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# Perspectives on Deafness With Autism: Changing How We Think

Deafness with Autism: What You Need to Know - A Psychological Perspective (Part 2)

# Perspectives on Deafness With Autism: Changing How We Think

Autism Spectrum Disorder: Overview of Symptoms & Treatment - *A Psychological Perspective (Part 1)* 

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# AUTISM & HEARING LOSS: WHAT YOU NEED TO KNOW

Ivette Cejas, Ph.D.





### **Outline**

- Overview of autism spectrum disorder (ASD)
- Autism Awareness

- Prevalence of ASD & hearing loss
- How to identify ASD in children with hearing loss
- Screening tools
- How to discuss concerns with families
- Beneficial services for children with hearing loss & ASD
- Cochlear implant outcomes in children with ASD





## **Autism Spectrum Disorder**

- Autism spectrum disorder is marked by:
  - Extreme unresponsiveness to other people deficits in socialemotional reciprocity
  - Severe communication deficits
  - Highly rigid and repetitive behaviors, interests, and activities
- Symptoms must be present in multiple settings
- Symptoms appear early in life, before age 3
- Symptoms must cause clinically significant impairment in social, occupational, or other areas of functioning



## **Features of Autism Spectrum Disorder**

### • Extreme unresponsiveness to other people

- Lack of responsiveness or interest in people
  - Abnormal social approach
  - Failure of normal back and forth conversation
- Impairment in nonverbal behaviors
  - Poor eye contact
  - Deficits in understanding and use of gestures
  - Lack of facial expressions
- Failure to develop peer relationships
- Lack of spontaneous seeking to share things with others
- Lack of social or emotional reciprocity



## **Features of Autism Spectrum Disorder**

#### Severe communication deficits

- Delay, or total lack of, development of spoken language
- Impaired ability to initiate or sustain a conversation
- Odd use of language
  - One common speech peculiarity is *echolalia*, the exact echoing of phrases spoken by others
  - Another is pronominal reversal, or confusion of pronouns



## **Features of Autism Spectrum Disorder**

- Highly rigid and repetitive behaviors, interests, and activities
  - Stereotyped or repetitive motor movements or use of objects (e.g., lining up toys, echolalia)
  - Strong attachment to particular objects (e.g., plastic lids, buttons)
  - Inflexible adherence to specific, nonfunctioning routines or rituals
  - "Self-stimulatory" behaviors (e.g., may include jumping, arm flapping, rockling)



## **Red Flags for ASD**







Visit Autism Society of America <a href="http://www.autism-society.org/">http://www.autism-society.org/</a>

- Information & Resources
  - Parents
  - Professionals
  - Advocates
  - Individuals with ASD

## **Prevalence of Autism & Hearing Loss**

#### **Autism**

- According to the CDC, approximately 1 out of 68 children in the US
- Males have a greater likelihood than do females of developing ASD
  - Ratio is as high as 5:1 (1 in 42 boys; 1 in 189 girls)
- Over 2 million individuals in the US are affected by ASD

### **Hearing Loss**

 Approximately 1 to 3 children per 1000 are born with a hearing loss (CDC, 2013)

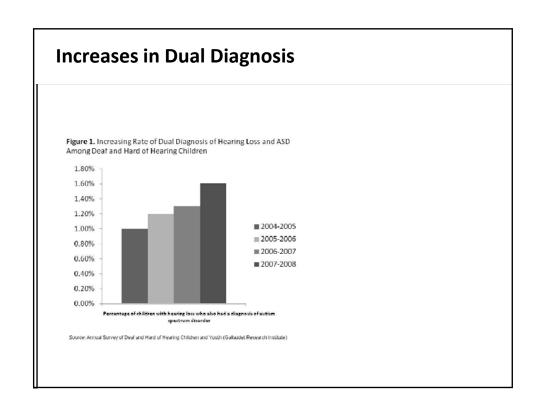


KIDSHEARNOW



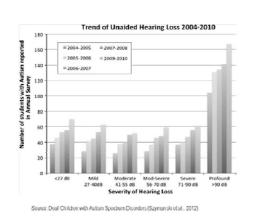
## **Prevalence of Dual Diagnosis: Autism & Hearing Loss**

- 1-6% of children who are deaf also have ASD
- Rosenhall et al., 1999
  - 1.6% unilateral
  - 7.9% mild to moderate
  - 3.5% profound
- Gallaudet Research Institute (2009)
  - 1 in 59 children with hearing loss receive services for ASD
- Jure et al., 1991
  - 5.3 % of deaf students



## The Effect of Hearing Severity on ASD Diagnosis

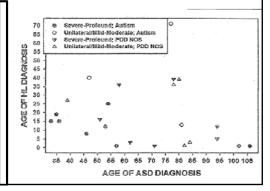
- Data from the 2004-2010 Annual Survey of DHH Children and Youth
- 37,828 deaf and hard of hearing children
- 39.9% of all deaf children had an additional disability
- Significant difference in the severity of hearing loss for children with ASD
- Disproportionate number of profoundly deaf children having a co-existing diagnoses of ASD (35.4%)



Szymanski et al. (2012) J Autism Dev Disord. 42, 2027-2037

#### **Delayed Diagnosis of ASD in Children with Hearing Loss**

- Co-occurrence of hearing loss and ASD may lead to delayed or missed diagnosis (Jure et al., 1991; Roper et al., 2005).
- Families have reported a time lag of 18 months to 15 years between diagnoses, especially when a hearing loss is identified first
- Recent study showed a 41 month delay between diagnoses (Meinsen-Derr et al., 2014)
  - Early Ages of ASD diagnosis
    - More severe HL
    - More severe ASD symptoms
    - Not correlated with:
      - Etiology
      - · Amplification (age or type)
      - Nonverbal IQ
      - Language abilities



### **Challenges with Identifying ASD in Children with Hearing Loss**

- Emotional state of parents coping with initial diagnosis (Myck-Wayne et al., 2011)
- Provider difficulty addressing concerns with family
- Communication impairments are inherent in both disorders (Easterbrooks & Handley, 2005)
- Difficulty testing individuals (Rosenhall et al., 1999)
  - Behavioral difficulties --- negatively impact hearing testing
  - Cognitive delays
  - No ASD screening and diagnostic procedures for children with hearing loss



HOW TO IDENTIFY ASD IN CHILDREN WITH HEARING LOSS

## **ASD & Hearing Loss: Relationship**

#### **Deafness**

- Relationships
  - Appropriate eye contact
  - Enjoys touch (hugs, kisses)
  - Joint attention/theory of mind (may be delayed)
  - Enjoys being around other children
     – attempts to play with others

#### Deafness/ASD

- Relationships
  - May not make or sustain eye contact
  - · Pulls away from hugs
  - Deficits in theory of mind (taking another person's point of view)
  - Appears disconnected from others
  - Difficulty with turn-taking

Creedon, M.P. (2006). Autism and Sight or Hearing Loss. The Diagnostic Challenges of Dual Diagnosis. *Autism Advocate*.

## **ASD & Hearing Loss: Communication**

#### **Deafness**

- Communication
  - · Uses gestures or pointing
  - Seeks to communicate with others
  - Uses facial expressions to communicate
  - Has difficulty with language, but spontaneously attempts to communicate

#### Deafness/ASD

- Communication
  - Problems with pre-linguistic communication (pointing)
  - Child may take person's hand to an object to indicate need or may become agitated
  - May not communicate feelings through facial expressions or signs
  - Exhibits echolalia (may be in sign language)

Creedon, M.P. (2006). Autism and Sight or Hearing Loss. The Diagnostic Challenges of Dual Diagnosis. *Autism Advocate*.

## **ASD & Hearing Loss: Behavior**

#### **Deafness**

#### Behavior

- Has preferences
- Accepts changes
- May experience externalizing behavior problems

#### Deafness/ASD

#### Behavior

- Difficulty with transitions/refuses to change
- May avoid or prefer certain lights, smells, tastes, and textures
- Self-injurious behaviors (head banging)
- Exhibits self-stimulating behaviors (rocking, humming)

Creedon, M.P. (2006). Autism and Sight or Hearing Loss. The Diagnostic Challenges of Dual Diagnosis. *Autism Advocate*.



## **SCREENING TOOLS**





## **Psychological Assessments**

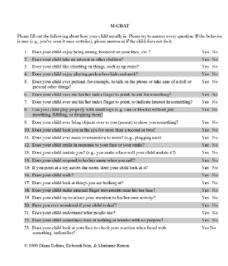
#### **Screening Tools**

- Modified Checklist for Autism in Toddlers (M-CHAT)
- Autism Spectrum Screening Questionnaire (ASSQ)
- Social Communication Questionnaire (SCQ)
- Parents Evaluation of Developmental Status (PEDS)
- Ages and Stages Questionnaire (ASQ-3)

#### **Diagnostic Measures**

- Autism Diagnostic Interview- Revised (ADI-R)
- Autism Diagnostic Observation Schedule (ADOS)

## **Modified Checklist for Autism in Toddlers (M-CHAT)**



- Ages 16-18 months
- 5-10 minutes to complete
- Scoring
  - A child fails when 2 or more critical items are failed
    - Numbers: 2,7,9,13,14,15
  - Or when any three items are failed

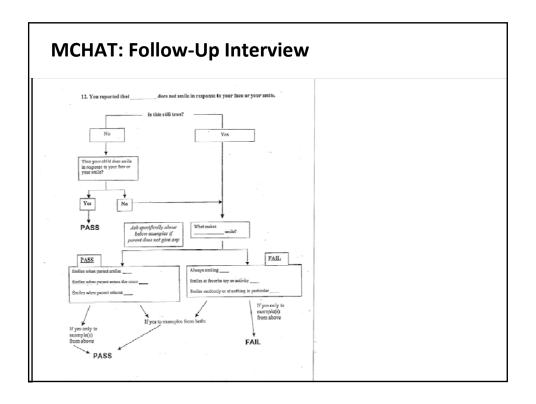
## **Scoring MCHAT for Children with Hearing Loss**

#### **Critical Items**

- 2. Does your child take interest in other children?
- 7. Does your child ever use his/her index finger to point, to indicate interest in something?
- 9. Does your child ever bring objects over to you to show you something?
- 13. Does your child imitate you (e.g., you make a face- will your child imitate it?)
- 14. Does your child respond to his/her name when you call?
- 15. If you point at a toy across the room, does your child look at it?

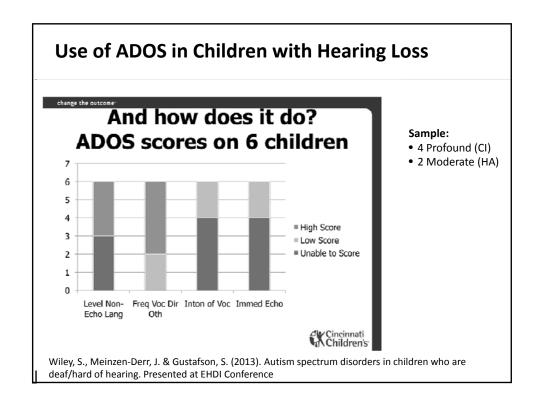
#### **Other Items**

- 20. Have you ever wondered if your child is deaf?
- 21. Does your child understand what people say?

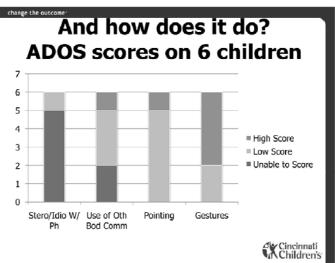


## **Autism Diagnostic Observation Schedule (ADOS)**

- Semi-structured assessment of :
  - Communication
  - Social Interaction
  - · Play (imaginative use of materials)
- 5 modules
  - Toddler Module Children between 12 and 30 months of age who do not use phrase speech
  - Module 1 Children 31 months and older who do not consistently use phrase speech
  - Module 2 Children of any age who use phrase speech, but are not verbally fluent
  - Module 3 For verbally fluent children and young adolescents
  - Module 4 For verbally fluent adolescents and adults
- Scores are compared with cutoff scores to yield one of three classifications: autism, autism spectrum, or non-spectrum







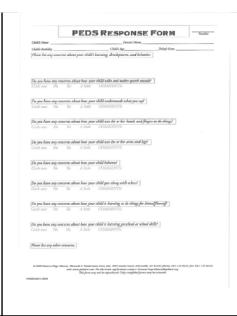
Wiley, S., Meinzen-Derr, J. & Gustafson, S. (2013). Autism spectrum disorders in children who are deaf/hard of hearing. Presented at EHDI Conference

## **Use of ADOS in Children with Hearing Loss**

- Meinsen-Derr, J., Wiley, S., et al., 2014
  - 24 children with dual diagnosis
  - Children completed comprehensive autism evaluation, including ADOS
  - Mean age of hearing loss diagnosis: 14 months
  - Mean age of autism diagnosis: 66.5 months
  - 41 months between ASD and hearing loss diagnosis
  - 67% had severe-profound hearing loss
  - 58% had received a cochlear implant
  - 38% used speech as their mode of communication
  - 33% of children who had a CI used some form of augmentative communication (PECS system)

Meinzen-Derr et al. (2014). Autism spectrum disorders in 24 children who are deaf or hard of hearing. *International Journal of Pediatric Otorhinolaryngology, 78,* 112-188.

## Parents' Evaluation of Developmental Status (PEDS)



- Birth to age 8
- 10 questions
- Elicits parents' perspectives
  - Sleeping
  - Eating
  - Vision
  - Hearing



## **DISCUSSING CONCERNS WITH FAMILY**





### **Talking to Parents About your Concerns**

- American Academy of Pediatrics
  - Recommends screening all children between the ages of 18 and 24 months
  - Recommends treatment to start when autism diagnosis is suspected, rather than when a formal diagnosis is made
- Your Role as a Hearing Health Professional
  - When you think the child has a developmental delay --- speak up!!
  - Trust your instincts
  - You are not trying to make a decision on the child's diagnosis--- you are trying to help the family get the child screened & begin early intervention services
  - · Have a list of referrals and resources that the family may use
  - Remember you are another pair of eyes—you might be the first person to bring up concerns to the family

## **Preparing for the Conversation**

- Things to do before you have the conversation
  - Document all your observations and concerns
  - If you are unsure ask another provider that is working with the child
    - Visit Autism Speaks website to view side by side comparisons of children with and without ASD
  - Ask how the child is doing in school are there any concerns?
  - When was their last pediatrician appointment? Were any concerns expressed?
  - Think about your discussion in advance how will you approach the conversation
  - Role play with a team member (Remember this might be the first time the family is hearing a concern)

## **Tips on Expressing Your Concerns**

- Be sensitive & choose your words wisely
  - Stay away from using the word "normal"
- · Be careful with the tone of voice
- Do a lot of listening
- Start with positives things that the child has been able to do successfully (be specific)
- Pick a characteristic that may be an early sign
  - For example: eye contact
  - My concern is ...
  - I'm worried about how this might impact his/her overall development and learning...
  - · The reason I am bringing this up is because....

## **Tips on Expressing Your Concerns**

- Remain objective
  - I observed ....
  - I understand you might not see some of these behaviors at home, but when he/she is here I see...
- Use any information from screening questionnaires or developmental milestone chart
  - By 4 years he/she should be able to...
- If a family starts expressing their concerns, STOP, and listen to them
  - Validate their thoughts and feelings
- Maintain ongoing communication to build trust and rapport with the family

## **Goal of Conversation**

- Early detection
- Recommend a developmental screener
  - Developmental Pediatrician
  - Psychologist
- Provide family with resources for children with developmental delays
- Make sure they are already enrolled in your local early intervention program (under 3 years) or public school (over 3 years)

Unique
Totally
Totally
Sometimes
Mysterious



## **BENEFICIAL SERVICES**





## **Interdisciplinary Approach to Treatment**

- Speech therapy
- Occupational therapy
- Behavioral therapy
- Social Skills training
- Music Therapy
- Possible medication management (for related co-morbid diagnoses)
- Dietary Interventions
  - Gluten-free
  - Casein-free
- Parent support services

## **Interdisciplinary Approach to Treatment**

- Collaboration among providers (Wiley et al., 2013; EHDI Conference):
  - Communication between therapists, educators, & medical professionals
  - Understanding the impact of 2<sup>nd</sup> diagnosis
  - Agreement on recommendations to the family
- Parents requested a conference-type setting to facilitate interdisciplinary communication

## **Speech Therapy**

- Non-verbal language skills
  - Use of gestures
  - · Basic signs
  - PECS (picture exchange communication system)
  - · Electronic talking devices
  - iPads or other alternative devices
- Speech pragmatics
  - Training on suitable speech context
- Conversational skills
  - How to have a back and forth conversation



- Concept skills
  - Understanding of abstract ideas, as they relate to communication

## **Overcoming Severe Language Delays**

- Many parents of children with autism have been told that if their child isn't speaking by age 4 or 5, he/she isn't likely to ever do so
- Current study published in Pediatrics (2013)
  - · Most children do go onto acquire language skills
  - 535 children, ages 8 to 17, diagnosed with ASD and with severe language delays at age 4
  - 47% became fluent speakers
  - 70% could speak in simple phrases
  - Children who developed language had higher IQs and lower social impairment
  - Stereotyped behavior/repetitive interests and sensory interests were not associated with delayed speech acquisition

Wodka, E., Mathy, P., & Kalb, L. (2013). Predictors of phrase and fluent speech in children with autism and severe language delay. Pediatrics, 131, 1128-1134.

## **Behavior Therapy**

- Applied Behavior Analysis (ABA)
  - The Early Start Denver Model (ESDM)
  - Pivotal Response Therapy (PRT)
  - · Verbal Behavior therapy
- Play Therapy Approach
  - Floortime
  - Relationship Development Intervention (RDI)

# Behavioral Intervention is the most effective method of addressing the needs of those who have ASD

"Intensive" intervention is needed – defined as 25-40 hours per week for 1 to 3 years – may help improve behavior, cognition, and language skills

## Applied Behavior Analysis (ABA) - Gold Standard

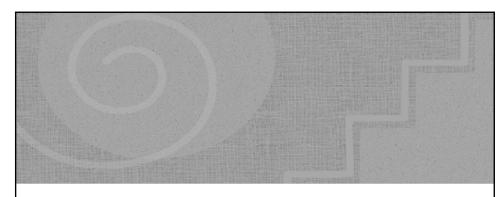
- ABA is the use of techniques and principles to bring about meaningful change in behavior.
  - Positive reinforcement (e.g., use of rewards) increase behavior
  - Punishment (e.g., time-out, removal of toys) decrease behavior
- ABA is considered the standard of care for ASD
  - Improvements in communication, social relationships, play, selfcare, school, and employment
- Goal: Reduce inappropriate behavior while increasing communication and increasing social behavior
- Focuses on changing the environment as opposed to variables that are beyond direct control
  - Learners day is structured to provide many opportunities to acquire and practice skills in both structured and unstructured situations

## What can you do in your practice?

- Visual Schedules & Predictable Routines
- Identify functional language targets --- core vocabulary
- Be creative with your assessments & therapy sessions
- Collaborate with other providers working with child
- Make sure that the "listening" piece of the puzzle is not missed
- Be sensitive to the challenges of raising a child with developmental disabilities
- Help connect parents with resources in the community

#### Resources

- Autism Society of American http://www.autism-society.org/
- Center for Autism and Related Disorders -<a href="http://www.centerforautism.com/">http://www.centerforautism.com/</a>
- Autism Speaks <a href="http://www.autismspeaks.org/">http://www.autismspeaks.org/</a>
  - Video glossary
  - Developmental Milestone Map
- Center for Disease Control –
   http://www.cdc.gov/ncbddd/actearly/index.html
- Cochlear Implant Online –
   http://cochlearimplantonline.com/site/autism-hearing-loss



# COCHLEAR IMPLANT OUTCOMES IN CHILDREN WITH ASD





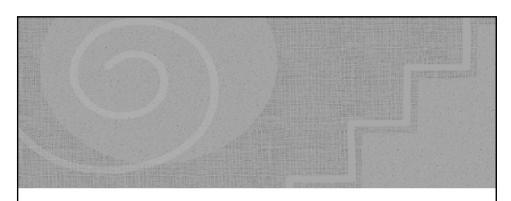
#### Research in Children with Cis and ASD

- A decade ago:
  - 5-8% of children with cochlear implants had a co-morbid diagnosis
- Today:
  - 27-46% of children implanted how a developmental disorder (Pyman et al., 2000; Wiley et al., 2004)
  - Gallaudet Research Institute: 30-40% of children with hearing loss
- Why the increase?
  - 1. Early pediatric CI clinical trials tended to exclude children with other conditions
  - Development of physiologically based techniques using electrical stimulation to evoke compound action potential (ECAP); stapedius reflex (ESR)
  - 3. Newborn hearing screening earlier implantation

Johnson, K.C. & Wiley, Susan. (2009). Cochlear Implantation in Children with Multiple Disabilities. In Eisengerg, L.S. Clinical Management of Children with Cochlear Implants.

## **ASD in Children with Cochlear Implants**

- Donaldson, Heavner, and Zwolan (2004)
  - 1.7% of their population (n=7)
  - 3 of four children showed improvements in auditory skills development and receptive vocabulary
  - One child implanted at 4 years achieved 100% recognition of familiar sentences by 24 months post-CI & significant growth in spoken language
  - 9 year old child showed a 25% improvement in word recognition by 6 months post-CI & some growth in expressive vocabulary



# LONGITUDINAL OUTCOMES OF CHILDREN WITH MULTIPLE DISABILITIES FOLLOWING COCHLEAR IMPLANTATION

Cruz, I., Vicaria, I., Wang, N., Niparko, J., Quittner, A.L., & CDaCl Investigative team. (2012). Language and Behavioral Outcomes in Children with Developmental Disabilities using Cochlear Implants. *Otology & Neurotology, 33,* 751-760.

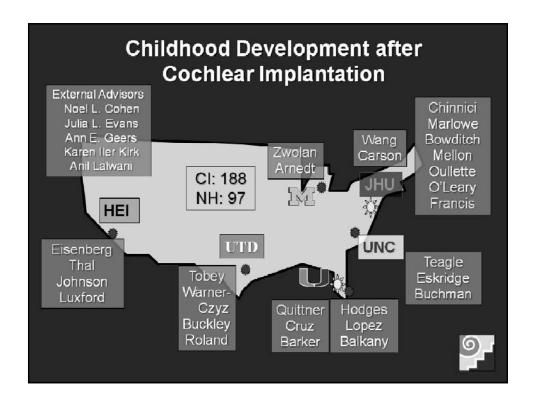
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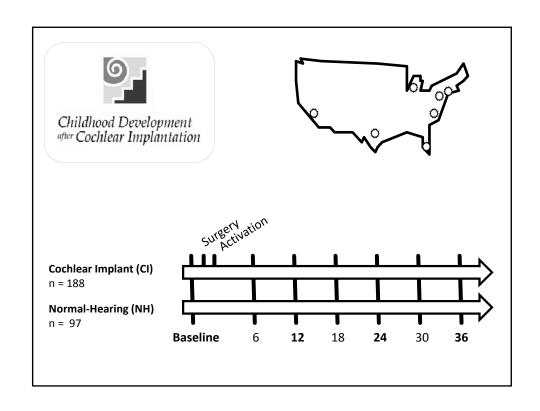
Childhood Development

NIDCD RO1 DC04797

## **Study Aims**

- To evaluate language and behavioral outcomes in deaf children receiving cochlear implants with developmental disabilities (AD) in comparison to a large, national cohort of deaf children with no additional diagnoses (CI)
  - H1: Lower receptive and expressive language compared to typically developing children prior to cochlear implantation
  - H2: Slower rate of growth in oral language skills over three years
  - H3: Higher rates of behavior problems
  - H4: Decrease in behavior problems post-implantation





## **Demographics**

Child	CI (n=157)	AD (n=31)
Age (months)	26.3 (14.4)	28.0 (14.7)
Gender		
Male	48% (76)	45% (14)
Female	52% (81)	55% (17)
Ethnicity		
Non-Hispanic	78% (122)	74% (23)
Hispanic	19% (30)	23% (7)
PTA4 (better ear)	104.06 (16.32)	110.56 (16.17)*

Parent	CI (n=157)	AD (n=31)
College Graduate	48% (76)	52% (16)
Income > \$100,000	16% (25)	19% (6)

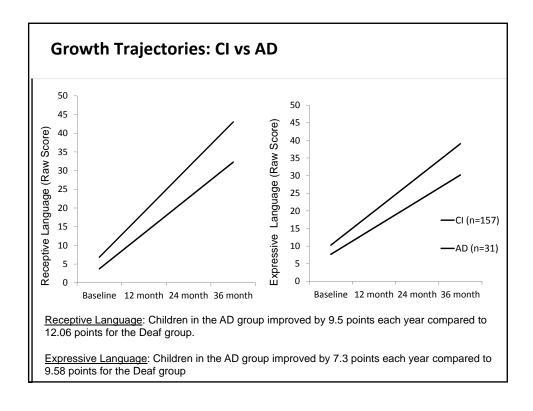
<sup>\*</sup>p <.05

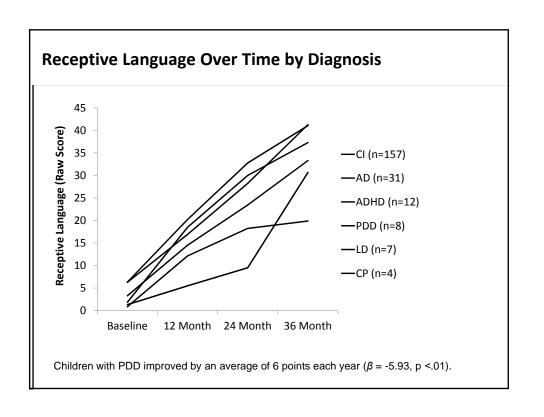
### Method

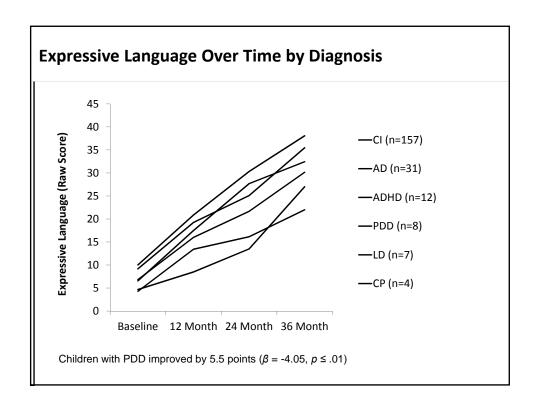
- Diagnoses included:
  - Attention Deficit Hyperactivity Disorder (ADHD; n=12)
  - Pervasive Developmental Disorder/Autism (PDD; n=8)
  - Learning Disability (LD; n=7)
  - Cerebral Palsy (CP; n=4)
- Reynell Developmental Language Scales
  - Well-validated language scale for children ages 1 to 7
  - 2 subscales: Verbal Comprehension, Expressive Language
- Child Behavior Checklist
  - Internalizing Behavior Problems: Emotional Reactivity, Anxious/Depressed, Somatic Complaints, Withdrawn
  - Externalizing Behavior Problems: Attention Problems, Aggressive Behavior
- Multilevel modeling techniques were used to predict oral language and behavior problems

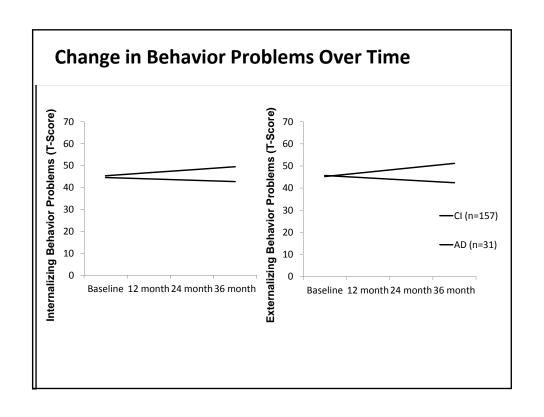
## **Baseline Group Differences**

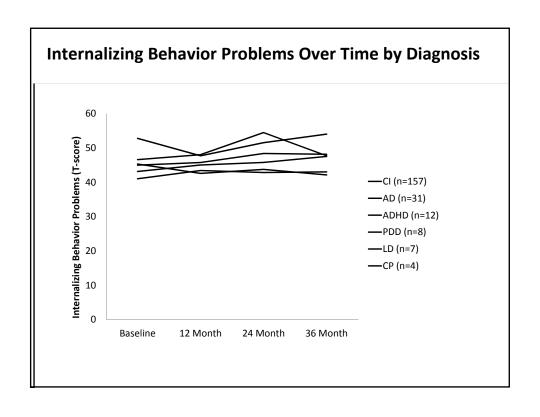
- Oral Language
  - No overall group differences on receptive or expressive language (p>.05)
  - Only children with ADHD had language scores that were similar to typically developing deaf children
  - Children with pervasive developmental disorders had the lowest language scores prior to implantation
- Behavior Problems
  - No overall group differences on internalizing or externalizing behavior problems (p>.05)
  - Children with CP had higher rates of externalizing behavior problems

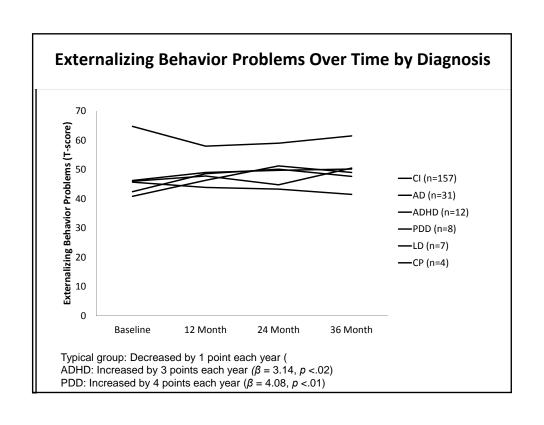












#### **Discussion**

- Language development was slower for children with developmental disabilities compared to typically developing, deaf children using Cl's
  - Children with PDD/Autism progressed at half the rate as typically developing CI children
- Behavior problems decreased in the typically developing CI children and increased for children with additional disabilities
  - Externalizing behavior problems increased for children with ADHD and PDD – decreased for children with CP and LD
- Future studies should continue to evaluate the benefits of cochlear implantation in children with multiple disabilities
- In summary, children with developmental disabilities benefit from cochlear implantation
  - Cochlear implant teams should focus on counseling families to develop realistic expectations of benefit

## **Summary**

- Autism spectrum disorder is marked by:
  - Extreme unresponsiveness to other people deficits in social-emotional reciprocity
  - Severe communication deficits
  - · Highly rigid and repetitive behaviors, interests, and activities
- 1-6% of children who are deaf also have ASD
- Disproportionate number of profoundly deaf children have a co-existing diagnoses of ASD (35.4%)
- Although there are no validated instruments for children with hearing loss, several measures have now been used with this population
- Interdisciplinary approach to treatment is ideal for children with dual diagnosis (behavior therapy, occupational therapy, speech therapy)
- Children with autism using Cls show improvement in both auditory and language measures; however, progress is slower than typically developing children

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Write down something new that you learned from today's presentation.



# Perspectives on Deafness With Autism: Changing How We Think

Deafness with Autism: A Music Therapy Perspective

May 6, 2014 • 12:00 p.m. Eastern/9:00 a.m. Pacific