list-style-type: none"> • Usually not demonstrated or very brief; able to move to new toys, objects
Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment	<ul style="list-style-type: none"> • Unusual sensory interests (visual inspection, smelling objects), fascination with lights/spinning objects • Indifference or oversensitivity to pain/heat/cold 	<ul style="list-style-type: none"> • May have some atypical sensory responses- or hyper/hypo sensitivities, these are more typically differences with vestibular processing; less likely visual inspection or persistent tactile/olfactory exploration of objects

Restricted/Repetitive Patterns of Behavior	D/HH + ASD
Highly restricted, fixated interests that are abnormal in intensity or focus	<ul style="list-style-type: none"> • Repeated play with toy or object (often rather than playing with a wide variety of toys) • Play with toy for other than intended purpose • Unusual interests of unusual intensity or for child's developmental age (e.g., perseveration on street signs, ceiling fans, researching all presidents of the US at age 3)
Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment	<ul style="list-style-type: none"> • With some DHH children, may see limited response to amplification¹⁰ (seem to be more deaf than you would expect based on their audiogram or amplified responses) • May show sensitivity to wearing amplification • Hypo and hyper-sensitivities³⁷ • Sensory seeking behaviors (pushing head on floor in inverted "V" position, repeatedly watching blinds opening and closing, sniffing non-food objects before use) • Unusual reactions to environment unlikely related to hearing loss (e.g., avoidance of smells/textures)

Other Diagnostic Considerations

Learning/Communication:

- Intellectual Disability
- Communication Disorders

Behavioral Conditions

- ADHD
- Anxiety disorder
- Obsessive compulsive disorder
- Sensory integration difficulties

Medical Condition

- Tourette's Syndrome
- Epilepsy
- Landau-Kleffner and other epileptiform language disorders(rare)
- Peripheral vision cuts
- Benign stereotypies

Diagnostic process & availability of appropriate interventions are severely lacking

Comorbidity significantly complicates language development

Misdiagnosis/failure to diagnose can greatly impact outcomes in this group of children

Interventions for Dual Diagnosis

- Evidence of effectiveness of interventions is lacking (mostly case studies).
- It seems reasonable to take interventions which have been successful for hearing children to modify/adapt for children who are D/HH
 - ABA approaches considered standard of care
 - Must be intensive, targeted intervention- 25-40 hours/week can improve language, social, cognitive, behavior skills
- Duality requires specialized intervention especially regarding communication

Cochlear Implants - Outcomes

- Daneshi & Hassanzadeh (2007)
 - CI outcomes (auditory perception) among those with secondary disability (e.g. ID, LD, ADHD, CP, blind, ASD)
 - All showed progress in speech perception, except for congenitally deaf-blind and ASD
 - CI NOT contraindicated but auditory perception may not be main outcome
 - May require “unique” rehabilitation
- Nikolopoulos, Archbold, Wever, Lloyd
 - Assess long term speech intelligibility in children with/without additional disability
 - 5 years post implant, 70% of children with additional disabilities developed connected intelligible speech vs. 96% control group (may be of poorer quality)
 - ASD among most salient contributing factor
- Cejas et al. (in press)
 - Results are generally positive. Speech/language progress may be slower. Early identification and intervention is key.
- Eshraghi et al. (in press)
 - Top 3 improvements reported by parents:
 - Name recognition
 - Response to verbal requests
 - Music enjoyment
 - Least improved behavior: eye contact

CI outcomes

- Wiley, Jahnke, Meinzen-Derr, Choo (2005)
 - Family perception of CI benefits among children with multiple disabilities
 - Insurance/barriers to accessing therapies
 - All children made communication progress post-implant
 - All felt would make the decision again for CI

Summary of outcomes

- Children with ASD with CI make progress, may be slower than peers without additional developmental disability
- Notable that some studies suggest children with ASD make slower progress than children with ID (therefore IQ not best predictor- ASD requires unique intervention!)

Changing outcomes (?)

- Children with ASD often have symptoms that may be expected to pose challenges for audiological assessment and intervention
 - Sensory challenges may make audiological testing challenging
 - Anxiety with new people, new places
 - Difficulty maintaining focus on auditory information
 - Audiologist's comfort level with child's behavior

- Sensory challenges preventing child from using CI
- Differences in child's style of engagement may make mapping and assessment of child's speech understanding difficult
- May have atypical responses/less responsiveness to environmental sound

Preparation for testing

- What parents can do:
 - Help child tolerate touch to head and ears
 - Several times per day
 - Head, shoulders, knees and toes
 - Wear hats, earphones, headbands
 - Playfully play with child's head/ears (massage)
 - Use ear plugs at home to desensitize
 - Visit clinic/booth prior to day of testing (take a tour)
 - Show picture schedule (provided by audiologist)

Preparing the clinic

- How to prepare the soundbooth before child walks in:
 - Ask about the child's interests/likes/dislikes
 - Favorite toys, video, comfort items, sensory devices
 - Remove distractions from booth
 - Eg. Cover computers/electronics with blanket
 - Out of sight, out of mind
 - Clear clutter – minimize distractions in room
- Show picture schedule again before you begin
- Think outside the box!

Be certain technology is working properly

- The child with ASD may not tell you that there is something wrong.
- Technology maintenance
- Parent involvement
- Proactively choose technology

Tips for encouraging device use

Start small

Parents in control

Start during enjoyable activities – ideally when hands are occupied

Gradually increase wearing time- Consult with other professionals if this plan is not working

Consult other professionals

Developmental approach is critical (teens resist for different reasons than infants)

ASD perspective

Capitalize on special interests

- Use skin-its, covers, stickers that are appealing to child



Adjust for sensory sensitivities

- Alternative ways to wear CI (off the ear, in hair, on belt)
- Begin part of HA only
- Try HA/CI turned off to first adjust to the feel, then introduce sound

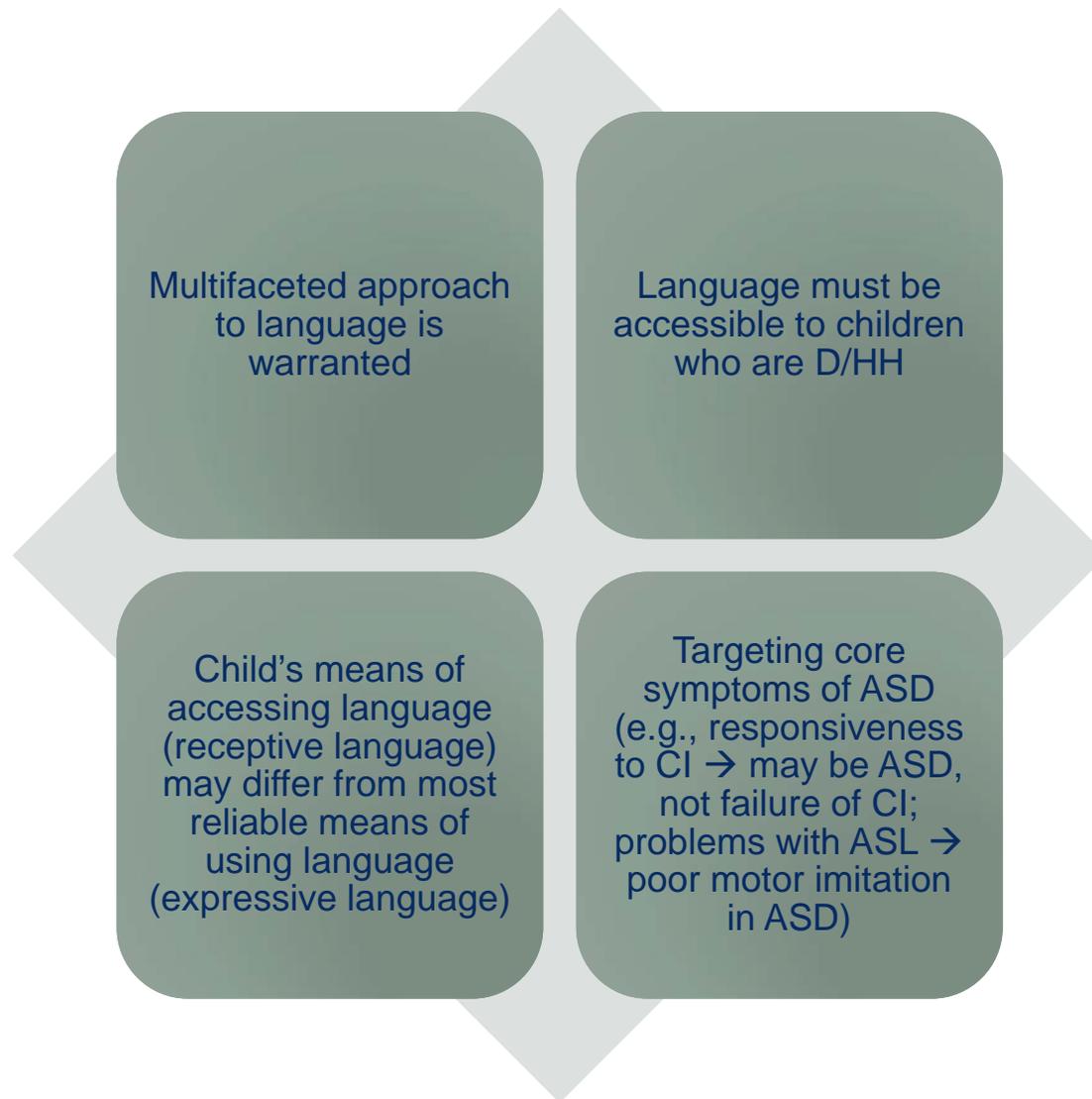
Think flexibly about rigidity

- Reintroduce with altered visual appearance (e.g., Skinits, stickers, covers, new earmold)

Success is a team effort

- Consider...
 - Occupational therapy
 - Speech/language therapist
 - ABA
 - School team

Communication intervention requires knowledge of both ASD and D/HH



- **Must develop functional auditory goals**
 - Attending to auditory environment if accessible (can be shaped)
 - Focus on connecting environmental sounds with meaning
- **Must develop functional communication skills**
 - May need to start at a different baseline- attending to social environment for communication
 - Emphasis should be on function, not form of communication (i.e., modality)

Remember to apply what we know about ASD

- We would not stop speaking around a hearing child with ASD because they were not responding- keep speaking/signing even if child does not appear to be attending
- We would not stop talking to a hearing child with ASD because they were copying what was said (i.e. echolalia)- therefore, do not stop talking/signing with child who is D/HH
 - Instead, consider adding additional visual supports
 - Model language as you want it to be said from their perspective
 - Work toward expanding spontaneous language

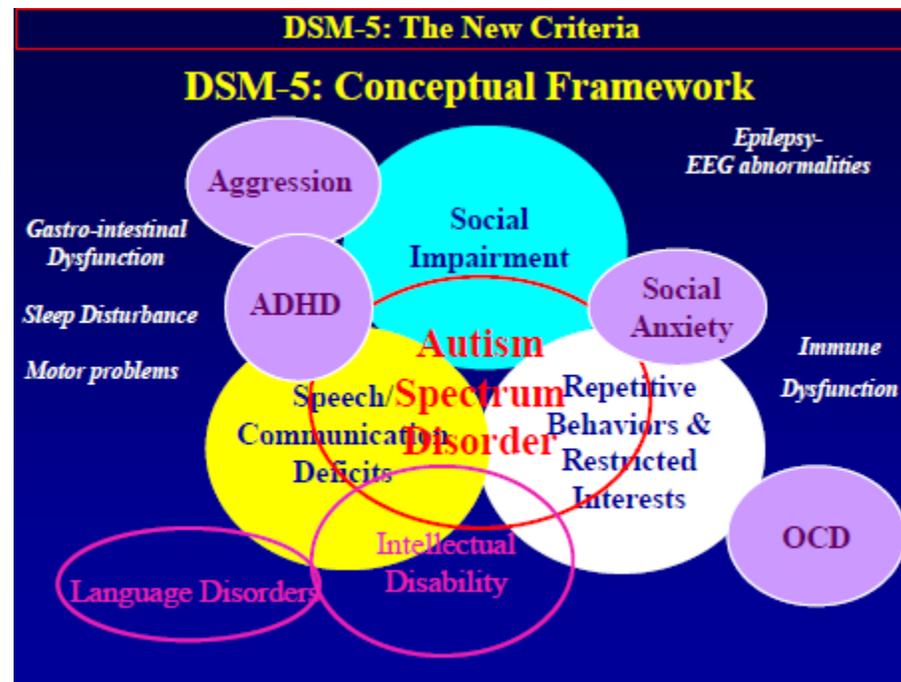
Evidence for early intervention ...

- Behavioral interventions work
 - No medications for core symptoms
 - Many models work
 - Most effective use combo of structured and naturalistic strategies
 - Result in:
 - Higher cognitive skills (Dawson et al., 2010; Smith et al 2000)
 - Better language skills (Dawson et al., 2010; Kasari et al.,2008)
 - Improved social skills (Kasari et al., 2012)
 - Families are less stressed/happier (Breterton & Tonge, 2004)

Educational considerations

- Very challenging – no “perfect” fit
- Encourage flexible collaboration between ASD and deafness experts
- Consider co-treat models
- Can educational experts join clinical providers?
- Programming may need to be more fluid-
 - EX: young child may need ASD program with DHH supports while developing prerequisite social/communication skills; then transition to DHH program

The “Big” picture



<http://autismconsortium.org/symposium-files/WalterKaufmannAC2012Symposium.pdf>

Joining with families

- Discuss observations without judgment, but with professional guidance, providing context for observed strengths and needs
 - Did you notice? ... I would typically expect.... That behavior is different than what we typically expect of a child with x hearing loss
 - Explore family concerns/fears
 - Provide information
 - Discuss communication challenges distinctly from communication modality issues
 - Provide (credible) resources-
 - Firstsigns.org
 - Autism treatment network/autism speaks
 - where to go for further evaluation of concerns?

- Family's adjustment to hearing loss diagnosis may impact their response
- Families may not know what is/is not attributable to hearing loss

Supporting Families

- Connect families with other families

***Save the date!!! Deaf-Autism
Family Day, September 23, 2017**

Co-sponsored by CO Hands & Voices, CSDB and Natural
Wisdom Counseling

See CO Hands and Voices FB page and website for details
to follow!

FRONTIERS IN HEARING CONFERENCE

- July 16, 2017
- Estes Park Conference Center
- Deaf/Hard of Hearing Children and Autism
- <https://www.mariondowns.com/education/frontiers-in-hearing-symposium>

Resources

- Gallaudet Odyssey special editions re: deafness/autism
 - www.gallaudet.edu/documents/clerc/odyssey-2008-v9i1.pdf and
www.gallaudet.edu/Images/Clerc/.../Odyssey_SPR_2012_Szyman ski.pdf
- See November 2014 special edition of *Seminars in Speech and Language*, 35, (4)
- Deafness and Family Communication Center of the Department of Child and Adolescent Psychiatry- Children's Hospital of Philadelphia
<http://www.raisingdeafkids.org/special/autism/>
- Colorado Hands and Voices- Deaf Plus
<http://www.cohandsandvoices.org/plus/index.html>
- Raising and Educating Deaf Children e-bulletin July 2016
[http://www.raisingandeducatingdeafchildren.org/category/ebulletins/#July 2016](http://www.raisingandeducatingdeafchildren.org/category/ebulletins/#July2016)

Resources

- Autism Society <http://www.autism-society.org/>
- Autism Speaks/Autism Treatment Network
 - www.autismspeaks.org
- Community Centered Boards (CCBs)
 - <http://www.colorado.gov/cs/Satellite/CDHS-VetDis/CBON/1251586997819>
- www.firstsigns.org
- CDE Guidelines for educational identification of ASD
http://www.cde.state.co.us/cdesped/guidelines_autismdid

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