

## Hearing, Listening and Autism (and other considerations in neurodiversity)

Gail M. Whitelaw, Ph.D.  
The Ohio State University  
The SAC Audiology Event  
May 12, 2023 3:30-5:00 pm

## Outcomes

At the end of this session, participants will be able to:

- 1) Discuss current research related to hearing and listening skills in people with autism
- 2) Describe modifications in testing procedures that will maximize obtaining accurate results and acknowledge the needs of the listener
- 3) Discuss current aspects of auditory consideration in people with autism including sound tolerance issues and auditory processing challenges

## What is the role of audiology with this population and why does it matter?

- This is a topic, area, and population in transition in the world and in the world of audiology
  - The concept of “nothing about us without us”
    - Creating a base for shared decision making
    - What does functional communication look like for people with autism: What do they tell us? What do we tell them?
- This presentation will begin with discussing children but will address both children and adults
- “Person first language”? Autistics
- Coming soon! **“The role of audiologists in supporting Autistic people”** SAC position statement

## What is the role of audiology with this population and why does it matter?

- Historic research is not clear as many studies speculate about hearing without measuring it: speculated hearing or hearing loss based on observation, etc.
- The future: What research suggests and how we use that to inform or reform how we work with people with autism; how do we address functional issues?

## Other considerations for today

- The concept of Universal design
  - If we set up situations for success hearing services for people with autism, we can better meet the needs for all patients!
    - Physical set up of the booth:
      - Light
      - Space
      - Physical support: "I don't like when my feet don't touch the floor" (this was also shared by his speech/language pathologist)
- Improving health outcomes for people with autism
  - People with communication difficulties that make it difficult to express or comprehend verbal language are at higher risk for adverse health outcomes
  - More likely to report poorer general health
  - Complicated medical histories and unmet needs (Stransky et al, 2018)

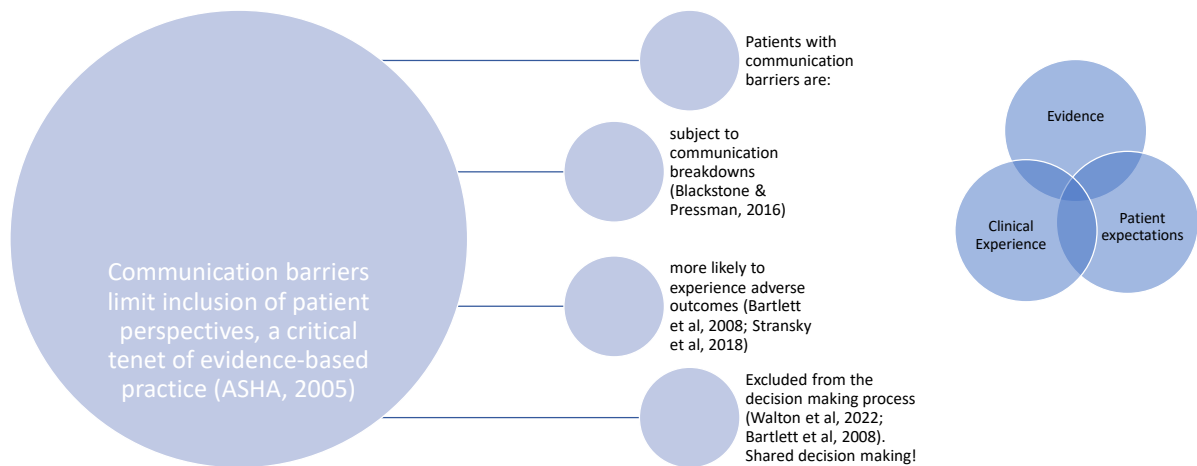
## ASD

- **Autism spectrum disorder (ASD) is a neurological disorder that impairs normal brain function and can significantly affect attention, behavior, communication, interaction and socialization, problem solving and thinking** (Evans et al, 1997; Stone et al, 1999; Landry & Bryson, 2004; Wetherby et al, 2004; Johnson & Meyers, 2007; Yirmiya & Ozonoff, 2007; APA, 2013)
- **May be referred to as a neurodevelopmental or neurocognitive disorder**
- **Cognitive abilities can range from gifted to severely impaired** (Evans et al, 1997; Stone et al, 1999; Landry & Bryson, 2004; Johnson & Meyers, 2007; Yirmiya & Ozonoff, 2007; APA, 2013)
- **Formerly recognized as distinct subtypes:**
  - Asperger syndrome
  - Autistic disorder
  - Childhood disintegrative disorder
  - Pervasive developmental disorder (PDD-NOS)

## Prevalence of Autism

- Rates of the diagnosis of autism (autism spectrum disorders) is estimated as 1 in 54 children and rates of diagnosis continue to rise (Centers for Disease Control, 2020)
  - CDC considers ASD an important public health concern
    - Occurs in all racial, ethnic and socioeconomic groups
    - 5x more common in boys than girls
  - Significant efforts being made to educate healthcare providers and the public
  - *Learn the Signs. Act Early.* (CDC, 2015)
- As audiologists, also must consider functional communication needs of adults who may have been identified with autism as a child OR have had a recent dx.

The “nothing about us without us” perspective in audiologic care for people with autism (Schroeder, Whitelaw, & Sonntag, 2023)



## What is the role of audiology with this population and why does it matter?

- The basic approach:
  - Since autism is often characterized as having impairments in speech/language or restrictions in communication, must assure that this is not related to loss of hearing as the underlying issue(s)
  - Delays in language development between ages of 12-14 months
  - Delays in the identification of autism
  - The potential impact that autism has on hearing/listening/learning

## “Hearing” and autism

- Autism is considered to be a “broad, variable developmental disorder that impacts communication and social interaction” (Beers et al, 2014)
  - Prevalence of autism have been contested but clearly have increased rapidly since 2000
  - What does this mean for people with autism and for the profession of audiology?
- Children with autism diagnosed with hearing loss were generally diagnosed 4-5 years later than typically developing peers
- Survey indicated that 1 in 53 children with hearing loss were also receiving school related services in the classification of autism (about 2%) (Szymanski et al, 2012)
- Hearing abnormalities have been estimated in 33-46% of confirmed ASD cases (Hitoglou et al, 2009)
  - May include peripheral hearing loss, decreased sound tolerance disorders (DSTD), auditory processing disorders

# Hearing and Development

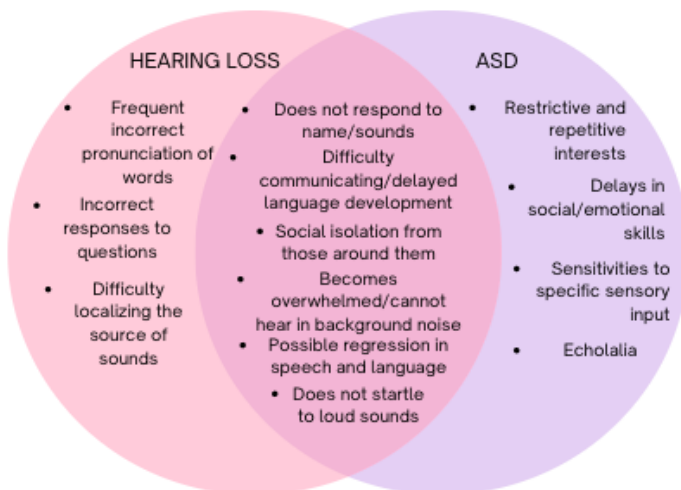
Hearing is important for:

- Verbal language development
- Social and emotional development
- Academic outcomes

Autism Spectrum Disorders:

- Often characterized by impairments in speech/language or restrictions in communication
- May demonstrate hyper-responsiveness to auditory stimuli (hyperacusis, misophonia, lack of habituation)
  - Beers et al., 2014
- Hearing is the most frequent concern mentioned by parents in the first year

When **any** communication delay/disorder is suspected, hearing loss must be ruled out as a possible cause.



## Characteristics of HL vs ASD

\*\*this is not a comprehensive list and not all of these signs/symptoms will be present in every case and for every child

## “Hearing” and autism

- Hearing impairment is more prevalent in individuals with Autism Spectrum Disorders (ASD) than the general population. ASD is not caused by hearing impairment, however behaviors may be more obvious by the co-morbidity of hearing loss (Demopoulos & Lewine, 2016).
- Research in hearing loss and autism is broad and inconclusive:
  - Varying definitions of the term “autism”, the term “hearing loss”, the term “auditory processing”
  - The role of auditory development: The science of developmental psychoacoustics/psychoacoustics
    - Speculation on the importance of intervention in improving listening and social communication by improving auditory system input
      - History of “Auditory Integration” but not based in science
  - So much more in terms of listening and auditory processing disorders

## Co-occurrence of HL and ASD

- ~40% of children with hearing loss have a co-occurring disability; prevalence of ASD/HL is estimated at 1 in 59  
Clason, 2017
- Higher prevalence of hearing loss in children with ASD than in the general population  
Cejas et al., 2015  
Not necessarily at an increased risk for hearing loss (Beers et al., 2013)  
Higher rates of autism reported in children with hearing loss compared to normal hearing peers
- Greater degree of hearing loss correlated with ASD dx
  - Szymanski et al., 2012

## Auditory Brainstem Response and Autism

- Studies have shown abnormal amplitude and prolonged latency in children with ASD
  - e.g., the responses are less intense and slower
- Cohort study: followed 139,154 newborns (including 321 later diagnosed with ASD)
- Findings:
  - ASD newborns had significantly slower brain responses than typically developing peers
- Conclusion
  - ABR results might be a predictor of ASD risk
  - More research needed!
- Miron et al., 2021

## Barriers to Diagnosis

- Autism is diagnosed 1-7 years later in children with hearing loss than those with typical hearing, despite earlier parental concerns
  - Mandell, 2005; Roper, 2003
- Possible reasons?
  - Overlapping characteristics between children with ASD and hearing loss
    - Roper, 2003; Garreau, 1984
- Diagnostic Overshadowing:
  - ASD symptoms might be attributed to hearing loss
  - For a child with a diagnosed DD, hearing loss may be overlooked
  - Late diagnosis of hearing loss might be misidentified as ASD
  - The value of universal newborn hearing screening
    - Fitzpatrick et al, 2014
- Adapted from Carbone, 2012, EHDI conference



## Barriers to Diagnosis

- Provider Bias
- Anecdotally, children with autism:
  - Are perceived as difficult to test behaviorally
  - Won't tolerate earphones
  - Won't sit quietly
  - Won't respond to speech testing

### Study of 106 children with ASD:

- Downs et al., 2005
- Found significant value in functional questionnaires
- Reliable behavioral results could be obtained
- Children with autism responded as well to speech stimuli as children who did not have a classification of autism

## Barriers to Diagnosis

- A reality:
  - The differential diagnosis provided by an audiologic evaluation is critical for children (or adults) with ASD
  - This population may present with challenges that impact testing due to differences in sensory processing and in development
  - May impact ability to obtain valid results, particularly if the evaluator is untrained with this population (e.g. hearing screening performed by a nurse) or has minimal experience
  - McTee et al (2019)

## The audiologist may be the first professional working with a child who has hearing loss and ASD

- Differential diagnosis
- Hearing loss is identified but the typical language development (oral or ASL) does not happen, despite appropriate amplification and language stimulation
- Deficits noted in social-emotional reciprocity; typically developing Deaf/hard of hearing child has social smile, eye contact, imitates behaviors, vocalizations, and/or signs
  - Child with ASD and hearing loss: May have poor eye contact, lack of pointing, poor joint attention
- Significant sensitivity to sound or resistance to wearing hearing aids/CI (the case of the orange hearing aids)
  - Ludwig et al, 2022

## The audiologist may be the first professional working with a child who has hearing loss and ASD

- No specific instruments to detect/diagnose ASD within the DHH population (Thompson & Yoshinago-Itano, 2014)
- Consider administering the Social Communication Questionnaire
- The ADOS-2, the Autism Diagnostic Observation Scale (the “gold standard”) used in identification of autism, effective in the population of children with ASD and hearing loss, even if ASL is primary form of communication (Ludwig et al, 2022)
- Modified Checklist for Autism in Toddlers Revised and Follow-up (M-CHAT-R and R/F). **Robins et al (2009)**

## Practical considerations for working with people with Autism: Overview



### Prepare in advance

[Social stories](#)

Visual schedules



### Control the evaluation

Clear direction/language

Use familiar person as a test assistant

Reduce transitions

## Practical considerations (Adapted from Schroeder et al, 2023)

- Visual supports: Facilitate patient-provider communication (Thunberg et al, 2022; Hurtig et al, 2019)
  - May include use of Augmentative and Alternative Communication (AAC) concepts

AAC systems and visual supports can be used to facilitate patient- provider communication (Thunberg et al, 2022; Hurtig et al, 2019)

Written language

Supplemental Handouts

Visual Analog Scales (VAS)

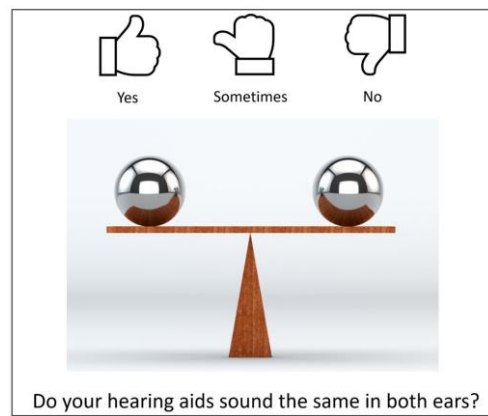
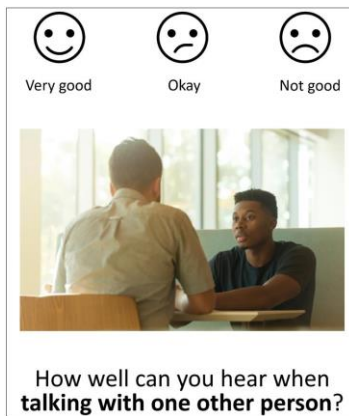
## Practical considerations (Adapted from Schroeder et al, 2023)

- Visual Supports
- Visual Schedules
- Photographs
- Social Narratives
- **Administration**
- Visual representation and auditory presentation (Walton et al, 2022)
- Visual supports and other forms of AAC have been widely used in audiologic evaluations

- **Individualized**
- Specific to the person or situation<sup>14,15</sup>
- **DEVELOPMENT CONSIDERATIONS** Universal design
- Materials suited for all abilities<sup>11,17</sup>
- Large,
- accessible font<sup>1,17</sup>
- Clear language<sup>8,12</sup>

## Practical considerations (Adapted from Schroeder et al, 2023)

- **DEVELOPMENT CONSIDERATIONS based on Universal design**
  - Materials suited for all abilities (Thunberg et al, 2022; Gray & Garand, 1993)
  - Large, accessible font (Walton et al, 2022)
  - Clear language (Walton et al, 2022)
  - Health Literacy
    - What level are materials we use/have access to at?
      - Part of social determinants of health (Healthy People, 2030: <https://health.gov/healthypeople/priority-areas/health-literacy-healthy-people-2030>)
      - Manufacturers, etc.
      - Create our own materials
      - Improved communication with a healthcare provider



Examples of visual analog scales appropriate for using with patients with ASD

## Social stories

- Autism is characterized by difficulty interpreting and participating in social contexts
- Social stories are clear and concise narratives that are designed to help people with autism to understand and anticipate specific situations, often those that are unfamiliar and/or may result in increased anxiety
  - Language should be clear, concise, and use age appropriate language
  - Generally written in first person from the listener/patient/student perspective
  - Guidance for writing social stories—Gray and Garand (1993)
    - Support with visual models (photographs of actual environment, videos, etc.)

## Social stories

- Social stories provide clear explanations of specific social situations designed to help people with disabilities to prepare for new experiences
  - What is going to happen in a specific situation and the reason that it will happen
  - Narratives that can provide both high and low support (how it can be incorporated for anyone and think about universal design)
  - Two types of sentences included: Descriptive and directive (More, 2012).
    - Two or more descriptive sentences are recommended for each directive sentence
      - Goal is to inform the child about the situation, not to direct them how to behave
      - Can be used in conjunction with role playing
- May consider with a visual, less formal story such as in the My World tool from the Ida Institute (<https://idainstitute.com>)

## Visual supports

- Can increase compliance with procedures
  - Reduce anxiety
  - Alert the person to transitions
  - Prepare for the appointment ahead of time (McTee et al, 2019)
- Can present repeated prior to the appointment by caregiver or school personnel (e.g. if hearing screening to be performed at school)
- Visual schedule: Most effective when presented one step at a time (such as order of testing)
  - "First"
  - "Next"
  - "Then"
- Visual model: If video, can be presented repeatedly then at the beginning of the assessment/evaluation

## Continuity of care (adapted from Bevan et al, 2023)

- Same audiologist at each appointment
- Pattern of response: May not be able to communicate their discomfort
- Scheduling of longer appointments
- Adapt sensory components of care (visual, auditory, and olfactory)
- Schedule first appointment of the day?

## Controlling the Exam (Felepelle, 2016)

- Applied Behavior Analysis (ABA) principle – “Gaining Instructional Control” • Directions and expectations
  - Clear and concise
  - Tell the parent what you need to complete testing
  - Reinforce with physical manipulation
- Physical control and restraint
  - Maximize safety and control
  - Protect the child, parent and yourself
- Using the parent/ caregiver as an assistant (Test assistant is novel, another transition)
- Pace
  - Don't waste time explaining things that aren't pertinent to complete testing
  - Avoid breaks and allowing child to get up and walk around → reduce TRANSITIONS

## Treatment of hearing loss

- Tharpe et al (2001)
  - AuD students do not learn about working with fitting children with multiple disabilities with hearing aids, either in the classroom or the clinic
  - Survey revealed that children with hearing loss and autism were fit 2-4 years later than their typically developing peers with hearing loss
  - Audiologists reported being “unfamiliar” with “expected outcomes” for children with hearing loss and autism who were fit with hearing aids
- Use pediatric audiology fitting guidelines (APSO, American Academy of Audiology, University of Western Ontario)
- Audiologists in the Leadership Education in Neurodevelopmental and Other Disorders (LEND) network

## Long-term management

Limited research around behavioral/educational strategies for children with ASD and hearing loss

Hearing aids (acoustic hearing)

- Objective fitting standards (Real Ear Measurements)
- Subjective fitting standards depend on level of support needs

Cochlear implants (electrical hearing)

- Might help with sound recognition, music, vocalization, but not to the extent of those without ASD
- Edwards, 2007
- Outcomes reliant on age of implantation/duration of hearing loss



[Image Source 1](#)  
[Image Source 2](#)



# Visual supports and social stories related to hearing aid fitting/use

## How do I change a wax guard?

**Step 1:** Take off the dome

**Step 2:** Get a fresh wax guard

**Step 3:** Hold the hearing aid wire in one hand and wax guard in the other

**Step 4:** Push the black end into the old wax guard

**Step 5:** Pull out the old wax guard

**Step 6:** Put the fresh wax guard into the end of the hearing aid wire

First, my audiologist will put long, tiny microphones into my ears.

Then, she will put my hearing aids on and play a story about carrots.

I will sit quietly and listen to this story a few times in a row.

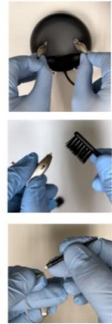
This story lets my audiologist set my hearing aids so I am hearing the best I can.

Descriptive Sentence  
Directive Sentence



## How do I take care of my hearing aids?

1. Put them in the charger every night
2. Keep them in a safe, dry place
3. Wipe off wax with a tissue or towel
4. Brush them off once a week
5. Change the wax guard once a month
6. Visit the audiologist if I need any help



## Additional auditory considerations in people with autism: Normal hearing yet behavioral concerns

- Individuals with autism with normal peripheral hearing acuity often still experience listening and communication difficulty, as reported in the literature
- Research supports that people with autism spectrum disorders (ASD) require a more favorable signal-to-noise ratio
  - Deficits in auditory filtering and deficits focusing on foreground to background
  - Difficulty with temporal processing, dichotic listening, and use of spatial cues
  - Deficits in tests shows differences in “auditory filtering” between those with ASD and those viewed as typically developing (Schafer, Mathews, & Dunn, 2019)

## Auditory Processing Disorder (APD)

- APD: A breakdown in auditory speech understanding, with normal peripheral hearing and cognitive abilities
- Typical auditory systems:
  - Listen effectively in wide range of situations
    - Noise, classrooms, distractions
  - Fast and flexible
  - Follow a developmental time course
- APD and ASD:
  - Issues with attending, focusing, coping in less-than-optimal listening environments
  - Models of diagnosis and treatment in one might apply to the other

## APD and ASD

ASD = more global sensory processing skills

- Auditory processing difficulties in ASD are most likely to present while processing complex auditory information; more severe for speech than non-speech stimuli
  - O'Connor, 2012
- Part of larger cognitive atypicality, not necessarily a strict auditory processing disorder
  - Sensory processing issue, not necessarily “auditory processing” (Crasta et al, 2020)
- Question:
  - Does a diagnosis make a difference in intervention?Answer: maybe!

## Functional communication issues related to “auditory processing”

- Difficulty separating foreground from background
- Use of HAT (hearing assistive technology) has been demonstrated to be a viable solution to the speech-in-noise perception in children with ASD
  - Significant improvement in speech in noise performance in noise and reduced perception of listening difficulty
    - Xu et al, 2023

## Additional considerations

- People with ASD may also demonstrate hyper-responsiveness to auditory stimuli
  - “A pattern of exaggerated behavioral reactions to sensory stimuli often displayed by children with ASD and is an umbrella term that includes hyperacusis, hypersensitivity, sensory defensiveness, sensory modulation dysfunction, aversion, avoidance, hyperarousal, and lack of habituation to sensory stimuli” (Beers et al, 2014)
  - “Decreased sound tolerance disorders (DSTD) are routinely observed in autism spectrum disorder (ASD). The most common types...are hyperacusis and misophonia” (Danesh et al, 2021)

## Hyperacusis/Misophonia

### Hyperacusis: decreased sound tolerance

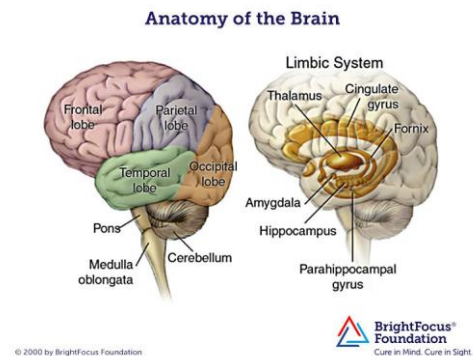
- Children with ASD might have global sensory sensitivities but **not** meet the clinical definition of hyperacusis
- Clinical definition: Loudness Discomfort Level (LDL) below 70 dB HL
  - Testing implications?
- Misophonia: emotional response to specific sounds
  - "Trigger" sounds are often specific to certain people, commonly loved ones
  - e.g., chewing, swallowing, coughing
  - No clinical diagnostic criterion
- Phonophobia: learned behavior, a "fear of sound"

# Hyperacusis

- Hyperacusis is highly prevalent in autistic people and adversely impacts social and academic domains due to sensory-based reactions to auditory stimuli (Danesh et al, 2021)

## Underlying cause (?)

- **Limbic system:** responsible for
  - Behavioral and emotional responses to external stimuli
  - Autonomic nervous system (e.g., fight or flight)
  - Long-term memory
- Auditory information processed in the temporal lobe can influence the limbic system
  - Leads to a conditioned response to certain sounds
- **Lingering questions:**
  - Is this purely auditory?
  - Is there a larger sensory integration issue innate to ASD?
  - Does this model even apply to kids with ASD?

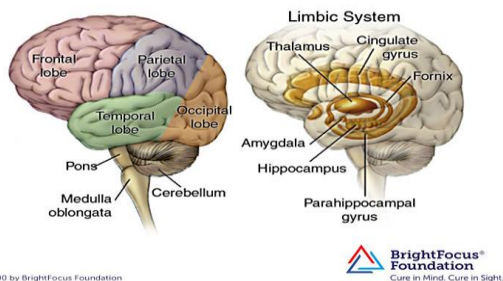


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## Underlying causes in people with autism

- Genetic predisposition
- Anatomical differences
- Differences in sensory processing capabilities (Danesh et al, 2021)

Anatomy of the Brain



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## Treatments

- Earplugs
  - **NOT recommended**
  - "After wearing earplugs for several days, participants rated sounds as louder than before" (Sheldrake, Diehl, and Schaette, 2015).
  - "These effects reveal direct evidence for adaptive plasticity of loudness, induced by changes in the listeners' chronic sound background" (Fromby et al., 2003).
    - Further suggested that incorrect use of hearing protection can intensify the hyperacusis symptoms
  - Increased perception of tinnitus
  - Exacerbates the response of hyperacusis when earplugs are out
  - Creates dependence on hearing protection
- Better approaches:
  - Cognitive Behavioral Therapy (CBT)
    - Re-training the brain to respond in a more productive way
  - Sensory integration support
    - Habituation/desensitization

[Source](#)

## Cases

### Kurt

- 18 year old adult with autism
- Graduated from high school in June, 2022
- Works as a dishwasher and as a piano tuner
- Difficulty listening in all situations; mom describes it as one of the most impactful aspects of Kurt's autism for his entire life
- Speech in noise issues, withdraw from conversations, etc.
- Poor ability to monitor vocal loudness
- Mom contacted me to discuss APD and trial use of hearing aids

# Kurt

- After meeting Kurt and learning of his functional communication deficits, poor speech in noise performance, and auditory fatigue reported, shared decision to try hearing aids in our demo hearing aid program
  - Real ear verification
  - Three days into trial, mom called me to tell me that Kurt's tutor was "shocked" by positive behavioral changes; focus, better ability to listen in less than optimal environments
  - Talked about the message in the church less that week...had never done that previously (went to church to be able to go to breakfast after ☺)
  - Improved communication with family and work colleagues/residents at the nursing home
  - Kurt wanted to wear the aids all waking hours based on benefit
    - Shared responsibility for care

# Kurt

- Family moved ahead to purchase hearing aids for Kurt
  - Opted for entry level technology based on success with this level in trial
  - Originally ordered rechargeable RICs but issues with moisture from dishwashing exposure resulted in an "old school" decision: conventional battery with slim tube fitting
    - Data log supports report of both Kurt and his mom: Wears hearing aids all day, every day
  - Tutor and communication partners report that Kurt is a "faster" and more focused communicator
  - Kurt reports that wearing the hearing aids help him to be "confident"
  - Bluetooth technology
  - Live Listen



## J

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- 20 year old college student with diagnosis of autism
- Arrived at the clinic with main concern that he has difficulty hearing in noise
  - Changes from high school to college
    - Different communication expectations
    - Varied listening environments
    - Desire to “fit in” as a communicator
- Normal peripheral hearing acuity with very poor speech in noise performance, significant fatigue based on responses on Vanderbilt Fatigue Scale
- Wanted to try hearing aids to address listening situations and fatigue
  - Had tried DM system provided by University, liked the listening but not the remote mic
- Based on his perceived communication demands, he wanted to try advanced hearing aid technology

## J

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- Fit with advanced technology: Rechargeable RICs
  - Originally with domes with retention tags however he complained about the “sensory” aspects of this
  - Opted for custom mold for receivers; much prefers the feel and the “sound”
  - Real ear verification and improved ability to hear in less than optimal situations
- J reports these aids help him tremendously in class (less speech/language confusion, less fatigue)
- Payer option
- “You need to work with more people like me”

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