



Assessing Autism in Deaf/Hard-of-Hearing Youths: Interdisciplinary Teams, COVID Considerations, and Future Directions

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Abstract

Autism spectrum disorders are more prevalent in children who are Deaf or Hard of Hearing (D/HH) than in the general population. This potential for diagnostic overlap underscores the importance of understanding the best approaches for assessing autism spectrum disorder in D/HH youths. Despite the recognition of clinical significance, youths who are D/HH are often identified as autistic later than individuals with normal hearing, which results in delayed access to appropriate early intervention services. Three primary barriers to early identification include behavioral phenotypic overlap, a lack of “gold-standard” screening and diagnostic tools for this population, and limited access to qualified clinicians. In the current article, we seek to address these barriers to prompt an appropriate identification of autism by providing recommendations for autism assessment in children who are D/HH from an interdisciplinary hearing and development clinic, including virtual service delivery during COVID-19. Strengths, gaps, and future directions for implementation are addressed.

Keywords

autism, Deaf/Hard of Hearing, assessment, diagnosis

Autism spectrum disorder (i.e., “autism”¹) is a prevalent neurodevelopmental disorder estimated to affect up to one in 38 children ages 8 to 11 years (Maenner et al., 2023). Autism frequently co-occurs with numerous psychiatric disorders (American Psychiatric Association, 2013) and sensory differences, including auditory and visual (e.g., Kancherla et al., 2013). Despite the high rates of co-occurrence of autism and hearing differences, the process of assessing autism in children who are Deaf or Hard of Hearing (D/HH) remains complicated because of overlapping behavioral phenotypes (e.g., Shield, 2014), a lack of validated assessment measures for autism in D/HH youths, and a lack of clinical experts in both deafness and autism (Szarkowski, Mood, et al., 2014). In the current article, we outline the assessment process employed by an interdisciplinary team in a university-based center at an interdisciplinary D/HH autism clinic with the aim of distilling

more than 20 years of collective knowledge for the assessment of autism in D/HH youths. We also address assessment challenges related to COVID-19 and some of the mitigating strategies employed and discuss future clinical and research directions.

In the current article, “D/HH”² is defined as any type of mild, moderate, severe, or profound hearing levels that may benefit from audiologic intervention (e.g., hearing aids, cochlear implants) and alternate language modalities (e.g., Cued Speech, American Sign Language [ASL]). Hearing differences and autism coincide frequently; rates of autism in children who are D/HH are higher than rates of autism in the general population

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at comparison rates of 7% to 9% (compared with $\approx 1.7\%$ – 2% ; Kancherla et al., 2013; Van Naarden Braun et al., 2015). Approximately 50% of autistic youths have altered hearing levels (primarily sensorineural, including auditory neuropathy), a rate significantly higher than the reported 15% of nonautistic youths (Demopoulos & Lewine, 2016). High rates of autism in children who are D/HH may be due to comparable or shared underlying etiologies, such as prematurity (Stephens et al., 2012); in-utero developmental trajectories, such as congenital cytomegalovirus (Yamashita et al., 2003); or genetic syndromes, such as fragile X (McLennan et al., 2011), CHARGE syndrome (Hartshorne et al., 2005), Trisomy 21 (Richards et al., 2015), or Usher syndrome (Dammeyer, 2012). Thus, individuals who carry a dual diagnosis of D/HH and autism represent a substantial clinical population.

Despite the known high co-occurrence of these two conditions, children who are D/HH are slower to receive an autism diagnosis. D/HH individuals receive an autism diagnosis on an average of 3 years later than their hearing counterparts (Roper et al., 2003; Szarkowski, Flynn, & Clark, 2014). Average ages of diagnosis range from 66.5 months to 76 months (about 5.5–6.5 years; Meinzen-Derr et al., 2014), which is substantially later than the conservative national average of autism diagnosis of 38 months (about 3 years; Mandell et al., 2005; van't Hof et al., 2020). This discrepancy in age of first diagnosis can be attributed to numerous factors, including a complicated differential diagnosis (e.g., Hall et al., 2017); lack of validated, “gold-standard” assessments for autism in the D/HH population (Szarkowski, Mood, et al., 2014); and lack of clinician expertise (Mood & Shield, 2014). In fact, when reviewing retrospective charts of co-occurring D/HH and autism diagnoses, more than 60% of families indicated that the only reason they received an autism diagnosis was because of parents pursuing additional testing and referrals beyond those offered by medical providers (Szarkowski, Flynn, & Clark, 2014). As a result, parents of D/HH children experience delays in assessment and diagnosis, diagnostic uncertainty, and delays in accessing appropriate and tailored early intervention services (Young et al., 2019).

One of the first barriers to an earlier autism diagnosis in D/HH youths is the behavioral-phenotypic overlap, which can contribute to diagnostic overshadowing (Rosen et al., 2018). The similarity in several behaviors blurs the differential diagnostic, which can make clinical rule-outs or rule-ins challenging (Hall et al., 2017). Several behaviors have been observed in both populations, including language delays, limited show/give behaviors, poor use of integrated facial expressions and gestures, echolalia, idiosyncratic gestures, sensory-seeking

behaviors, distorted speech/intonation/volume, and poor response to name (Szarkowski, Mood, et al., 2014). These similar behaviors can often contribute to diagnostic overshadowing, in other words, explaining the behaviors as related to Deafness and ignoring the possibility of another etiology or contributing diagnosis. Although many behaviors overlap, there are behaviors observed in D/HH children that are distinct from those associated with autism that can be used to elucidate this diagnostic picture, such as eye contact, joint attention, interest in peers, and gesture use (Shield, 2014). For a detailed summary of overlapping and distinguishing behaviors, see Szarkowski, Flynn, and Clark (2014).

In the cases of overlapping behavioral presentations, clinicians rely on evidence-based, “gold-standard” assessments to derive sensitive and specific identification of disorders. However, with autism, no research has established best practices for assessing autism in D/HH youths. Common pipelines to identifying autism often begin with screening tools, such as those administered in pediatrician offices (e.g., the Modified Checklist for Autism in Toddlers [M-CHAT]; Robbins, 2008). Broadly speaking, most screening measures have demonstrated poor sensitivity and specificity in identifying autism in D/HH children, both overidentifying and underidentifying autism (e.g., M-CHAT and the Social Communication Questionnaire; Rutter, Bailey, & Lord, 2003; Szarkowski, Flynn, & Clark, 2014). Recent studies have identified other screener approaches with emergent validity for the identification of autism in D/HH samples, such as the MacArthur Bates Communicative Development Inventory (Fenson et al., 1993; which was used only in retrospective samples, Kellogg et al., 2014), the Language ENvironment Analysis Language and Autism Screen (only when paired with the social quotient from the Child Development Inventory, Carr et al., 2014), and an adapted version of the Social Responsiveness Scale (Constantino & Gruber, 2012), which removed two items, added a novel item, and still reported specificity rates of only 67% (Wright et al., 2020). In these studies, other co-occurring conditions such as attention-deficit/hyperactivity disorder and anxiety were not assessed, which are established confounds for reliable assessment on these screeners (e.g., Capriola et al., 2021). Therefore, even if children pass on these screening measures, it is recommended they be referred for a comprehensive evaluation.

Current “gold-standard” assessments for autism include the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012) along with a detailed developmental history often obtained using the Autism Diagnostic Interview, Revised (ADI-R; Rutter, LeCouteur, & Lord, 2003). Despite widespread use around the world, the ADOS-2 specifically states that it

was not intended for use with children with sensory differences, as is the case for D/HH children (Lord et al., 2012) because it relies on verbal speech to assess differences in social affect and communication and many D/HH children use a different communication modality (Mood & Shield, 2014). Even with these considerations in mind, several studies have characterized the use of the ADOS-2 to assess autism in D/HH children (Allgar et al., 2021; Holzinger et al., 2022; Mood & Shield, 2014). Groups who have administered the ADOS-2 in D/HH groups have transparently described the approaches they used during data collection in the absence of evidence-based modifications, which included task modifications (e.g., response to name) and scoring modifications (e.g., overall language level; Mood & Shield, 2014). Even with these modifications, the scoring paradigms change between modules, which makes the reliability and validity of the earlier modules (e.g., Modules 1 and 2) better compared with the later modules that rely more heavily on spoken language (e.g., Modules 3 and 4; Mood & Shield, 2014). Recent adaptations to the ADOS-2 for D/HH youths using sign language were evaluated in the United Kingdom by Phillips et al. (2022), which included both task and scoring modifications for Modules 1 through 4, including response to name, demonstration task, and the use of trained interpreters. Phillips et al. reported sensitivity and specificity between 71% and 79%, depending on the module. In an attempt to adapt the ADOS-2 for D/HH adults with intellectual disability, Holzinger et al. (2022) reported poor to excellent internal consistency, which additionally required expertise in deafness, intellectual disability, autism, and proficiency in signed languages. Finally, Wright and colleagues (2022) adapted the ADI-R for D/HH children suspected of autism with excellent sensitivity and specificity (89% and 81%, respectively). When used together, the Deaf-adapted ADOS-2 and ADI-R show excellent diagnostic specificity (e.g., reducing false positives) when relying on the autism cutoff values for both instruments (Allgar et al., 2021), thus underscoring the importance of capturing current behaviors in addition to a thorough developmental history. In summary, these studies demonstrate emergent validity to support Deaf-adapted measures of the ADOS-2 (Phillips et al., 2022) and ADI-R (Wright et al., 2022), both of which required the removal and addition of items, task modifications, and scoring modifications; these changes still require validation as a novel measure in groups with complicated medical and genetic co-occurrence. The specific works cited here (e.g., Mood & Shield, 2014; Phillips et al., 2022) have pioneered efforts in autism assessment modifications for Deaf youths who use a sign-based language modality. For parents who have chosen a

spoken-language modality or combination of modalities, some clinicians are uncertain how best to assess autism.

Because most clinics do not have access to the aforementioned adapted “gold-standard” measures, “in the absence of validated tools, best practice relies on informed clinical opinion” (Szarkowski, Mood, et al., 2014, p. 246), which contributes to the final barrier to an earlier diagnosis: a lack of knowledgeable providers. Because there is a dearth of providers who are trained in both autism and deafness, it comes as no surprise that there is limited diagnostic agreement when assessing for autism in D/HH youths (Mood & Shield, 2014). Taken together, the overlapping behavioral phenotypes, novel emergent validity for “gold-standard” assessments, and a lack of knowledgeable providers have resulted in diagnostic delays (or oversight) in D/HH samples. Because the most recent published collection discussing this topic was published in 2014 (Szarkowski, Mood, et al., 2014), in the current article, we seek to condense more than 20 years of experience in this domain and discuss the assessment of autism in D/HH youths using an interdisciplinary clinical model. In addition, we provide information on adjustments and accommodations related to COVID-19 and future directions for clinical assessment with this population.

Clinical Assessment

The Hearing and Development Clinic (HDC) at the University of North Carolina at Chapel Hill (UNC-CH) is an interdisciplinary clinic that operates out of the Carolina Institute for Developmental Disabilities (CIDD), which is based in the UNC-CH School of Medicine. For more information about the creation of the HDC and the CIDD, see Roush and Wilson (2013). The HDC assessment team meets twice per month and comprises a group of professionals with expertise in audiology, speech/language pathology, psychology, education, and occupational therapy. The physical clinic is equipped with closed-circuit video cameras, large conference rooms, and multiple testing rooms, including one that contains audiological equipment. A HIPAA-compliant Zoom platform is also used during virtual and in-person visits to coordinate a large, multidisciplinary clinic. Currently, the clinic primarily serves clients in infancy through the teen years, occasionally seeing young adults, and works with the entire D/HH spectrum. Approximately 85% to 90% of clients seen through the HDC are from families who have chosen a spoken-language modality as their primary means of communication and thus represent a unique sample from the D/HH spectrum that has not been previously discussed in relation to autism assessment.

Interdisciplinary team

The team of professionals at the HDC includes an audiologist and two speech/language pathologists, one who specializes in working with D/HH populations and is a certified auditory verbal therapist (who is proficient in ASL and Cued Speech) and another who specializes in developmental disabilities and alternative/augmentative communication (AAC) approaches. A child psychologist and learning specialist or school psychologist are also present. As needed, other providers, such as occupational therapists, are present to evaluate sensory and mobility concerns. Across all disciplines, graduate students are included as part of clinical training. In circumstances in which additional needs are present or behaviors warrant further evaluation as detected in the preclinical interview, other disciplines may also participate, including neurology, psychiatry, social work, genetics, and physical therapy. Parents and caregivers are also considered vital participants in the child's assessment. When invited by parents, the team also welcomes input from early interventionists, therapists, or teachers who have expertise in the child's care.

Evaluation components

Referral pipeline. The HDC primarily accepts referrals from pediatric-audiology colleagues at UNC Hospitals and the Children's Cochlear Implant Center at UNC. After more than a decade of training and collaboration with the HDC team, the pediatric-audiology and cochlear-implant teams are well versed in traits and behaviors commensurate with ASD in D/HH youths and commonly refer children at multiple steps in their hearing journey and with a wide range of hearing etiologies. Given the referral pipeline primarily originates from audiologists intervening with hearing aids or cochlear implants, a majority of families seeking an autism evaluation have chosen a spoken primary language for their child. Although, some people, especially individuals with more profound levels of Deafness or multiple disabilities, use a combination of communication modalities. For a brief description of clients referred, see Roush and Wilson (2013). The most common behavioral referral concerns are poor eye contact, reduced showing and giving behaviors, poor joint attention, reduced gesture use, slow development of language despite hearing concerns being fully addressed, lack of functional or creative play (or repetitive play, such as lining up or arranging toys), and co-occurring sensory concerns not related to hearing status (e.g., staring at lights, fans).

Assessment procedure. After a referral is received, families are contacted by a family advisor to obtain a

detailed case history and request information from the early intervention team, school, and other health-care providers. The family advisor, a role that rotates through the primary disciplines (psychology, education, speech), conducts a thorough review of the case history and supporting documents using a standardized summary form, found in Roush and Wilson (2013). The family advisor prepares the family for the structure of the day, which includes a full-day assessment and interpretive feedback session.

The day of the assessment, the full team meets for a preevaluation meeting and makes decisions about the order of assessments and the day's agenda. The day follows a typical schedule of preevaluation staffing, conducting direct assessments and parent interviews, lunch and a confidential team conference, and then continuing with direct assessment and parent interview. The family interpretive is delivered by the family advisor at the end of the day or a later date if necessary. In some cases (e.g., for early developmental assessments), assessments are administered arena-style (Foley, 1990), often with family members observing or directly involved in the evaluation. The lunch break acts both as a break for the client and family and as a way for the team to convene to discuss preliminary findings from the morning and determine the afternoon plan. The family receives a nontechnical summary of the findings and recommendations the same day; the full report, which runs an average of more than 20 pages, is generated 4 to 6 weeks after the appointment.

Measures. Throughout the full-day assessment, a multitude of measures are used in collecting a holistic, clinical picture of the child and the child's context. These measures include parent interviews, parent-report forms, standardized assessments, and semistructured play-based observations. In addition, teachers and interventionists from the child's care team are invited to contribute notes, qualitative observations, or teacher-report forms. Each discipline on the team uses clinical judgment in their measure selection based on the referral question, child demographics (e.g., age, language level), and family factors (e.g., language modality). The main areas of the assessment, including specific measures, are described below in alphabetical order. A flowchart depicting the typical chronological process of assessments, in addition to acquiring data about the individual's hearing and listening skills to inform the autism evaluation, is available in Figure 1.

Academic skills. Assessment of academic skills is conducted based on the referral concern, especially as it relates to the child's individualized education planning. Measures of academic skills are selected based on the

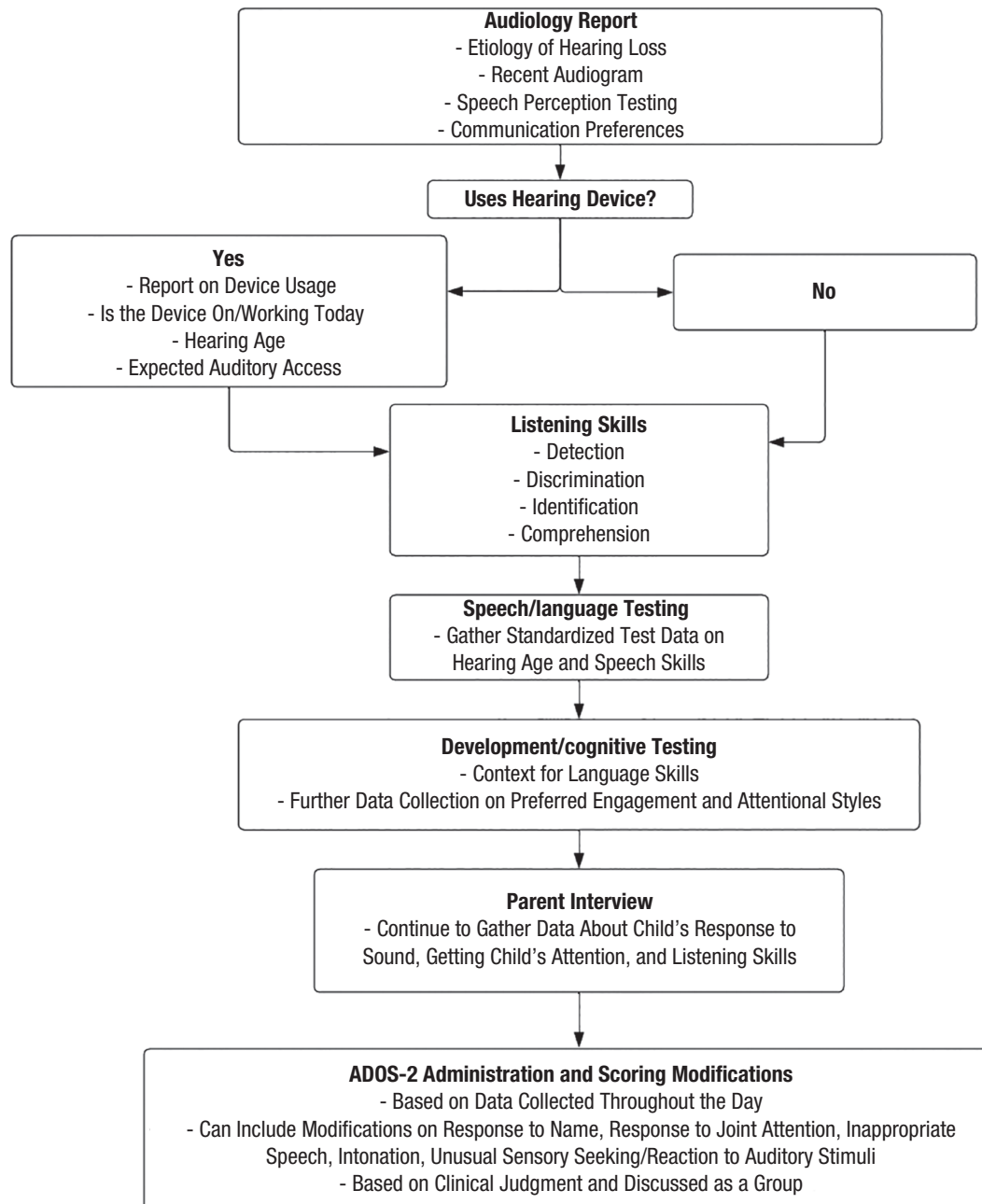


Fig. 1. Clinical flowchart depicting assessment process of determining testing accommodations based on hearing and listening levels.

referral, age, and communication modalities of the child. In addition, hearing level and use of hearing technology also affect test selection, administration, and interpretation. Common academic measures include the Bracken School Readiness Assessment (Bracken, 2002), Bracken Basic Concept Scale (Bracken, 2006), Kaufman Test of Educational Abilities (Kaufman et al., 2014), Test of Reading Comprehension (Brown et al., 2009), and Woodcock Johnson Tests of Achievement (WJ-IV; Schrank et al., 2014). Of the above measures, the WJ-IV

is commonly used in psychoeducational assessment with D/HH students because it includes manualized recommendations for administration and scoring/norming for D/HH students (Morere, 2020; Schrank et al., 2014). Many issues related to the development and use of standardized measures for D/HH learners exist related to both the heterogeneity of the population and the dearth of validated and normed measures; for an overview on the history of academic testing in D/HH youths, see Morere (2020).

Adaptive behavior. Measures of adaptive behavior are essential to understanding daily living skills and functional independence. Either the Adaptive Behavior Assessment System (ABAS; Harrison & Oakland, 2003, 2015) or the Vineland Adaptive Behavior Scales (VABS; Sparrow et al., 2005) parent-report forms are administered to the caregivers in their native language; interpreters are used as needed. Decisions on which adaptive measure to use are made clinically by the psychology team; both the ABAS and VABS are normed for autistic youths (Dupuis et al., 2021). Although the VABS has been validated in D/HH populations (Dunlap & Sands, 1990), the ABAS has shown greater sensitivity to floor effects in autism (Lopata et al., 2013) and is therefore used more frequently. Although some studies with D/HH autistic youths have measured adaptive functioning (e.g., Meinzen-Derr et al., 2014; or autism in CHARGE syndrome, Smith et al., 2005), no adaptive interview or parent-report form has been explicitly normed for use with D/HH youths with co-occurring autism. Although adaptive functions are important skills to assess in this population, little attention has focused on items from the VABS or ABAS that may not sufficiently measure skills in autistic, D/HH populations. For example, items asking about receptive language skills commonly rely on a listening response (Harrison & Oakland, 2015; Sparrow et al., 2005), which may be altered in this population. In addition, these adaptive measures often fail to recognize or include use of sign, Cued Speech, or AAC devices as adaptive skills. Taken together, a fair and valid use of these adaptive measures requires clinical interpretation and close examination of item-specific responses.

Audiology history and hearing status. A brief history of the child's hearing status and audiologic management is presented at the beginning of the interdisciplinary team meeting by an audiology doctoral student and supervising audiologist. Relevant history, including hearing status at birth, etiology of hearing loss, recent audiologic assessments, communication preferences, use of hearing technology (hearing aids/cochlear implants), and device usage, are reported. Clinically obtained speech-perception scores may be shared if poor speech-recognition ability could affect the validity of team assessments. The age of intervention or implantation is also discussed and considered for the assessment, including the potential for language deprivation as a factor of delayed intervention. The graduate student also provides a summary of known co-occurring conditions and/or syndromes. Communication strategies are often provided to the team, including emphasizing whether there is a better hearing ear to speak to and reiterating the need for clear and concise speech. It is always recommended to speak when facing the child to enhance the acoustics of speech and

reception of facial expressions and other visual cues. The audiology graduate student also discusses the hearing thresholds based on the most recent audiogram and consequent implications for assessment procedures, including anticipated responses to auditory stimuli (described in further detail below). The clinic has an audiology suite equipped to provide a full range of audiologic assessment procedures; however, most referrals to the HDC team are for children already receiving regular follow-up from their managing audiologist. Thus, audiologic assessment is not the priority during this evaluation, although parents are asked if they have any audiology-related concerns. In addition, the child's hearing technology is checked for adequate functioning before beginning the assessment.

Autism traits. In the assessment of autism traits, the ADOS-2 (Lord et al., 2012) is used as the primary semi-structured behavioral observation (conducted or supervised by providers who have obtained research reliability), paired with a detailed developmental history (described below). Although the ADOS-2 manual explicitly states it is not intended for use with individuals with sensory differences, it remains one of the best clinical tools when used in tandem with a developmental interview and thus has been used with D/HH individuals with adaptations.

For youths whose parents have chosen a sign-based language modality, administration and scoring adaptations are made in accordance with clinical recommendations (Phillips et al., 2022); further adjustments will continue to be made as more work is conducted with the ADOS-2 specifically for D/HH individuals. Importantly, ADOS-2 modifications reflect a nascent field that requires further study and validation; thus, the modifications that follow can be best described as clinically informed, not evidence-based. Administration accommodations include use of a sign-based language for administration, response to name, and initiating joint attention (or, measuring the child's response to joint attention). For response to name, standard verbal procedures are first used when calling the child's spoken name. If there is no response, which would be expected for a child with severe to profound hearing levels not using hearing technology, the clinician signs the child's name within their peripheral vision. If still no response, the clinician uses attention getters commonly used with individuals who sign, such as waving within sight (Phillips et al., 2022). Following those attempts, physical prompts such as shoulder taps were assessed. Although a lack of response to name is expected with profound hearing levels in children not using hearing technology, D/HH children would still be expected to respond to culturally appropriate ways of garnering their attention in the absence of autism (Phillips et al.,

2022). For the clinician initiating joint attention, instead of using the word “look,” the sign for “look” is used in its place. However, because the sign for “look” takes a similar approach as using a pointing gesture, it is not included in early presses for joint attention (Phillips et al., 2022). In addition, Deaf cultural considerations are encouraged when asking questions related to Modules 3 and 4, especially when relying on an interpreter in a sign-based language. For instance, asking what is different from a friend and someone you go to school with can be a challenging question in ASL or for an ASL interpreter to reliably convey. Scoring modifications for D/HH youths using ASL take into consideration the number of signs per utterance. When ASL is used, intonation is scored by measuring the rate of signing, precision of signs, mixed hand dominance, or signing errors. Unusual verbal sounds produced are not coded as atypical. Echolalia scores can be maintained when evaluating sign-based repetitions. When scoring for gesture use, formal signs are not included as gestures, but pointing and descriptive hand movements could still be scored. Finally, idiosyncratic/stereotyped speech is coded by evaluating overly formal sign-based language, palm rotation errors, or consistent use of a specific gesture when the sign is in the child’s known repertoire (Phillips et al., 2022).

For youths whose parents have chosen spoken language as a primary means of communication, representing the majority of clients assessed at the HDC, the ADOS-2 is administered using a standardized protocol (Lord et al., 2012) with additions and modifications as needed based on the child’s hearing status. Again, because this approach has not been validated in these populations, these protocols are best described as transparent descriptions of clinical processes used to date. When considering the ADOS-2 prompts, the team is concurrently considering the individual’s access to language. With recommendations from audiology team members (described above) and speech/hearing team members (described below), the team approaches the ADOS-2 with a baseline understanding of the participant’s level of auditory access and listening skills. Prepared with reports from the parents/caregivers, the clinicians usually have an expectation about which sound(s) the individual will respond to, including technology sounds (e.g., the music box) and speech/language sounds (e.g., response to name), while the individual gets acclimated to the room. Importantly, the clinicians need to gather a solid understanding of how to get the child’s attention, whether that be via sound, touch, vision, or a combination. The team also gathers information from parents/caregivers about the child’s preferred toys, ways of playing, and ways of interacting to facilitate the ADOS-2 and promote rapport. Scoring

modifications such as those addressed above (Phillips et al., 2022) are also considered; for example, unusual intonation is often not coded for Deaf individuals with cochlear implants given limited access to auditory information in guiding their intonation and speech patterns, which can contribute to atypical speech production and perception (Peng et al., 2008). Other considerations related to the etiology of hearing differences are also taken into consideration when scoring; for example, for etiologies related to facial nerves (e.g., Moebius syndrome), codes related to facial expressions are not coded. In sum, the ADOS-2 is used flexibly and in a nonstandardized manner to create situations in which behaviors commensurate with autism may be elicited or isolated. Although in most instances the ADOS-2 is scored in accordance with the manual, some ADOS-2 administrations with D/HH youths are simply used to generate behavioral observations and obtain qualitative information. A flowchart of clinical decision-making processes in determining best strategies to use on a case-by-case basis for assessing autism traits is available in Figure 1. As recommended in the manual, the ADOS-2 is only one of many tools used to assess for autism, and in the case of deafness, can be used similarly—as a clinical tool that, along with developmental history, behavioral screeners, and clinical judgment, can be used to inform a diagnostic question.

In addition to the ADOS-2, parent-report screeners to assess for difficulties related to social communication (based on language, child age) are often administered, including the Social Responsiveness Scale (Constantino & Gruber, 2012) and the Social Communication Questionnaire (Szarkowski, Mood, et al., 2014). As discussed in the introduction, most autism screeners demonstrate poor validity, either underestimating or overestimating autism in D/HH youths when considered independently (Wright et al., 2020). Thus, these measures are used in tandem with other parent-report measures and behavioral observations in collecting a comprehensive, clinical picture.

Behaviors. A broadband measure to address behavioral concerns and presentations is administered to the parents/caregivers in their native language by the psychology team. Measure selection is based on the child’s age, prior assessments, and clinical relevance. The two most common measures administered are the Behavior Assessment System for Children (Reynolds & Kamphaus, 2004) and Child Behavior Checklist (Achenbach & Rescorla, 2000, 2001), both of which provide scaled scores based on age and sex for internalizing and externalizing domains. Both measures have been validated for use with autistic youths (Bradstreet et al., 2017; Hoffman et al., 2016) and have been used in samples with D/HH individuals (e.g., Gouma

et al., 2011; Nassrallah et al., 2019), but neither are meant to be screeners for autism symptoms specifically. Because both measures are broadband screeners by design, they are used in tandem with the comprehensive evaluation to gain more data about behavioral presentations of the child; they are not used in the process of a diagnostic differential.

Cognition. Assessing the child's cognitive or developmental level is a standard practice for all HDC clients because understanding the level of functioning informs both the autism-specific assessment and recommendations for future intervention. Despite its global importance, intelligence testing with D/HH children and adults has a mixed history that includes inappropriate usage in determining "mental retardation" categories (Maller & Braden, 2011) and a lack of validated and normed measures for populations with different communication modalities and levels of hearing (Maller & Braden, 2011). Depending on the child's language level, age, and prior testing history, clinicians select an appropriate cognitive/developmental measure, which could include the Bayley Scales of Infant and Toddler Development (Bayley, 2009), Mullen Scales of Early Learning (Mullen, 1995), Leiter (Roid & Miller, 1997), or Differential Ability Scales (DAS; Elliott, 1990). On occasion and when warranted, other measures such as the Oregon Project (e.g., in the case of vision impairment; Anderson et al., 2007), Developmental Assessment of Young Children—Second Edition (Judith & Maddox, 2013), or Developmental Profile (Alpern, 2007) may be administered. Of these, the DAS and Leiter both include administration accommodation guidance and score interpretation guidance and have been normed with groups of D/HH youths (Reesman et al., 2014) and are thus preferable when appropriate. Importantly, because many of these items rely on language-based reasoning, greater emphasis is placed on the nonverbal subtests of the relevant developmental/cognitive assessment. Considerations when choosing a cognitive/developmental measure include the child's language modality, fluency, need for an ASL interpreter, and referral. The administration of measures is always in the child's preferred language. For a more nuanced discussion of intellectual-assessment considerations in D/HH populations, see Reesman et al. (2014).

Developmental history. The child's developmental history is gathered via a semistructured parent interview conducted by the psychology team in the parents' native language (and/or with an interpreter if needed). The developmental-history interview asks about a range of topics, including early signs of autism, developmental milestones, behavioral challenges (e.g., transitions, toileting, sleeping, eating, compliance, attention), medical

history, family structure and history, social history, educational history, current presenting concerns, and strengths. Occasionally, an abbreviated version of the Autism Diagnostic Interview, Revised (Rutter, LeCouteur, & Lord, 2003) emphasizing algorithm items will also be conducted during the developmental-history interview with the parents/caregivers.

Sensory processing. The Sensory Profile (Dunn, 1999) is commonly administered to a parent/caregiver by the occupational-therapy team to assess the child's sensory-processing differences and inform treatment recommendations. The short version, the Short Sensory Profile (McIntosh et al., 1999), has evidenced strong discriminant validity for autistic youths. D/HH youths, of course, may also present with sensory differences that may mask, work in opposition, or further accentuate differences related to autism (Alkhamra & Abu-Dahab, 2020), which makes reliance on this instrument for a differential diagnosis ineffective. Because of this phenotypic overlap and given empirical recommendation (Williams et al., 2018), total Sensory Profile scores are not used; instead, individual subtest scores are interpreted by considering item-specific elevations to inform treatment recommendations.

Speech, language, and communication. Common referral concerns for HDC clients include concerns about speech and language development, whether parents have chosen spoken language or a sign-based modality. Indeed, families of D/HH autistic youths report using a wide range of communication strategies, including spoken, sign, written, and other augmentative communication approaches (Wiley et al., 2013). The first step for the speech/language team is to get an understanding of the child's listening skills on the day of assessment. After the audiology team reports on hearing status, hearing thresholds, device usage, age of identification, and speech-perception results (described above), the auditory/verbal therapist evaluates the child's listening response using a battery of tools, including the Ling Six Sound Check (Advanced Bionics, n.d.), Learning to Listen Sounds (Estabrooks & Birkenshaw-Fleming, 1994), and environmental sounds (e.g., knocking on the door). If warranted, other standardized measures such as the Cottage Acquisition Scales for Listening, Language, and Speech (Wilkes, 1999) can also be administered to determine hearing age. These approaches allow clinicians to get an understanding of the child's ability to detect, discriminate, identify, and comprehend sounds (Estabrooks, 2006). The child's listening skills are continually assessed throughout the day. Following the auditory-skills assessment, the speech/language team can proceed to standardized speech and language testing (Fig. 1).

Depending on the child's age, language status, and referral concerns, the speech/language team selects

appropriate assessments emphasizing speech (e.g., Goldman-Fristoe Test of Articulation, Goldman & Fristoe, 2000; Khan-Lewis Phonological Analysis, Kahn & Lewis, 2002) or language (e.g., Preschool Language Scales [PLS], Zimmerman et al., 2011; Oral Written and Language Scales [OWLS], Carrow-Woolfolk, 1995; Clinical Evaluation of Language Fundamentals [CELF], Semel et al., 1995). Clinical decisions on which assessment to use is informed by previous literature suggesting empirical support for the PLS and CELF (for children with higher language levels) in D/HH autistic youths (e.g., Meinzen-Derr et al., 2014) and the OWLS for differentiation between autistic and nonautistic youths (Hartley et al., 2008). Importantly, clinical recommendations include using a language quotient or age equivalent because many measures have a floor of a standard score of 50, which may not provide a comprehensive picture of the client's language skills (Meinzen-Derr et al., 2014). If a client has limited spoken language and would benefit from communication modalities other than ASL or Cued Speech, a Communication Matrix (Rowland, 2004) is administered, and consultation regarding augmentative and alternative communication is provided.

Clinical conceptualization and recommendations.

Clinical conceptualization is an interdisciplinary and ongoing process throughout the full day of assessment. After testing is complete, a confidential team meeting is held with all disciplines present, and discussion begins with the child's strengths and behavioral observations. Each discipline shares test results and one to two tailored recommendations; after all disciplines have shared, diagnostic decisions are made by consensus using best clinical judgment in tandem with parent-report forms, developmental history, accommodated/adjusted autism evaluations, and behavioral observation. Importantly, each child is considered more than the sum of the individual assessment components, and thus test scores are not weighted as having the most importance when discussing diagnostic decisions. Throughout the day, children being assessed for autism are not penalized for items that may be consistent with their hearing levels (e.g., language delays, lack of response to name, speech abnormalities, mishearing of words), and consistent reminders are provided throughout the day to trainees related to this process. Differential diagnoses such as intellectual disability, global developmental delay, speech and/or language delay, apraxia of speech, learning disabilities, and attention-deficit/hyperactivity disorder (as an example) are also considered.

Recommendations are provided to families at two time points. First, condensed, immediate recommendations are provided during the interpretive feedback

(e.g., Medicaid waivers, parent support groups, psycho-educational materials, intervention approaches). The interpretive feedback with family members is conducted by the family advisor and begins by emphasizing the child's strengths, followed by test scores from standardized findings and formal diagnoses. Questions are encouraged throughout the interpretive feedback, which terminates with suggesting primary recommendations for the family. More detailed, discipline-specific recommendations are provided in the final comprehensive report. Recommendations are personalized to focus on functional outcomes, emphasizing goals and progress indications and school-based objectives and providing local resources targeted to the child's area of need.

COVID-19 Considerations

The HDC model described above was thrown off course by the introduction of the social-distancing rules and regulations resulting from COVID-19 starting in March 2020. As many services transitioned to a virtual space, HDC, too, pivoted to a virtual format. As clinics started reopening in 2021, several facets of the assessment procedure were altered to support social distancing and safe COVID-19 practices. Both the virtual visit and alterations to in-person assessment protocols are described below.

Tele-assessments

In the wake of COVID-19, the HDC team transitioned to virtual assessments, when possible, as indicated by parent interest and child age (younger children were prioritized because of assessment modality and available instruments). Whereas much of the above in-person assessment remained the same (e.g., parent-report forms, developmental history, and speech, language, and cognitive measures were obtained online if feasible), the main crux of the autism evaluation was affected by the inability to administer an ADOS-2. In its place, providers used a combination of caregiver-mediated tele-assessments (e.g., TELE-ASD-PEDS [TAP], Corona et al., 2020) and a clinician rating form, the Childhood Autism Rating Scale, Second Edition (CARS-2; Schopler et al., 2010). If needed, other measures such as a *Diagnostic and Statistical Manual of Mental Disorders* checklist with developmental anchors or the CARS-2 Questionnaire for Parents/Caregivers were administered (with careful consideration of sections related to hearing levels).

TAP. The TAP is a caregiver-mediated tele-assessment tool for use by providers and families (Corona et al.,

2020). In this assessment, the provider walks caregivers through several play-based tasks with their child in their home for approximately 10 to 20 minutes, during which the provider (and HDC team) watches and notes behaviors commensurate with autism (Corona et al., 2020). The TAP rates seven behaviors on a 3-point Likert scale wherein higher scores indicate more atypical performance. The TAP was designed for use with children under 36 months who have yet to acquire fluent speech and thus was appropriate for only a subset of children at HDC. During this time, only children who could be adequately evaluated with the TAP were seen at the HDC for virtual visits, which is a noted limitation. The TAP is a diagnostic instrument that, when used along with other diagnostic tools, demonstrates good reliability and validity and high clinician confidence and generates strong parent satisfaction (Wagner et al., 2021).

To our knowledge, no prior work has reported using the TAP in D/HH youths with ASD; D/HH youths were excluded from the norming process (Wagner et al., 2021). Clinically, during the TAP scoring process, item scores were summed to determine an overall score, which was evaluated using the standard cutoff recommendations. Administration accommodations were made in some cases, for instance, when parents are asked to call their child's name, as discussed above. Scoring accommodations were made where needed, particularly for the domain of "unusual vocalizations," which are common in D/HH youths (e.g., Moeller et al., 2007), and "socially directed speech," to include socially directed sign or other communication modalities. These changes were made on a case-by-case basis and have not been validated in the current sample, thus underscoring the importance of clinical decision-making with an interdisciplinary team who has expertise in this domain.

CARS-2. The CARS-2 is commonly considered a screening tool for ASD, comprising 15 items on a 7-point Likert scale completed by clinicians (Schopler et al., 2010). Scores on these items can be gathered from any source, including parent interview, direct observation, or cognitive testing. Reliability and validity are reported to be satisfactory to good (Malcolm, 2014). The CARS-2 has been used with individuals with sensory differences (e.g., de Vaan et al., 2018) and CHARGE syndrome (e.g., La Spata, 2020) but has not been validated for use with D/HH individuals.

The interdisciplinary team co-scored the CARS-2 for youths who were above the age cutoff for the TAP (e.g., 36 months+) as the final measure of the day, after observations from the testing session, scoring the parent-report forms, and observing the developmental parent interview. In the scoring paradigm that followed and in the absence of evidence-based recommendations,

clinicians relied on clinical expertise when discussing how individual items and the entire measure should be scored. The majority of codes on the CARS-2 did not require adjustment or accommodation because of deafness with the exception of the listening-response code. Listening response is coded "based on the person's response to sounds and how the listening response is coordinated with the use of other senses," which includes response to name and over- or underinterest in sounds (Schopler et al., 2010). Given the inappropriateness of this code for D/HH individuals, it was evaluated on a case-by-case basis or excluded from the scoring paradigm.

In-person, COVID-19 modifications

After the return of in-person services, several COVID-19 specifications remained, which altered the standard assessment protocol described above. Primarily, the use of personal protective equipment (PPE) and social-distancing requirements slightly altered the assessment approach. The structure of the day remained the same as it did before COVID, including the providers on the team and the family visiting the clinic in person. Before arriving at the clinic, the family conducted a COVID-19 screener asking about current health, prior travel, and known exposures. All clinical rooms were equipped with high-efficiency particulate air filters. Providers and family members wore PPE, which comprised KN95 grade or higher masks for the parents/caregivers (provided in the lobby) and KN95 grade or higher masks and eye protection for the clinical providers. Youths were not required to wear masks if they were unable to do so. Note the potential impact that mask wearing has on comprehensibility given the nonnegligible acoustic attenuation observed with masks, primarily in the high-frequency range (Martarelli et al., 2022). Although the medical-grade masks worn during the assessment preserve more acoustic properties than community masks (Martarelli et al., 2022), the sound attenuation was an important clinical feature to note during the assessment process and clinical reports, especially when working with D/HH youths. Finally, to reduce the number of providers in the large conference rooms and with the family, some team members conducted virtual interviews with family members on HIPAA-compliant Zoom with the family members in a private clinical room.

Additional modifications were made for specific testing, such as the ADOS-2 and speech and language testing. Providers and interpreters working directly with the child for these assessments wore clear paneled masks to allow for optimal visibility of the mouth, lips, and facial expressions. Although the use of masks or

face shields for the ADOS-2 has been advised against because of likely achieving slightly different clinical information (e.g., Lord, 2020), the use of transparent masks and goggles for an in-person assessment was, for many families, preferred over a virtual assessment and/or more appropriate for older youths than conducting a virtual autism play-based assessment with caregivers. If the child was able to wear a mask during the assessment, the caregivers were asked permission for the child to remove their mask during the ADOS-2 to evaluate the child's facial expressions or wear a child-sized clear mask. Otherwise, if the child remained masked in a way that blocked access to facial expressions, certain aspects of the ADOS-2 codes were scored a 0, including codes related to directing of facial expressions and social smiling, in addition to the in-person administration and scoring accommodations described in the sections above. The write-up of the ADOS-2 indicated that it was conducted in a nonstandardized fashion with the use of PPE (clear masks and goggles) and thus scored accordingly. Despite this nonstandardization, ample clinical information was derived from the ADOS-2 and full-day assessment to inform clinical judgment and diagnoses.

Summary

Comprehensive, interdisciplinary assessment of neurodevelopmental disorders should always be a flexible and adapted process based on the family, clinical presentation, and referral concerns. This is especially important when working with children who are D/HH. Although several standardized instruments exist for the specific and sensitive detection of autism in the presence of other co-occurring conditions, standardized measures cannot replace clinical conceptualization and decision-making. Although some of the procedures outlined in the current article diverge from standardized protocols and have yet to be systematically evaluated as evidence-based recommendations, clinical measures applied judiciously that provide behavioral data and observational opportunities in a culturally sensitive way can be helpful when well-established standardized instruments are not yet available. When relying on clinical expertise, it is crucial to ensure the assessment is equitable and culturally sensitive, which can be helped by ensuring the team of providers is well versed in D/HH culture, knowledgeable in multiple communication approaches, and collaborating over the course of the entire assessment. The HDC team views cultural competence as an ongoing value and integrates knowledge and training from Deaf community families, experts in Deafness, and providers who use a sign-based language, Cued Speech, or AAC approaches. The HDC

team also seeks continual professional development, including ADOS-2 trainings specifically tailored to working with D/HH populations. Ideally, all assessments would be conducted by Deaf experts or D/HH individuals (Phillips et al., 2022); however, until these topics are covered in educational programming for trainees, further research is warranted on the impact of clinician knowledge and D/HH expertise on the validity of autism evaluations in this demographic.

Challenges and benefits

The approach described above has numerous challenges and benefits when considering both the clinicians' and family's perspectives. For families, traveling across the state can result in long days of travel or overnight stays. The testing environment is largely unfamiliar to the child, which can be exhausting, especially with a long day of testing. Especially when considering the multiple co-occurring conditions that characterize many of these clients, a full day of testing with unfamiliar adults can result in behavioral challenges and fatigue. Clinically, standardized measures are often inappropriate for this demographic, which requires teams to adapt existing measures. As discussed in the introduction, some measures are better tailored to D/HH youths than others (e.g., a developmental interview is easily adaptable; the ADOS-2 is not as easily adaptable). Because of a lack of resources unique to the geographic region, many services the family may benefit from are not available, such as consultation regarding AAC. From the team perspective, interdisciplinary evaluations are time-consuming and expensive. Assessments of this nature are most likely to be feasible in university and children's hospital environments where there is a broad mission that includes teaching and research to afford these larger, interdisciplinary teams to operate. Space is also a challenge given that clinics would be required to have two to three testing rooms, a large conference room, and the infrastructure to support the interdisciplinary team conducting arena-style assessments. Finally, as indicated by the limited referral pipeline, many more children present with needs that unfortunately cannot be accommodated, which serves as a call to action to other clinics, universities, and hospitals.

Despite these challenges, there are numerous benefits to an interdisciplinary-team approach, as has been observed in other interdisciplinary autism clinics (e.g., Prelock et al., 2003). Families can obtain expert opinions from several professionals in a single day, which reduces confusion and frustration with conflicting advice. A full day of multiple disciplines affords the family to get a holistic understanding of the child,

paired with tailored recommendations for overall growth and wellness. Clinically, interdisciplinary approaches increase cross-disciplinary collaboration and learning, and including graduate students and other trainees provides benefits from a training perspective. Globally, teams of this nature can address an important, unmet need of the area.

Future Directions

As evidenced by limited training opportunities, challenges to the assessment, and lack of standardized assessment protocols for this demographic, there are numerous future directions for researchers and practitioners. First, increasing educational opportunities and knowledge of autistic traits in D/HH children is imperative to reduce the discrepancy in age of diagnosis. Training opportunities should be made available to clinicians conducting psychodiagnostic assessments, audiologists who may be the frontline providers working with this demographic, and researchers who are working at these intersections. Of course, we also recommend these topics be covered and discussed in educational programming preparing future clinicians and providers given the prevalence of these overlapping phenotypes. Second, additional research must be conducted on modifications and adaptations for standardized assessments, in particular the ADOS-2, for D/HH groups, as is being conducted by Phillips and colleagues (2022) in the United Kingdom. In the absence of standardized measures and clinical trainings, it is imperative for interdisciplinary teams to connect and learn from one another to continue to develop and improve on best practices.

Locally, extending the referral pipeline for professionals and clinicians in other domains will help reduce the barrier to assessment and early diagnosis of autism in D/HH youths. The HDC hopes to forge extended collaborations with other statewide partners, such as the North Carolina Department of Public Instruction. Furthermore, interdisciplinary clinics such as the HDC are called to systematically evaluate the outcome and impact of clinical operations in a reproducible way to (a) replicate in other locations, (b) generalize to novel patient demographics, and (c) provide training and clinical procedures to other institutions aiming to adapt these approaches.

Transparency

Action Editor: Tina M. Lowrey

Editor: Interim Editorial Panel

Declaration of Conflicting Interests

The author(s) declared that there were no conflicts of interest with respect to the authorship or the publication of this article.

Funding

T. C. McFayden was supported by a training fellowship from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (2T32 HD040127-21).

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Acknowledgments

We are grateful to all the families who participated in clinical services at the University of North Carolina at Chapel Hill Carolina Institute for Developmental Disabilities and University of North Carolina at Chapel Hill Children's Cochlear Implant Center. Jackson Roush and Jean Mankowski are co-senior authors. No portion of this work has been previously presented.

Notes

1. Identity-first language (e.g., "autistic") is used instead of person-first language (e.g., "person with autism") to be consistent with clinical and research recommendations (Bottema-Beutel et al., 2021; Kenny et al., 2016). Historically, autism spectrum disorder (ASD) has been described from a medical lens in accordance with diagnostic frameworks (e.g., diagnostic statistical manual). Recent works, however, have underscored the importance of understanding autism from a neurodiversity framework, including avoiding disorder-based language such as "autism" instead of "ASD," "traits" instead of "symptoms," and "co-occurring" instead of "comorbid."
2. The term "D/HH" is used to encompass the entire spectrum of children with varied hearing levels per recommendations from the Joint Committee on Infant Hearing (Year 2019 Position Statement, 2019). In accordance with these recommendations, the term "hearing loss" is replaced by "hearing levels" or "D/HH" where appropriate.

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