Interdisciplinary Assessment of Children With Hearing Loss and Multiple Disabilities

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Abstract

Meeting the complex needs of children with hearing loss and multiple disabilities requires the expertise of several professional disciplines. This article describes an interdisciplinary Hearing and Development Clinic at The Carolina Institute for Developmental Disabilities at the University of North Carolina-Chapel Hill professionals and graduate students with expertise in audiology, speech-language pathology, psychology, education, and physical/occupational therapy see children and their families.

Many children who are congenitally deaf and hard of hearing face additional challenges related to one or more neurodevelopmental or related disabilities. These conditions include autism, intellectual disabilities, social-emotional disorders, sensory integration dysfunction, visual impairment, motor delays, and learning differences. Meeting the complex needs of these children requires the expertise of professionals from multiple disciplines. Unfortunately, families whose children have complex needs often encounter difficulty obtaining an accurate diagnosis or an appropriate treatment plan (Roush, Holcomb, Roush, & Escolar, 2004; Wiley, 2012; Wilson & Roush, 2012). Indeed, the Joint Committee on Infant Hearing, in its most recent position statement (JCIH, 2007), cites lack of specialized services for children with multiple disabilities and hearing loss among the most important challenges for the future development of successful early hearing detection and intervention (EHDI) systems.
In an effort to address this need in our state, a group of professionals at the University of North Carolina-Chapel Hill with expertise in audiology, speech-language pathology, psychology, education, and physical/occupational therapy recently created an interdisciplinary Hearing and Development Clinic (HDC) at The Carolina Institute for Developmental Disabilities. The mission of this clinical program is to provide an interdisciplinary evaluation for children with hearing loss whose families or service providers suspect additional challenges or disabilities. The program accepts referrals from pediatric audiology colleagues at University of North Carolina (UNC) Hospitals and UNC’s pediatric cochlear implant team. Professionals and graduate students from several disciplines see children and their families for a full-day evaluation. In this article, we share our experience with this new clinical program; encourage other institutions to consider developing similar programs where needs exist; and invite dialogue from colleagues already engaged in interdisciplinary team assessments for children with hearing loss and other disabilities.

**Conditions and Disabilities That Occur With Hearing Loss**

Gallaudet University’s Research Institute (GRI) has been collecting demographic, audiological, and educationally relevant information on children with hearing loss since 1968 through its Annual Survey of Deaf and Hard of Hearing Children & Youth (Gallaudet Research Institute, 2011). One component of the GRI survey asks respondents to identify “educationally relevant conditions for which a child has been referred and diagnosed.” As summarized in Table 1, more than 60% of the children represented in the survey had no apparent disabilities in addition to hearing loss, but the remainder, nearly 40%, includes a variety of comorbidities that range in severity from life-threatening conditions at birth to relatively mild learning differences that are not apparent until school age. The most prevalent conditions, as categorized by GRI, include intellectual disabilities (8.3%), defined as significantly impaired general intellectual functioning that exists concurrently with deficits in adaptive behavior impacting a child’s educational performance; learning disabilities (8%), which include disorders specific to reading, writing, or mathematical calculations and including perceptual disabilities, brain injuries, minimal brain dysfunction, dyslexia, and developmental aphasia; and developmental delays (5.3%), which, for the purposes of this survey, include children younger than 9 years of age with special needs related to physical, cognitive, communicative, adaptive, or social-emotional development. “Other health impairments” (5.8%) include conditions that adversely affect a child’s educational performance or educational environment because of limited strength, vitality, or alertness related to a chronic or acute health problem. Common diagnoses associated with this classification are asthma, diabetes, and seizure disorders. Wiley (2012) notes that for some of these conditions the prevalence is similar to that of the general population, whereas others appear to occur more frequently in children who are deaf and hard of hearing.
Table 1. Summary of Conditions That Co-Occur With Hearing Loss, Based on the 2009-2010 Regional and National Summary of Deaf and Hard of Hearing Children and Youth (N=37,828).

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>Deafness with no other disabilities</td>
<td>61.1</td>
</tr>
<tr>
<td>Low vision</td>
<td>3.8</td>
</tr>
<tr>
<td>Legal blindness</td>
<td>1.7</td>
</tr>
<tr>
<td>Developmental delay</td>
<td>5.3</td>
</tr>
<tr>
<td>Learning disability</td>
<td>8.0</td>
</tr>
<tr>
<td>Orthopedic impairment</td>
<td>4.4</td>
</tr>
<tr>
<td>ADD/ADHD</td>
<td>5.4</td>
</tr>
<tr>
<td>Traumatic brain injury</td>
<td>0.3</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>8.3</td>
</tr>
<tr>
<td>Emotional disturbance</td>
<td>1.8</td>
</tr>
<tr>
<td>Autism</td>
<td>1.7</td>
</tr>
<tr>
<td>Usher syndrome</td>
<td>0.2</td>
</tr>
<tr>
<td>Other health impairment(s)</td>
<td>5.8</td>
</tr>
<tr>
<td>Other conditions</td>
<td>8.5</td>
</tr>
</tbody>
</table>

Note: Percentage total is greater than 100 because multiple responses were permitted (Gallaudet Research Institute, 2011)

When congenital hearing loss is first detected and there are no other concerns or obvious medical conditions, the emphasis is, understandably, on the diagnosis of hearing loss and the application of hearing technology such as amplification or cochlear implantation. But it is clear from the GRI survey and other sources that congenital hearing loss is frequently accompanied by a variety of conditions and comorbidities that occur alone or in combination (Perigoe & Perigoe, 2004). The diagnosis of these conditions is, in our experience, often delayed. Indeed, the decision to develop the new interdisciplinary clinic at UNC was motivated in part by our pediatric audiologists, whose observations revealed developmental concerns that were not being adequately addressed.

Clinical Setting

The Carolina Institute for Developmental Disabilities (CIDD), based in the UNC School of Medicine, was established in 2007 by merging several longstanding UNC programs that provided clinical service, research, and personnel preparation related to serving the needs of people with developmental disabilities and their families. The Institute brings together research teams from multiple disciplines for collaboration on a range of disorders and underlying mechanisms, with the overarching aim of translating basic science and clinical research to real-world interventions in the clinic and community. The Institute is one of only a few centers in the United States that combines the collective resources of three federally funded programs: a University Center for Excellence in Developmental Disabilities (UCEDD), a program in Leadership Education in Neurodevelopmental and Related Disabilities (LEND), and an Intellectual and Developmental Disabilities Research Center (IDDRC).
**Format for Interdisciplinary Assessments**

At this time, we only accept referral to the Hearing and Development Clinic from audiologists at UNC; specifically, from UNC Hospitals where audiology diagnostic services are provided and where approximately 700 children with hearing aids are followed by a team of pediatric audiologists. We also accept referrals from UNC’s Carolina Children’s Communicative Disorders Program, where approximately 600 children with cochlear implants are followed by a team of physicians, audiologists, speech-language pathologists (SLPs), auditory-verbal practitioners, and early childhood specialists. Although the needs in our state extend well beyond our own patient populations, we lack the capacity at this time to accept outside referrals. The children referred to the HDC by our UNC colleagues are those that clinicians, parents, or in many cases, both, worry may have undiagnosed conditions or disabilities.

Families interested in pursuing a team evaluation must complete a detailed case history and request additional information from the child’s early intervention team or school, as well as other service providers. Once we receive the case history and supporting materials, a member of the team reviews the presenting concerns to determine which professional disciplines are needed (Table 2). Once the professional disciplines are identified, a “family advisor,” who serves on a rotating basis, conducts a thorough review of the case history and supporting documents using a standardized summary form distributed to team members prior to the assessment (see appendix A). Even for a young child, the case histories often are lengthy and complex. The pre-assessment summary is more efficient than having each team member review the entire chart, although individual team members examine the records pertinent to their areas of expertise. On the day of the assessment the team meets for a pre-evaluation staffing led by the family advisor. The team makes the final decision at that time regarding the order of assessments and the day’s agenda.
Table 2. Core members of UNC’s Hearing and Development Team.

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>SLPs (2)</td>
<td>The primary SLP is a Listening and Spoken Language Specialist (LSLS) Certified Auditory-Verbal Therapist (AVT) who specializes in pediatric hearing loss. When there are concerns related to autism or augmentative and alternative communication (AAC), a second SLP who specializes in autism spectrum disorders and AAC participates in the team evaluation.</td>
</tr>
<tr>
<td>Audiologist</td>
<td>The audiologist assists in coordinating referrals and provides a summary of the child’s hearing loss, hearing history, and use of hearing technology. Because referrals come from UNC audiologists the team evaluation does not include an audiologic assessment.</td>
</tr>
<tr>
<td>Learning Specialist</td>
<td>For children at a prereading level or school-age, a learning specialist provides an educational assessment and recommendations.</td>
</tr>
<tr>
<td>Child Psychologist</td>
<td>A psychologist is responsible for cognitive assessment and diagnosis of social-emotional disorders; recommendations are made based on the outcome of these assessments.</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>An occupational therapist assesses sensory processing/integration, fine motor skills, and self-regulation.</td>
</tr>
<tr>
<td>Physical Therapist</td>
<td>A physical therapist evaluates balance, mobility, strength, coordination, and motor planning as well as positioning of the child during the evaluation.</td>
</tr>
<tr>
<td>Other</td>
<td>Based on the outcome of the evaluation some of the children are referred to other CIDD teams such as the Behavioral Medicine Clinic which draws on the combined expertise of psychologists, developmental pediatricians, and a child psychiatrist.</td>
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The morning assessment is typically done “arena-style” (Foley, 1990) with family members observing from an observation room or closed-circuit video. In some cases parents or caretakers are directly involved in the evaluation. At about noon the family takes a lunch break and the team convenes to discuss the morning and determine if additional assessments are needed. The team also begins drafting a same-day summary report (see appendix B). The team typically conducts 1 to 2 more hours of additional assessment in the afternoon. At the end of the day, the family advisor and one or two other professionals meet to provide a “family interpretive,” which consists of a nontechnical summary of our findings and recommendations. Students observe the interpretive on closed circuit video. The conferences can be emotional and upsetting to parents when the team delivers news related to the diagnosis of autism or an intellectual disability. In other cases, if our findings are consistent with the parents’ expectations or with a previous diagnosis, the conference may provide a sense of relief. The team implemented the same-day report to provide a succinct summary for parents, family members, and professionals in advance of the full report which may run 30 pages and require 3–4 weeks for completion.

Summary of Children Referred

At the time of this writing, 31 children have been seen in HDC. They have ranged in age from infancy to mid-teens and have come from a variety of urban and rural communities in North Carolina. The families were made aware of the HDC by their UNC clinicians and all were
receptive to having their child seen for interdisciplinary assessment, either because they had concerns that were not being adequately addressed or because they lacked confidence in an earlier diagnosis. Most of the children have been from English speaking homes, but we have seen several children whose first language is Spanish. The hearing losses have ranged from mild to profound; most are cochlear in nature but we have seen 7 children with a diagnosis of auditory neuropathy spectrum disorder. Most are using amplification or a cochlear implant; however, some are not receiving benefit from either technology. A few have had hearing losses associated with a known syndrome or comorbidity; others have unknown etiology. The children have used a variety of communication approaches including formal and informal sign systems although over half were judged to have no formal communication system.

**Evaluation Outcomes**

The team’s primary focus on the day of evaluation is to address the concerns and questions identified by the child’s family and service providers. In some cases, the family is seeking a second opinion to confirm or reject an existing diagnosis, while other families seek evaluation to address ongoing questions or new concerns about their child’s communication abilities or behaviors. Occasionally, following initial interactions, team members may notice particular behaviors or “red flags” indicating the need for an additional evaluation that was not discussed during the initial parent conference. For example, in two recent cases the child displayed characteristics of autism, but the parents elected not to proceed with an autism evaluation. In contrast, two other children presented with a diagnosis of autism but did meet criteria based on our assessment. These examples serve to emphasize the critical need for an interdisciplinary team with expertise in a broad range of developmental disabilities.

Most of the children referred to our team have demonstrated severe language delays or disorders and several have required further evaluation for augmentative and alternative communication (AAC). In most cases a clinical setting is not optimal for AAC evaluations. Rather, assessment is needed in multiple settings such as the home, school, and other places where the child spends time. In these cases, our team has made general recommendations with referrals as needed. Finally, for children with obvious concerns related to attention and activity level, the team has referred families to CIDD’s Behavior and Medicine Clinic which provides joint assessment by a clinical psychologist and a child psychiatrist.

**Challenges and Benefits**

Team assessments, although advantageous in many ways, create a number of challenges for the child and family. Most families must travel some distance to Chapel Hill, which means either an early morning departure or an overnight stay. Once they arrive, the child is faced with unfamiliar people in a new environment. These conditions would be challenging for many typically developing children, but for a child with special needs they can create anxiety and apprehension. Full-day assessments also are fatiguing for many children making it difficult for the team to evaluate children at their best. Even if a child is comfortable in an unfamiliar environment, diagnostic assessment of children with special needs is a complex and multifaceted endeavor. Standardized measures often are inappropriate for these children, and clinicians must adapt existing measures to obtain diagnostic information related to cognition, language, vocabulary, speech, auditory skill development, phonemic awareness, and phonological processing. Assessment of cognition and intelligence are approached carefully and conservatively to avoid an inaccurate diagnosis that could result in lowered expectations, an inappropriate educational placement, or both. Likewise, a diagnosis of autism requires team consensus based on results of the Autism Diagnostic Observation Schedule and careful interpretation of test items that are dependent on hearing. Regrettably, we lack the resources to accept referrals for comprehensive AAC evaluation since this would usually require several team members to travel to the child’s natural environments.
Interdisciplinary team evaluations are inevitably time-consuming and expensive. Although some team members are able to see other patients during the day, several must commit a full day. This results in several unreimbursed hours of service on the day of the assessment, plus additional time involved in consultation with team members and students, report writing, and follow-up. Another challenge, even in a large tertiary care medical center, is access to specialized expertise when and where it is needed. For example, there was a period when the team was without an occupational therapist. This hiatus, although temporary, underscored the critical role of occupational therapy in assessing these complex children. Having the appropriate clinical space for team evaluations is another challenge in many settings. We are fortunate to have space at the Carolina Institute for Developmental Disabilities designed for this purpose. Clearly, interdisciplinary assessments of this nature are most likely to be feasible in universities and children’s hospitals where there is a broad mission that includes teaching and research.

When interdisciplinary assessment is possible, there are many benefits for families, students, professionals, and the institution. Families are able to obtain expert opinions from several professionals on a single day. This is not only advantageous from a logistical standpoint, but more likely to produce a consensus of opinion. Many of our families have shared the frustration they have experienced with conflicting advice from multiple evaluations conducted in separate facilities. Students benefit from opportunities to see interesting patients under the mentorship of experienced clinicians; clinicians enjoy the satisfaction and challenges associated with delivering specialized services in an interdisciplinary environment; and the university is able to address important unmet needs in our state.

Conclusions and Future Directions

The team perspective provides valuable insights regarding the impact of hearing loss on learning and development. For these complex children, because case history information or assessments from other service providers may yield conclusions that differ from those of our team, we have come to avoid explicit expectations before observing and assessing the child. The interdisciplinary environment also has contributed to a more holistic understanding of the child and an appreciation that each child is more than the sum of his or her individual evaluations. One of the most important things we have learned is that additional conditions, disabilities, and comorbidities may be overlooked because symptoms displayed are attributed to hearing loss, especially in cases involving autism, attention deficit hyperactivity disorder, sensory dysfunction, or lack of communication development. An interdisciplinary hearing and development team requires core expertise in deafness, communication, psychology, learning, and, in many cases, occupational and physical therapy. We are reminded frequently that test scores are not an end in themselves, but tools for intervention planning and the development of functional goals. Above all, we have learned that experienced professionals can become confident in evaluating children with hearing loss even if they don’t have a background in deafness. This is a key point and one we believe is relevant to other clinics and centers seeking to expand their capacity to serve children with hearing loss and multiple disabilities.

In the future, our focus will be even more intensively directed toward ensuring that recommendations are aimed at functional outcomes, and that our recommendations are useful to the educators and clinicians who work with the child and family. As Wiley (2012) observes, the goals and timelines for children with complex needs will differ significantly from those of their typically developing counterparts, but when achievements occur and progress can be measured, the rewards may be even more satisfying.

Another goal for the future is to examine more systematically the outcomes of our team assessments and their impact on the child and family. An important initiative now underway involves formalizing our partnership with the North Carolina Department of Public Instruction. Because the children seen are all enrolled in state-sponsored intervention and education
programs, collaboration with local and regional service providers should strengthen our assessments and facilitate implementation of our recommendations. Related to that goal, future plans include a teleclinical component that should enable timely and effective consultation with families and local service providers. Teleclinical resources also could be used to provide technical assistance to other interdisciplinary teams seeking to expand their capacity to assess children with hearing loss. Finally, there is an on-going commitment to securing the financial resources needed to further develop and sustain our program in the future.

Hearing loss with multiple disabilities requires a team of specialists committed to individualized, interdisciplinary assessment and intervention. Unfortunately, access to such assessments is limited for many families. Although there are no studies we are aware of that address this issue specifically, anecdotal reports from parents and professionals indicate that families often have a difficult time locating comprehensive interdisciplinary evaluation services, and that findings and recommendations from individual service providers can be contradictory. Although the challenges involved in developing and sustaining a hearing and development clinic are many, the collaborative efforts of audiologists and speech-language pathologists, in partnership with specialists from other professional disciplines, are needed to ensure that each child's developmental outcomes are achieved to the fullest extent possible. Acknowledgements

The authors gratefully acknowledge the many contributions of our colleagues on the Hearing and Development Team at the Carolina Institute for Developmental Disabilities: Margaret DeRamus, Emily Furgang, Katie Ollendick, Jean Mankowski, and Donna Yerby.

Comments/questions about this article? Visit SIG 9's ASHA Community and join the discussion!

References


# Appendix A. Sample HDC Chart Review

<table>
<thead>
<tr>
<th>Name: Jane ___</th>
<th>MR #:</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOE:</td>
<td></td>
</tr>
<tr>
<td>DOB:</td>
<td></td>
</tr>
<tr>
<td>Age: 2 years 11 months</td>
<td></td>
</tr>
<tr>
<td>Notes: See scanned documents regarding: Expressive and Receptive communication examples and Annual assessment through NC EI Program</td>
<td></td>
</tr>
<tr>
<td>Parents’ names/address/phone:</td>
<td>Siblings: None</td>
</tr>
<tr>
<td>Referral source and reason for referral: CCCDP Audiologist/Parent</td>
<td></td>
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<tr>
<td>Questions/Concerns: Jane is starting preschool in the Fall, and parents want to make sure they are “doing everything to help her.” Specific concerns include:</td>
<td></td>
</tr>
<tr>
<td>• Motor delays (not walking yet)</td>
<td></td>
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<tr>
<td>• Learning how to communicate with others, especially unfamiliar people</td>
<td></td>
</tr>
<tr>
<td>• Social skills, i.e., engaging in appropriate play with peers his age</td>
<td></td>
</tr>
<tr>
<td>• AugCom usage</td>
<td></td>
</tr>
<tr>
<td>• Mom also notes sleep difficulties – wakes up at 4:30 AM and may or may not go back to sleep.</td>
<td></td>
</tr>
<tr>
<td>Expectations: To learn more strategies about how best to help Jane.</td>
<td></td>
</tr>
<tr>
<td>Difficulties/Challenges: Jane was diagnosed with CHARGE syndrome at birth and has significant medical and developmental challenges as a result, including:</td>
<td></td>
</tr>
<tr>
<td>• Profound hearing loss</td>
<td></td>
</tr>
<tr>
<td>• Communication difficulties</td>
<td></td>
</tr>
<tr>
<td>• Motor and other global delays</td>
<td></td>
</tr>
<tr>
<td>• Jane also has a tracheostomy and a g-tube for feeding (diet is Nutren Jr. w/ Fiber) since</td>
<td></td>
</tr>
</tbody>
</table>
Jane has trouble with swallowing, chewing, and gagging

- Vision difficulties (bilateral optic nerve coloboma)
- Multiple hospitalizations and surgeries since birth including:
  - Tracheostomy – 11/2009
  - G-tube 12/2009 and revisions of g-tube an Mickey button (04/2010)
  - Tubes in both ears 06/2010
  - Heart catheterization – 07/2010
  - PICC line placement – 03/2011
  - Cochlear implant in his right ear at Chapel Hill – 02/2011 (mother reports Jane is hearing “normal speech sounds” and alerts to sounds)

Jane is followed by several specialists, is on a variety of medications, and uses a nebulizer routinely

Other Issues: Parents or mother may need to be in the room during testing. Jane mostly uses sign to communicate and while parents understand her, it’s harder for unfamiliar adults to understand. Testing history also indicates separation difficulties and difficulties with engaging with new, unfamiliar adults.

Strengths: Loves to explore and learn new things, has a sweet laid-back temperament, has made consistent progress in various therapies, able to communicate with signs, can communicate needs and wants to parents most of the time.

School Information/Early Intervention History

School/El History (when were services first sought? Why? When did services begin? Which ones?)

Children’s Developmental Services Agency (CDSA) evaluation at 3 months of age due to CHARGE syndrome.

Qualified for NC Infant-Toddler EI services and has received CAP-C services since.

School Placement: STEPS Developmental program, since (month/year); is in the pre-K classroom; attends 2 days per week for ½ day each

Current Services:

Has an IFSP and is well-connected in terms of current services. All services received since month/year.

- Occupational Therapy (Hippo Therapy) – 2x week 60 mins (Early Bird Developmental).
Services)

- Physical Therapy – 2x week 60 mins
- Speech & Language – 2x week 60 mins (Child & Family services)
- Vision – 1x week 60 mins (Gov. Morehead School)
- Hearing – 1x week 60 mins (DPI)
- Play therapy – 1x week 60 mins

**Intervention/School Concerns:** Teacher notes some concerns with doing what is asked, responding to simple commands, seeking help, working in a group, social skills with peers, transitions, and safety awareness. She also notes some concerns with physical activity and mobility and definite concerns with communication skills.

**Previous Evaluations**

(For each, please provide date, who completed evaluation, why, and general results that includes list of tests and scores/age equivalents)

Please see assessment summary at the end.

**Additional Information**

**Developmental/Birth History:** Born at 41 weeks by C-section, weighing 7 lb. and 3 oz. Had breathing difficulties, infection, and feeding difficulties at birth. Stayed in the hospital for 3 months after birth.

**Family History:** Mother has “mild LD” but nothing else noted

**History of any genetic testing?** None noted other than diagnosis of CHARGE at birth

**Please provide a background and referral information summary for the report:**

Jane is a nearly 3 year old girl with significant medical issues (CHARGE Syndrome, Trach, and g-tube, profound hearing loss, and other global delays). She is tube fed Nutren Jr. with Fiber, attends the STEPS developmental programs in ___, NC, and is starting pre-school soon. Parents would like to get an overall estimate of functioning and know how to help Jane best when she starts pre-school. They have significant concerns regarding “all areas” - walking, communication with others, peer play, and AAC. Jane has an IFSP and receives EISC and developmental monitoring through the NC Infant-Toddler program.

Jane was initially referred to the CDSA by his/her mother when she was 3 months old due to concerns about how his/her congenital anomalies might impact developmental progress. Parents knew prenatally that she had only one functioning kidney, but did not know about all the other complications leading to a diagnosis of CHARGE syndrome until after birth. Parents note no behavioral concerns and they describe Jane as “laid-back.” She is an only child. Teacher notes some concerns with aggression, age-appropriate behaviors, and anxiety, and definite concerns with doing what is asked, responding to simple commands, seeking help appropriately, safety awareness, working with other kids etc. Jane is on a number of medications and nebulizer in addition to the feeding tube, and is followed by numerous specialists.
Parents have provided a list of hospital stays/surgeries. The mother has also included a very nice sample of expressive and receptive communication, and there are updated notes from the SLP and evaluation reports from PT, OT, vision, and speech in the chart.

Initially referred to the CDSA in (month/year) by the mother due to concerns about how CHARGE may affect overall development. Initial CDSA assessment at 3 months demonstrated global delays on the ELAP and was determined eligible for NC-Infant Toddler Program. Showed developmental progress on the ELAP during follow-up at 9 months and 15 months, especially in cognitive and fine motor functioning. Delays still evident in gross motor, speech-language, self-help, and social-emotional functioning, although still improved. Hearing, vision, and language deficits that were a function of CHARGE negatively impacted testing performance.

A CDSA updated eval dated __ (age 2 years,10 months) notes that the mother is most concerned about Jane's ability to communicate with others in new situations and safety issues. On the Bayley-3, she achieved a composite of 65, (age equiv: 18 months). However, they note that based on “valuable information provided by his/her OT and mother,” Jane’s skills may fall more between 22-24 mo of age. They also did a VABS, but have not reported scores. Instead, they have qualitatively described strengths and challenges in each domain. In general, it was noted that all test results be interpreted with caution since Jane was minimally interactive with the clinician and testing items, and most conclusions were drawn based on the mother, OT-, and home health nurse reports. The CDSA concluded that her global delays are secondary to his/her CHARGE syndrome. The family already appears to be well-connected to a number of appropriate services, and the CDSA recommended continuation of most of the services already in place in preparation for his/her transition to preschool.
Appendix B. Sample Same-Day Report, Hearing and Development Clinic

Name: John ___  DOB: Age: 13:6  Date:

Following is a brief summary of your child’s evaluation at CIDD to share with family members and service providers. A detailed report will follow in 3-4 weeks.

KEY CONCERNS:

John ___ was seen at the CIDD Hearing and Development Clinic for evaluation due to concerns about challenging behaviors and lack of communication development. His mother, Ms. ___ also requested assistance regarding planning for his future. John’s moderate to severe bilateral sensorineural hearing loss was diagnosed in ___ and he was fitted with hearing aids which he has worn at school but not at home. John was diagnosed with fetal valproate syndrome and underwent heart surgery at one week of age. He has a history of seizure disorder, visual impairment, and hypotonia.

ASSESSMENTS COMPLETED:

- Leiter International Performance Scale-Revised (Leiter-R) Brief IQ
- Mullen Scales of Early Learning(Mullen) – Visual Reception subtest
- Vineland Adaptive Behavior Scale—Survey Form (Vineland)
- Test of Auditory Comprehension of Language-3rd Edition (TACL-3)
- Informal Augmentative and Alternative Communication (AAC) assessment
- Parent interview
- Informal observation

FINDINGS:

- Results of the Leiter-R, a non-verbal cognitive assessment indicated a moderate intellectual disability (318.1). Performance on the Mullen-Visual Reception subtest, part of a developmental assessment indicated problem solving skills at approximately a 29 month old level.
- Parent report on the Vineland indicated overall adaptive behavior abilities in the Low range, with relative strengths in domestic and coping skills and relative weaknesses in communication, community skills, and play and leisure time.
- The TACL-3 could not be completed due to inconsistent responses; however, it was confirmed that John exhibits a mixed receptive and expressive language disorder (315.32).
- John did not respond to environmental sounds or speech sounds presented, consistent with his diagnosis of sensorineural hearing loss (389.18).
- Because John presented with multiple characteristics of an autism spectrum disorder, an autism assessment was warranted. To assess autism symptoms, the ADOS-2 was administered to John, and his mother and grandmother were interviewed about John’s communication, social reciprocity, and restricted and repetitive behaviors. Results of this assessment indicated that John meets criteria for autism (299.00).
- Aided language strategies were attempted. John intermittently attended to the examiner as she modeled the use of aided language boards within activities. He also imitated the use of these boards and appeared to understand that they were a means to request an action from the examiner within the activity; however, it was not clear that he understood the actual meaning of vocabulary selected. An iPad was also introduced to John to determine whether he
might benefit from a touchscreen device for educational or communication purposes. He demonstrated some understanding of cause and effect, activating a program by touching the screen; however, he had some difficulty isolating a finger to select items or to drag items across the page.

- In sum, the team determined that John meets criteria for autism and intellectual disability, both of which contribute to his lack of communication development and challenging behaviors.

**RECOMMENDATIONS:**

- Contact Mr. __ ____, the principal at ___ Middle School, to relay John’s recent diagnosis of autism and to inquire about changing his school placement to one of the ___ classrooms. John requires a classroom environment that is highly structured, both physically and visually.
- Contact your local TEACCH to relay John’s recent diagnosis of autism and to request consultation regarding structuring the home environment and determining John’s interests.
- John will benefit from the use of visual structures (e.g., picture schedules, choice boards) both at home and in the school setting. Such structure provides understanding of daily schedule, tasks, and the expectations related to each activity.
- In addition, use of a multi-modal communication approach (e.g., pictures, signs, gestures, and objects) is recommended. Information about aided language communication will be provided in the full report as well as information about software for his touchscreen computer at home.
- Ms. ___ may wish to consult with John’s case manager about obtaining a medical identification bracelet for John that includes his identification information and the contact information for his mother and primary caregivers. An ID bracelet will help keep him safe in the event of an emergency or if he becomes separated from his family or caretakers. The following websites have examples of such medical ID bracelets: http://www.roadid.com/kids/ and http://www.americanmedical-id.com/
- The ARC offers guardianship options and may provide assistance for developing legal documentation <address and phone number>
- The parent advocate at the ___ County Chapter of Autism Society of North Carolina http://autismsocietyfc.org/ may be able to recommend professionals (e.g., dentists, pediatricians) who work well with people with autism.

**FOLLOW UP PLAN:**

Please contact Dr. ___ at (919) 966-5171 if you have questions. You will receive a detailed report in 2-4 weeks.

Sincerely,

*Signature of Team Leader*