

A Summary of Current Understanding Regarding Children with Autism Spectrum Disorder Who Are Deaf or Hard of Hearing

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ABSTRACT

This article provides a consensus perspective based on the authors' expertise and the limited available literature regarding our understanding of children with an autism spectrum disorder (ASD) who are deaf or hard of hearing (D/HH). The challenges in the accurate identification of an ASD in children who are D/HH, including red flags for a potential ASD and screening and assessment for ASD, are described in this article. Additionally, strategies to guide professionals in their communication about a possible ASD with families and to frame the need for expanding aspects of communication important for this group of children are suggested.

KEYWORDS: Deaf, hard of hearing, autism spectrum disorder, assessment

Learning Outcomes: As a result of this activity, the reader will be able to (1) identify "red flags" warranting referral for a possible autism spectrum disorder (ASD) for a child who is deaf or hard of hearing (D/HH); (2) describe issues that arise in screening and assessing ASD in children who are D/HH; (3) be able to discuss concerns with family members when there is suspicion about ASD for their child who is D/HH.

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It is well known that the incidence of autism spectrum disorders (ASDs) has increased dramatically in the last two decades; the CDC recently estimated that 1 in 68 children in the United States has ASD.¹ This increase has been accompanied by an increased need for services for these children. There is also a need for trained clinicians who are able to screen children for ASD, diagnose ASD, and treat ASD.

Children who are deaf or hard of hearing (D/HH) appear to be diagnosed with ASD at similar, if not higher, rates than hearing children. Szymanski and colleagues reported that 1 in 59 deaf American children had an educational diagnosis of ASD.² Other reports have found that the rate of hearing loss in the population of individuals with an ASD is higher than in the general population.³ Therefore, individuals who carry a dual diagnosis may constitute a reasonably sizable clinical population. Yet to date very little research exist describing this population, nor are there instruments specifically designed to detect ASD in children who are D/HH or interventions tailored to the particular needs of children with this dual diagnosis (see Thompson and Yoshinaga-Itano, in this issue).⁴

Children who are D/HH and have ASD may have unique challenges in learning and development. Children who are deaf often do best when exposed to language visually, and visual attention (particularly attention to faces) is often disrupted in children with ASD,^{5,6} thus posing a particular obstacle to children who may not be able to rely on their hearing to take in information. Complicating matters further, the differing structures of spoken and signed languages may lead to different linguistic manifestations of ASD (see Shield, in this issue).⁷

The authors have experience working with children who have been dually diagnosed. Clinically, various challenges are related to accurate diagnosis of ASD in children who are D/HH. When ASD is misdiagnosed in children who are D/HH, they will not receive the intensive support and early intervention that has been shown to be beneficial in addressing the symptoms of ASD.⁸ When hearing status is determined early in life, efforts to intervene and promote children's development are often fo-

cused on addressing issues known to commonly arise in children who are D/HH, such as speech-language communication therapy (e.g., through the use of a signed language to promote communication skills, or through auditory training and spoken language support when assistive listening devices benefit the child). The focus on addressing, supporting, or mitigating the challenges that can be associated with reduced hearing can decrease the amount of attention given to children's other behaviors. There is some evidence to suggest that this may play a role in delaying the diagnosis of ASD,^{9,10} which has negative impact on overall development and language and social development in particular (also see Szarkowski et al, in this issue). Research has demonstrated that earlier intervention typically yields better outcomes.⁸ At times, parents and family members are certain that a child has a neurobehavioral condition in addition to hearing loss, yet few professionals are competent and qualified to diagnose ASD in the D/HH population (Szarkowski et al, in this issue).⁹

In addition to difficult cases, such as those described above, instances in which children who are D/HH were diagnosed appropriately with ASD do exist. The challenge lies in determining how best to screen, assess, diagnose, intervene, and meet their needs. This issue of *Seminars in Speech and Language* aims to begin to address some of these important issues. This collection of information and research has the potential to help clinicians who work with children who are D/HH or with children with ASD understand how to best serve children who may be dually diagnosed. We seek to increase awareness of the intersection of ASD with hearing loss and set an agenda for research in the coming years. Ideally, we will provide clinicians with useful tools for detecting ASD in this population as well as implementing services and interventions that are specifically designed for these children.

MEDICAL CONSIDERATIONS

Some medical conditions are associated with higher rates of ASD. For example, children with fragile X syndrome (a genetic cause of intellectual disability) have higher rates of ASD

than the general population.¹¹ Due to the linkage between genetic conditions and an ASD, genetic testing is considered a standard of care.¹² Even with advancements in genetic testing, up to 80 to 90% of children with an ASD do not have a cause of autism identified. There are descriptions of higher rates of learning difficulties, language delays, behavioral disorders, and mental health disorders in the families of children with an ASD.¹³ Approximately one third of children with ASD show regression between 1 and 3 years of age.¹⁴ A loss of previously acquired developmental skills (i.e., children stops using words they previously used in a variety of contexts) warrants concern, and the children should be referred for developmental evaluation.

Our understanding of etiologies of hearing loss that put children at a higher risk of an ASD is fairly limited. However, small case reports suggest that children with CHARGE syndrome (coloboma, heart defect, atresia choanae or choanal atresia, retarded growth and development, genital abnormality, and ear abnormality),¹⁵ children with congenital cytomegalovirus,¹⁶ and children with Usher syndrome¹⁷ may have a higher risk of having an ASD. Children with extreme prematurity have higher rates of positive autism screening; however, definitively higher rates of autism spectrum diagnoses have not been confirmed.¹⁸ A higher index of monitoring and intervention may be warranted in these children.

Children with ASD can have comorbid medical concerns. Common issues include intellectual disability (50 to 75%); seizures (25 to 30%); sleep disturbances; gastrointestinal difficulties such as reflux, loose stools, or constipation (16 to 85%); and pica syndrome (eating nonfood items).¹³ It is important to address these issues as they can be an initial trigger for behavioral problems and can markedly impact quality of life and ability to learn and respond to interventions.

Children referred for an evaluation of ASD could have other disorders with behaviors that look like autism but are not indicative of a diagnosis of ASD. In addition to medical diagnoses that commonly co-occur with ASD, several medical diagnoses have some symptoms that may overlap with ASD. Several

of these are listed in Table 1. Assessment for ASD should be a process of ruling out these possible conditions as a singular explanation for the child's presenting symptoms but also should consider the possibility of multiple comorbid diagnoses. Failure to provide correct diagnosis could result in failure to receive appropriate intervention.

RED FLAGS OF A POSSIBLE AUTISM SPECTRUM DISORDER

Complicating the diagnosis of ASD among children who are D/HH are factors commonly associated with hearing loss that may also be associated with autism. Among others, these include: overall language delays and difficulties with particular areas of language functioning,¹⁹⁻²¹ delayed theory of mind,²² failure to respond to one's name, and pragmatic language difficulties.²³

However, even many of these apparently overlapping symptoms can be distinguished from symptoms of ASD upon closer scrutiny. For example, children who are D/HH may be more likely to have language delays than peers without hearing loss. Yet, with the widespread adoption of newborn hearing screening procedures and earlier intervention, we expect that when provided access to early intervention and appropriate early intervention, typically developing children who are D/HH will demonstrate a language development trajectory much more similar to their hearing peers.^{21,24} Thus, if a child is demonstrating marked language delays despite early identification of their hearing loss and appropriate early intervention, this should be considered a red flag for a possible additional developmental disability, such as autism. Similarly, although deaf children of hearing parents may show delayed theory of mind, the delay is not as significant or persistent as in the case of children with ASD.²²

Diagnosing ASD among children who are D/HH requires familiarity with expectations of development for typically developing children who are D/HH. It is critical to recognize and distinguish patterns of atypical development that may be associated with ASD. It is important to understand the various factors that contribute to heterogeneity within the D/HH

Table 1 Diagnostic Rule-Outs (If it is not autism, what could it be?)

Diagnostic Rule-Out	Differential Diagnosis
Intellectual disability	Developmental profiles are generally stable over time and follow a pattern of delayed rather than atypical development. Though there may be some differences, developmental areas tend to be similarly depressed. Play and communication skills (including preverbal behavior) should be commensurate with cognitive/developmental level. Children who are D/HH and are late identified or who have additional communication disorders, such as specific language impairment, apraxia, or dysarthria, may demonstrate overall language delays and behavioral symptoms that may mimic autism because of high levels of frustration with communication. Appropriate interventions should diminish these negative behaviors.
Communication disorders (receptive language, expressive language, apraxia, pragmatic language)	Children with selective mutism may choose not to communicate with certain individuals or in particular social contexts. Social communication with familiar individuals with whom they do communicate should be unaffected. Children with anxiety disorders may demonstrate reduced eye contact, restricted sharing of affect, limited reciprocal conversations, and reduced social engagement, within the context of an evaluation with an unfamiliar adult. Children with anxiety may show an increased resistance to change/adherence to routines generally. Developmental history should not be significant for symptoms of preverbal skill deficits and repetitive behaviors/restricted interests. Anxiety disorders commonly co-occur with ASD.
Anxiety disorders (such as selective mutism, generalized anxiety disorders)	Landau-Kleffner is a specific type of EEG abnormality that tends to occur during sleep (and not associated with specific motor movements seen in seizure disorders) that is associated with a language regression. The language regression in this disorder tends to occur between 3 to 5 years of age.
Landau-Kleffner and other epileptiform language disorders (substantial processing deficits)	Children with ADHD may demonstrate difficulties with appropriate social overtures/responses due to poor impulse control and difficulty processing feedback from peers. Because they may intrude on others' personal space, these children may appear to have reduced understanding of nonverbal cues. Young children with ADHD may demonstrate reduced eye contact and it may be difficult to obtain their attention to engage in joint attention. Other deficits in early preverbal communication skills and symbolic play unlikely. Atypical communication
Attention Deficit/Hyperactivity Disorder (ADHD)	

Table 1 (Continued)

Diagnostic Rule-Out	Differential Diagnosis
Obsessive Compulsive Disorder (OCD)	<p>features and repetitive behaviors/restricted interests are not part of the ADHD clinical presentation. ADHD can co-occur with ASD.</p> <p>Children with OCD may have perplexing repetitive, ritualistic, and rigid behaviors. Children may show high anxiety during disruption of routines. Repetitive behaviors are driven by a need to reduce anxiety. Obsessions are distressing; children typically recognize their social impact. Obsessions/rituals do not cause concern for children with ASD. Atypical language characteristics and pragmatic deficits associated with ASD are not part of the OCD clinical picture. OCD can co-occur with ASD.</p>
Tourette syndrome (often associated with OCD, ADHD)	<p>Tourette syndrome is characterized by the presence of uncontrolled motor and vocal behaviors that may appear repetitive. Atypical patterns of social communication and restricted interests associated with ASD are not commonly associated with Tourette syndrome. However, Tourette syndrome and ASD can co-occur.</p>
Benign stereotypies (all flapping is not ASD)	<p>Typically does not occur prior to 5 years of age and may be transient into adolescence. Atypical patterns of social communication and restricted interests associated with ASD are not present. Symbolic gesture and play should be typically developing. These children may have hypo- or hypersensitivity to touch, visual or auditory stimuli, or sensory-seeking behaviors. Communication, social skills, gestures, symbolic play, and joint attention should not be impacted. Children with seizure disorders, especially those of the absence type (staring spells) can miss information during the time of their seizure. This makes them seem inattentive or lost about what just happened. Seizures can co-occur with an autism spectrum disorder and/or other developmental concerns. Sometimes medications used for treatment of seizures can cause sedation, emotional lability, and other side effects that may impact how they respond to the environment and their peers. Children with seizure disorders could display emotional lability. Their behaviors, especially as a result of pharmaceuticals, could result in an inability to engage socially. However, in general, these children should show developmentally appropriate symbolic gesture, symbolic play, eye gaze, and joint attention when young.</p>
Sensory integration dysfunction (common overlap with ASD, ADHD, anxiety disorders)	
Seizure disorders (specifically, absence seizures, may miss information while having seizure)	

(Continued)

Table 1 (Continued)

Diagnostic Rule-Out	Differential Diagnosis
Peripheral vision field cuts	Adolescents/adults with Usher syndrome may appear aloof to others trying to gain attention within the individual's peripheral vision. Typically Usher syndrome is progressive, so prior to the vision loss progression, development of symbolic gesture, play, eye gaze, joint attention, social interaction, and language development should follow typical developmental expectations.
Posttraumatic stress disorder/lack of exposure (extreme neglect, abuse)	Children who have experienced extreme trauma, neglect, or abuse may show autistic-like behaviors as a result of these experiences (e.g., social withdrawal, poor eye contact, heightened reactions to sensory stimuli associated with trauma). These symptoms typically improve with treatment. More appropriate social communication skills are demonstrated as treatment progresses and social environment stabilizes.

Abbreviations: ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; OCD, childhood-onset obsessive compulsive disorder.

Note: Common stereotypes include the following: thumb or hand sucking; body rocking; head banging; nail biting (most common stereotypy of later childhood); trichotillomania; bruxism; and recurrent headaches. Complex motor stereotypies include the following: flapping, waving, opening and closing the fist, finger wiggling, wrist flexion and extension, atypical gazing at objects or fingers, and abnormal pacing, running, and skipping. These secondary stereotypies are strongly associated with autism.

population (e.g., degree of hearing loss, etiology of hearing loss, communication preference, educational method, medical intervention, family background/communication match), which may influence the development of social/communication skills and behavior. In the absence of validated tools for assessing ASD for children who are D/HH, best practice relies on informed clinical opinion based on interpretation of data gathered from multiple sources. Unfortunately, many providers will not have experience with both ASD and D/HH and may have difficulty interpreting this information. Based on a review of the literature as well as clinical experience, the authors of this article, all of whom have training and experience working with children with ASD who are also D/HH, have compiled a review of symptoms. This list may be useful in distinguishing features of ASD from typically developing D/HH characteristics. Table 2 compares features of typical development for children who are D/HH versus symptoms more consistent with ASD among children who are D/HH. Notably, this table is not exhaustive. It

is NOT intended to be used as a stand-alone ASD screening or assessment measure. However, it may be helpful in guiding conceptualization of developmental concerns and assisting in determining when a referral for further assessment seems appropriate.

Social Communication and Social Interaction

With the exception of difficulty acquiring particular speech sounds, grammatical features/vocabulary, and idioms, deafness is primarily a model of delayed language development, rather than atypical language development. In particular, we do not typically expect hearing loss to interfere with the acquisition of preverbal social communication skills. Symptoms of ASD among young children who are D/HH may present similarly to those in children who can hear in terms of absence of or reduced eye contact, limited show/give behaviors, reduced gesture use (see Kellogg et al, in this issue²⁵), lack of pointing for shared enjoyment, reduced

Table 2 Possible Red Flags for ASD among Children Who Are D/HH^{38,39}

DSM-V Criteria ⁴⁰	ASD	Typically Developing D/HH	D/HH + ASD
<p>DEFICITS IN SOCIAL/ COMMUNICATION AND SOCIAL INTERACTION</p> <p>Deficits in social/emotional reciprocity</p>	<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^{33,34} 	<ul style="list-style-type: none"> • Reduced/absent social smile • Limited or inconsistent eye contact • Limited give/show behavior (Mood and Shield, this issue)²⁸ • Reduced sharing of affect • Difficulties with joint attention (Mood and Shield, this issue)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
<p>Deficits in communicative behaviors for interaction</p>	<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 	<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 demonstrate poorly integrated sign and spoken language (if utilizing total communication approach) • Shifting of signing space below typical visual spatial space³⁹

(Continued)

Table 2 (Continued)

DSM-V Criteria ⁴⁰	ASD	Typically Developing D/HH	D/HH + ASD
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 	aspects of verbal communication ^{19–21,23} <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) 	<ul style="list-style-type: none"> • 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) • Reduced shared enjoyment • Delayed acquisition of symbolic play skills (Kellogg et al, in this issue)²⁵ 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



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Table 2 (Continued)

DSM-V Criteria ⁴⁰	ASD	Typically Developing D/HH	D/HH + ASD
RESTRICTED/REPETITIVE PATTERNS OF BEHAVIOR			
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 	<ul style="list-style-type: none"> • Echolalia in sign or spoken language (Shield, and Mood and Shield, both in this issue)^{7,26–28} • Idiosyncratic gestures (e.g., persistent use of made up gesture, distinct from home sign (Mood and Shield, this issue)²⁸, when formal sign taught/used) • Palm rotation errors (Shield, and Mood and Shield, both in this issue)^{7,28,32} • Difficulty with pronoun use (not using point gesture to indicate others, finger spelling name instead of using pronoun/point, “you”/“I” confusion in auditory/verbal children; see Shield, in this issue)⁷ • Rocking, twirling, flapping, spinning • Highly repetitive play with objects (e.g., persistence in lining up toys with significant upset if disrupted)
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 	<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

(Continued)

Table 2 (Continued)

DSM-V Criteria ⁴⁰	ASD	Typically Developing D/HH	D/HH + ASD
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 	<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 United States at age 3)
Hyper- or hyporeactivity 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-/hyposensitivities, these are more typically differences with vestibular processing; less likely visual inspection or persistent tactile/olfactory exploration of objects 	<ul style="list-style-type: none"> • With some D/HH 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 nonfood objects before use) • Unusual reactions to environment unlikely related to hearing loss (e.g., avoidance of smells/textures)

Abbreviations: ASD, autism spectrum disorder; D/HH, deaf or hard of hearing; DSM-V, Diagnostic and Statistical Manual of Mental Disorders (5th ed.).

joint attention, poor imitation skills, problems with turn taking, and problems with making choices. As outlined by Shield (in this issue),⁷ several atypical communication patterns commonly associated with autism have also been

demonstrated among children who are D/HH and also have autism. Among these are echolalia (i.e., repetition of others' linguistic productions, often without communicative intent),^{26,27} pronoun avoidance, idiosyncratic language (see

Mood and Shield, in this issue²⁸), and neologisms (i.e., children who invent signs/words rather than using a formal sign/word). A greater tendency is also seen to reverse the palm when imitating or spontaneously producing signs, similar to that observed in hearing children copying gestures.^{29–32} Although not yet described in the D/HH-specific literature, other symptoms of atypical language development, such as use of others' hands as tools to communicate (i.e., using their parents' hand to point, manipulating their parents' hands to engage a toy), has been observed clinically among children who communicate using visual and oral communication.

Typically developing children who are D/HH do not generally demonstrate the difficulties with social/emotional reciprocity observed in autism, with the exception of not responding to their name when called. Most typically developing children who are D/HH will respond to their name if it is accessible to them through their hearing or will readily respond to traditional attention-getting measures (i.e., tapping the floor/shoulder, waving within visual space). Difficulty with joint attention, even when cultural adaptations for obtaining joint attention are considered, have been observed clinically (see Mood and Shield, in this issue).^{28,33,34} Children who are D/HH with ASD may be less likely to integrate eye contact, facial expressions, and gestures to engage others and may be less likely to imitate others' behavior. Similarly, typically developing children who are D/HH may recognize more emotions (68%) than children with ASD (46.5%) during the signing of British Sign Language sentences.³⁵ Another study by Denmark suggested that adolescents with ASD who are D/HH may be specifically impaired in their ability to comprehend and produce specific adverbial facial markers.³⁶

Symptoms of ASD may interfere with the acquisition of symbolic play skills. When compared with typically developing children who are D/HH, those who also have ASD demonstrate delays in symbolic play (Kellogg et al, in this issue²⁵), may be disinterested in toys, and may play with toys in rigid, repetitive, unimaginative ways. Similarly to hearing children with ASD, children who are D/HH with ASD demonstrate difficulties in developing and

maintaining social relationships appropriate to their developmental level. Typically developing children who are D/HH are interested in peers and able to form relationships when communication is accessible. In contrast, children with an additional ASD may show reduced interest in social relationships or may have difficulty engaging other children in age-appropriate ways, even when communication barriers are removed. Clinically, negative and unusual social overtures (e.g., backing into their parents without looking at them, a greater tendency to use physical means of initiating interactions even when more appropriate communication strategies exist within their repertoire) have been observed among children with ASD who are D/HH (Mood and Shield, in this issue).²⁸ It has also been noted clinically that children with ASD who are D/HH may have difficulty with pragmatic aspects of social interaction that are culturally specific (e.g., difficulty entering/exiting conversations, poor understanding of appropriate use of attention-getting conventions).

Repetitive Behaviors/Restricted Interests

Patterns of repetitive behavior or restricted interests that are part of the diagnostic criteria for ASD are usually not demonstrated among typically developing children who are D/HH. However, stereotyped or repetitive motor movements can sometimes be observed among developmentally delayed children who are D/HH in the absence of ASD. In some cases, self-injurious behavior (i.e., hitting self) or movements that appear repetitive/stereotyped have been observed among children who are D/HH before communication is well established. These behaviors often diminish as communication skills improve. Likewise, although children who are D/HH may have difficulty adjusting to changes in their routine or managing transitions, this difficulty is typically similar to developmental expectations if changes are clearly communicated. Typically developing children who are D/HH may have some atypical sensory responses or hyper-/hypo-sensitivities. Among children who are D/HH, vestibular and auditory processing differences may be more common.³⁷ Auditory processing sensitivities may contribute

to clinical findings that children with ASD who are D/HH may be more likely to resist (and persist in resisting) wearing amplification devices. However, it is less common to see unusual visual, tactile, or olfactory exploration of objects associated with ASD (e.g., closely visually inspecting objects, pressing objects against their body/seeking out particular textures, or routinely smelling/licking nonfood items) among typically developing children who are D/HH.³⁷

CONSIDERATIONS IN SCREENING AND ASSESSMENT OF ASD WITH CHILDREN WHO ARE DEAF/HARD OF HEARING

Screening

There are currently no ASD screening tools for children at any age that have been validated for use with children who are D/HH. Earlier identification of ASD in children who are D/HH could lead to the most appropriate intervention services and might reduce the severity of the symptomatology. Thus far, the research documents only a few screening or assessment tools that have been administered to small samples of children who are D/HH (Autism Behavior Checklist⁴¹; Sensory Profile⁴²; Baby and Infant Screen for Children with aUtism Traits, also known as the BISCUIT).^{10,43} In this issue, two articles discuss the use of tools that show promise as a potential screen in early childhood for children who are D/HH between birth and 3 years of age. Kellogg and colleagues (in this issue²⁵) provide a case study retrospective review of children who are D/HH and who were later diagnosed with ASD, demonstrating that early childhood profiles on the McArthur Bates Child Development Inventory may provide early warning signs of ASD. Carr and colleagues (in this issue⁴⁴) also discuss use of a nontraditional screening measure, the Language ENvironment Analysis, and its usefulness when combined with other common early developmental screening tools (i.e., the McArthur Bates Child Development Inventory).

Although not yet published, several of the authors of articles in this special issue have collected clinical data suggesting that other common screening tools such as the Modified Check-

list for Autism in Toddlers (M-CHAT)⁴⁵ and Social Communication Questionnaire (SCQ)⁴⁶ may be problematic when applied to children who are D/HH, with mixed results demonstrating that these tools may both overidentify children and underidentify ASD in this population. Clinical data suggest standardized cutoffs for the SCQ may not apply with children who are D/HH and that caution should be used when administering the SCQ to parents who are deaf and who communicate using American Sign Language (ASL). Therefore, it is still advisable to 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.

Assessment

As in the case of screening instruments for ASD, there are no diagnostic tools that have been validated for use with children who are deaf and hard of hearing. In fact, the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2),⁴⁷ one of the assessments considered the "gold standard" in assessing ASD, directly states that it was not intended for use for children with sensory impairments (i.e., deafness). This issue contains an exploratory study describing use of the ADOS-2 with children who are deaf and who have deaf parents (i.e., native signers) who were previously identified with ASD (Mood and Shield, in this issue).²⁸

Administration of available ASD diagnostic tools to small samples of children who are D/HH is not sufficient to validate their use with children who are D/HH. Unfortunately, limited research specifically explores how well these tools perform in differentiating ASD from features commonly associated with typically developing children who are D/HH. The Mood and Shield study in this issue²⁸ indicates that caution should be used when using diagnostic tools such as the ADOS-2 with children who are D/HH due to limitations regarding applying the tool to children who may use not only a different language (ASL rather than English), but a different communication modality (e.g., visual communication versus spoken language). Children who are D/HH with ASD may be misidentified when the ADOS-2

is administered following standardized procedures. However, when used in a clinical manner by a professional trained in working both with children who are D/HH and children with ASD, certain ADOS-2 activities may provide useful information. Other authors in this special issue, Wiley and colleagues,¹⁰ have presented ADOS data and similarly found that use of the ADOS algorithms in a standardized manner is inappropriate. Scoring communication items was particularly problematic when applied to this population.

Valid assessment of ASD among children who are D/HH is complicated not only by a lack of standardized tools for the population, but also by limited availability of providers who are trained in working with children who are D/HH as well as children with ASD. The authors of the ADOS-2 caution in the manual that training on the ADOS-2 in itself is not sufficient, but that users should have “prior education, training and experience that includes the use of individually administered test batteries as well as extensive exposure to ASD.”⁴⁷ Likewise, given the complexities necessary to disentangle apparently overlapping symptoms of ASD from features commonly associated with D/HH, it seems reasonable that one must have a strong understanding of both populations to facilitate appropriate diagnosis.

In the case of working with children who are D/HH and who communicate using ASL (or another formal system of visual communication), the subtleties of identifying atypical language features associated with ASD require a strong understanding not only of what the features look like in hearing children, but how the symptoms may present in a visual language (Mood and Shield, and Shield, both in this issue).^{7,28} It is unlikely that these features could be appropriately assessed by a practitioner who is unable to communicate directly with the individual, as interpreters unfamiliar with language features unique to ASD may not recognize or communicate to the evaluator the presence of these features during their interpretation. Although one prior study indicated no differences in results when a cognitive test was administered to a child who is D/HH by an interpreter or an ASL-fluent clinician,⁴⁸ one cannot make the assumption that the same

would hold true for administration of the ADOS-2. In addition to features of atypical communication that may be lost in translation, it has not yet been studied how presence of an interpreter influences the ability of the examiner to establish necessary rapport with a child utilizing a language other than the clinician’s in order for that clinician to adequately evaluate the child’s social communication skills.

CURRENT UNDERSTANDING OF BEST PRACTICE IN ASSESSMENT

Early Identification

Early diagnosis of ASD is critical in facilitating access to interventions to mediate the impact of ASD on developing language, cognitive, social, and behavioral skills. In the past, earlier diagnosis of ASD may have been delayed by the need to disentangle symptoms associated with early communication delays that often accompanied hearing loss. The adoption of newborn hearing screening procedures and emphasis on early intervention enabled parents and professionals in the field of deafness to become more comfortable identifying early symptoms of social communication deficits not attributable to hearing loss alone. However, barriers to receiving an early diagnosis still include a lack of dually trained professionals and an absence of screening and diagnostic tools that have been validated for use with children who are D/HH (Szarkowski et al, in this issue).⁹

Recognizing the critical importance of early intervention specifically targeted to ASD, best practice is to refer children who are D/HH for further evaluation by an appropriately trained professional (e.g., psychologist, developmental behavioral pediatrician, neurologist, etc.) as soon as concerns are raised regarding a child’s social/communication skills and behavior. This article provides information regarding “red flags,” which warrant a referral. Providers may use this information to help engage families in discussions about behaviors that appear inconsistent with expectations of typical development for children who are D/HH, focusing on both the child’s strengths and areas of concern (see Wiley and Innis, in this issue).⁴⁹

Professional Collaboration

Although best practice is to refer to a professional trained in both hearing loss and ASD to conduct the evaluation, it is uncommon to have this resource in many areas. In these situations a collaborative approach, in which professionals trained in ASD work closely in consultation with those trained in deafness, represents best practice. In some situations, this has been accomplished by parents requesting that D/HH professionals involved in their child's care accompany them to their evaluation with an ASD-trained professional. When this is logistically impractical, it may be helpful to sign a release allowing a phone consultation or providing a letter written by the D/HH provider outlining observations of how the child's development differs from typical expectations of children who are D/HH. Alternatively, referral to a D/HH specialist who consults with a professional with ASD experience would be appropriate.

Communication Considerations

Best practice also assumes that assessment is conducted by an evaluator who can communicate with a child in his or her preferred communication modality. Mood and Shield (in this issue)²⁸ caution that administration of commonly used ASD assessments such as the ADOS-2 may be particularly difficult to interpret when administered to a deaf child via an interpreter unfamiliar with the nuances of ASD. Extreme caution should be used in such cases. Practically speaking, it may often be necessary to utilize an interpreter. In these situations, given the idiosyncratic language use sometimes demonstrated by children with ASD who are D/HH, it may be helpful to use interpreters familiar with the child's language if possible (i.e., using the child's school interpreter in a clinical setting).⁵⁰ It is also helpful to meet with the interpreter prior to the evaluation to discuss what the evaluation is trying to accomplish so that the interpreter can stay aligned with the items on the assessment as well as provide additional observations about the child's communication and social interaction that may be missed by an evaluator with limited or no signing skills. Keep in mind,

however, that some young children may not have had experience with an interpreter and this could influence the results. Further research is necessary to examine the impact of administering ASD assessment tools via an interpreter. Reliability of the diagnosis is likely impacted by the communication match between the examiner and child when assessing core symptoms of autism (i.e., deficits in social/emotional reciprocity). This also warrants further exploration.

Best Practice Guidance from *The Standards for Educational and Psychological Testing*

The challenges of ASD assessment with children who are D/HH in some respects parallel the challenges of assessing individuals from other cultural and linguistic backgrounds that differ from those represented in the test's standardization sample. Although research presented in this issue suggests some promising new directions for screening children who are D/HH for ASD and steps are underway to adapt other tools for children who are D/HH, currently no tools for screening and assessing ASD have been validated for children who are D/HH (Kellogg et al and Carr et al, both in this issue).^{25,44} Additional research is necessary to develop and/or modify ASD assessments for children who are D/HH.

In the absence of validated assessment tools, the *Standards for Educational and Psychological Testing* (hereafter referred to as *The Standards*) developed jointly by the American Educational Research Association, the American Psychological Association, and the National Council on Measurement in Education provide best practice guidelines for assessing individuals from diverse cultural/linguistic backgrounds⁵¹; these should be followed when assessing children who are D/HH for a possible ASD. (Note that the revised standards are expected this spring but were unavailable for review at the time of this publication.) *The Standards* caution that tests should be selected and interpreted cautiously in light of individual and evaluator factors. Most importantly, multiple sources of information should be used as an indicator of the individual's functioning. When modifying a particular test to suit the needs of

individuals who were not included in the standardization sample, best practice is to clearly document modifications, as well as the rationale for modifications, and to field-test the modified test with a population sample to run tests of equivalence. Research in this area is in its infancy, with a few studies describing modifications to standardized tests (Mood and Shield, in this issue).²⁸ Additional work is necessary to empirically determine whether these modifications result in equivalent tests.

As described by *The Standards*,⁵¹ one must consider issues of “fairness” in testing. This can be done by ensuring that the test selected is valid for use with the individual and that there are no factors unique to the individual or testing situation that introduce “construct irrelevant components” that result in scores that are markedly different from the standardization sample for identifiable groups of examinees (in this case, children who are D/HH).⁵¹ Problems can arise in utilizing ASD diagnostic tests standardized on hearing children when applied to children who are D/HH when the content of the test measures skills that may be influenced by the nature of the child’s hearing, rather than symptoms of autism per se. An obvious example of this problem is items on several screening and diagnostic measures that refer to whether a child responds to his or her name. When applied to children who do not have a significant hearing loss, failure to respond to one’s name may be a symptom of autism; when applied to children who are D/HH, the impact of the child’s hearing loss, rather than ASD per se, may cause them to not respond appropriately to this item. Thus, as cautioned by *The Standards*, it is important to consider alternate possible explanations for the performance of children who are D/HH on a particular test before accepting their performance as indicative of ASD.

Difficulties with inadvertently introducing test bias when applying ASD assessments to children who are D/HH may also arise when using measures developed for use with children who communicate using spoken English with children who communicate using visual communication, such as sign language. *The Standards* caution that translating tests does not necessarily ensure that translation produces a

version that is equivalent to the original in terms of content, difficulty level, reliability, and validity. ADOS-2 data collected by authors contributing to this special issue highlight this point, noting that several of the items are still not interpretable, even when the test itself has been translated to ASL, and that a clinical interpretation of the child’s performance is necessary. Guidelines from *The Standards* also caution that if interpreters must be used, they should be fluent in both languages, have a basic understanding of assessment and its purpose, and should be educated as to their role in testing.

Furthermore, *The Standards* caution that behaviors that may appear typical in one culture may not appear typical when viewed by persons from another culture. Professionals unfamiliar with deaf cultural norms may misinterpret typical “attention-getting behaviors” (e.g., tapping the ground, waving in someone’s line of vision) or other behaviors (e.g., facial expressions, vocalizations, “blunt” statements) as inappropriate social overtures or responses. Likewise, many assessments may fail to capture elements unique to ASL users that provide rich clinical information pertinent to diagnosing ASD. For example, an assessment that was not developed for ASL users may not take into consideration features such as whether the individual is correctly producing signs rather than demonstrating atypical language features in ASL (i.e., palm rotation errors associated with ASD).³² Similarly, to date, no ASD assessments take into consideration whether the individual is correctly utilizing facial features as grammatical markers of ASL in a manner coordinated with their signing to communicate emotion or shifting their signing to represent perspective of different individuals about whom they are communicating, features of the language that may be impacted by ASD.^{35,52}

HELPING FAMILIES

Helping Families to Understand and Address Communication

Children with ASD are susceptible to impaired language acquisition, and children

with ASD who are D/HH are no exception. Children who are D/HH are a heterogeneous group and do not all share a common linguistic background: some are raised with a sign language, others are trained orally in a spoken language, and yet others are provided some combination of the two. A multifaceted approach to language and communication with children who have ASD and who are D/HH is warranted. Importantly, (1) language must be accessible to deaf children to be useful, and (2) children with ASD have particular deficits in visual attention that may limit their ability to attend to visually presented language (i.e., sign language as well as signs in combination with spoken language). Therefore, special efforts must be made to gain the attention of a child with ASD in order for language to be usefully perceived. This is an even greater challenge with children who are D/HH than with hearing children on the spectrum, because hearing children with ASD can still perceive spoken words even if they are not visually attending to the person speaking to them. Thus, although for many children who are D/HH visual communication is the most accessible form of communication, significant impairments in joint attention and social use of eye gaze may limit their ability to acquire sign language. Families may find it useful to employ augmentative or alternative communication devices as well as sign language, particularly for children who are minimally verbal. In addition, intervention to improve language should also target the underlying core deficit—that is, poor eye contact, joint attention, and motor imitation. Pure language interventions that fail to target the core deficit are not as likely to be successful.

Discussing Concerns with Families

Although it can be difficult to raise the possibility of an ASD to families, it is critically important to discuss this when providers notice atypical development or concerns (see red flags section). If we delay raising concerns or pursuing further diagnostic clarity, the children lose essential time to pursue interventions specifically targeting the core challenges in ASD.

Families may not have a lot of experience understanding how children who are D/HH typically develop language, play, and social communication skills. It is easy to want to believe a child's issues are solely related to the hearing loss. Families have already pursued understanding and acceptance about their child's needs in one area. Although it can be difficult to consider yet another identified need or label, families want to do what is best for their child. Therefore, even though a new journey is challenging to consider, families will often have the resilience to pursue the right type of help to see their children meet goals and milestones.

When discussing concerns with families, it is important to provide information in a kind and clear manner. Starting with a child's strengths can help families recognize that you see positive aspects of the child and family. It is also helpful to describe the attributes that you notice that might be attributable to hearing loss, as well as the attributes that you notice that are different than those shown by most children who are D/HH. It is important to recognize that children can look different in different settings. Exploring what families see as the child's strengths and needs can further help to guide the conversation. Exploring strengths and needs can help identify common areas for discussing what could be foundational challenges that need an intervention, beyond what has already been tried. Discussing next steps for further treatment options or diagnostic evaluations allows families, at the conclusion of the conversation, to feel like they know what to do next. Families may need time to process this new concern. Providers can let families know their availability to clarify information, answer questions, or restate next steps. Although resources for children with ASD who are D/HH are limited, guiding families to accurate information and networks of families with children who are D/HH with additional challenges can provide broader support. It is also important to indicate that the spectrum is broad; any information about autism spectrum should be filtered for what seems to apply to their child and to ignore aspects of information that does not seem to fit their child.

FUTURE DIRECTIONS

Assessment

Because no ASD diagnostic/screening tools have been validated for use with children who are D/HH, there are two competing schools of thought regarding assessment of ASD with children who are D/HH. One position argues that one should determine which tools are not reliable for use with children who are D/HH and discontinue their use in favor of developing tools uniquely designed specifically for the population. The other argues that there may be value in modifying current tools to be more appropriate for use with children who are D/HH. Colleagues in Great Britain are currently conducting research to adapt the ADOS-2 for children who are D/HH. Given the complexities involved in determining reliability and validity of instruments with a low-incidence population, both approaches have inherent challenges.

Several articles within this special issue allude to these different approaches for arriving at a clinical diagnosis of ASD. For example, the Mood and Shield article in this issue²⁸ describes the potential clinical use of modifying the ADOS-2 and interpreting results cautiously within the context of a battery of assessments. In their review of how ASD has been diagnosed in a clinical population, Szarkowski and colleagues (in this issue⁹) found that ASD diagnosis was most often arrived at by informed clinical opinion rather than use of ASD assessments not validated for D/HH. The variability in methods for diagnosing ASD among children who are D/HH suggests that moving forward, it will be imperative to develop a “clinical best estimate” approach specific to this population to enhance consistency in diagnosis across providers.

Intervention

A review of interventions for ASD with children who are D/HH is noticeably absent from this summary article, largely due to the limited literature in this area. The intervention research for children who are D/HH is limited primarily to small case studies.^{53,54} This issue contains a description of interventions and adaptations

when working with infants and toddlers who are D/HH (Thompson and Yoshinaga-Itano, in this issue).⁴ It is reasonable to expect that interventions documented to be effective with hearing children would be applicable to children who are D/HH.⁵⁵ However, adaptations and modifications may be necessary. Collaboration among professionals working with children with ASD who are D/HH will likely be critical to develop a body of case study evidence regarding the effectiveness of particular interventions and necessary adaptations for this population. In the meantime, parents and providers may access information regarding evidence-based interventions for ASD in the research literature as well as Web sites such as Autism Speaks (www.autismspeaks.org) and Autism Society (www.autism-society.org). Similar to the approach necessary for seeking assessment where often there are not professionals dually trained in ASD and deafness, it will likely be necessary to foster collaboration among ASD interventionists and deafness professionals involved in a child’s care.

It is our hope that disseminating this information in this special issue illuminating not only differences but also similarities between the presentation of ASD among hearing and children who are D/HH will assist professionals to develop confidence to *responsibly* assess and treat dually diagnosed children.

NOTES

Amy Szarkowski, Ph.D. and Deborah Mood, Ph.D. have contributed equally to this article and share co-primary authorship.

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