

Understanding the Needs of Children Who are Deaf/Hard of Hearing Plus

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Abstract

Children who are deaf or hard of hearing (deaf/HH) have a high rate of additional disabilities. Understanding developmental progress and recognizing when children are showing different rates of progress is helpful to intervene more effectively for a child's broader needs. Focusing on functional skill development, strong partnership with parents and clinicians from broad professional backgrounds can allow a stronger approach to intervention for children with complex needs. Being creative and innovative can assist in the identification of strategies to support a child's progress and successes.

Additional disabilities in children who are deaf or hard of hearing (deaf/HH) are fairly common, with rates reported as high as 40%. The term Deaf/HH Plus has been used to guide a positive perspective on this group of children. Specific additional disabilities in children who are deaf/HH occur at a higher rate than the general population. Table 1 compares rates of disabilities in children who are deaf/HH to the rates in the general population. This population of children has unique challenges. The complicating factors of the impact of hearing loss and an additional disability can make it challenging to plan an approach to effective intervention. Our goal should be to focus on children achieving their maximum potential. The rewards are great when children make progress, even if not at the rate of typically developing children.

One possible reason for this higher rate of disabilities among children who are deaf/HH is due to the presence of risk factors for hearing loss which are also known to be associated with developmental delays. Additionally, some syndromes associated with hearing loss can impact broader development. It is important to rec-

Type of Disability	Rate of disability in Children with Hearing Loss	Rate of disability in the General Population
Intellectual Disability	8.3%	0.71%
Cerebral Palsy	17-30% of children with cerebral palsy have hearing loss); 4.4% with orthopedic problems	0.39%
Vision Impairment	5.5%	0.13%
Autism Spectrum Disorders	7%	1%

Table 1: Rates of specific disabilities in children who are deaf/HH and the general population (Adapted from Boyle et al. 2011; Gallaudet Research Institute, 2011).

ognize that sometimes children can have risk factors for developmental delays which are unrelated to hearing loss, such as a family history of developmental problems. Risk factors for developmental delay can co-occur in children with hearing loss. Thus, the cause of their hearing loss doesn't "protect" them from other factors which can impact development.

Typical Developmental Progression

It is helpful to understand typical child developmental progression and recognize when children who are deaf/HH are not following this developmental trajectory. Although, hearing is an important aspect to consider in understanding how children learn language, developmental progression is largely about early brain development. In the first two years of life, there is exponential head growth. This growth is due to rapid changes in brain development and a rapid increase in neuronal connections that are made in early childhood, coupled with myelination. Myelination is the development of white matter around the nerves to help the signaling and messages to travel through the neural connections. Although many have considered the first three years of life as a critical window for child development, learning continues to occur after this period. In fact, myelination of the brain occurs into early adulthood (mid-20's).

Much of child development is based on a specific progression of brain development, and thus is fairly predictable in typically developing children. Environmental factors can impact development as well (Board on Children, Youth and Families, 2002). For example, early experiences allow children exposure to activities to support learning. Early Head Start programs have shown beneficial developmental gains for children when starting school with improved Kindergarten readiness (Roggman, Boyce & Cook, 2009). The interplay of genetics and experiences impacts brain development and how a child learns.

Motor Development

There is a broad foundation of understanding of the attainment of specific developmental milestones. These general premises also apply to children who are deaf/HH with just a few different considerations. For example, motor development follows a specific progression. In general, children who are deaf/HH should follow a similar developmental trajectory. There are a limited number of reasons why this would not occur, including inner ear malformations, vestibular problems, or vision impairment. If a child who is deaf/HH does not have a rational reason for motor delay, further work-up and evaluation may be warranted for brain-based or muscular problems.

Motor development is an orderly and predictable sequence which is initially built on a foundation of multi-sensory input with touch and vision followed by

proprioceptive and vestibular input. With motor movements repeated over and over, motor patterns are learned and next skills can be acquired. In general, motor skill development proceeds from head to toe and proximal to distal. Although, the continuum of motor development is not always smooth, there should be symmetry in motor movements and a general progression in skill development over time. When development of motor skills are atypical (i.e. not just delayed from the general skill progression), this can indicate more significant motor problems such as cerebral palsy.

Gross motor development is not a good proxy for cognitive development, as children with mild intellectual disability often have age appropriate early gross motor milestones and children with cerebral palsy may have significant motor impairment with intact problem-solving.

Cognitive Development

Cognitive capability is often more predictive of language capabilities as compared to the presence of a specific disability label (Meinzen-Derr, Wiley, Grether, & Choo, 2011). The exception to this premise is when a disability label has substantial impact on communication development such as in children with autism spectrum disorders. There are a number of theoretical frameworks for cognitive development in children. Piaget described an early foundational framework to provide an understanding of how children learn. In infancy and toddler years, children learn through sensori-motor exploration. Children then move into the pre-operational stage, relying on language as a way to learn about the world. Children understand the world through their own experiences. As children begin to approach early elementary ages, the concrete operational stage provides more logic and reasoning skills. This stage is followed by more abstract reasoning, including inductive and deductive reasoning, noted in the formal operations stage. (Augustyn & Zuckerman, 2009).

In general, using non-verbal measures of cognitive development are most appropriate for children who are deaf/HH when trying to understand cognitive capacity (Braden, 1992). For children who are deaf/HH, a strong language foundation is important for language-based problem solving. Thus, as higher abstract reasoning skills are required, the interplay of language and cognition on how children learn can allow us to develop an understanding of a child's strengths and use this to support learning in areas which are more challenging.

Language Development

Language developmental trajectories for children who are deaf/HH present with more challenges in understanding when a child may be experiencing a language disorder which is not merely due to the degree of a child's hearing loss. With the successful implementation of universal newborn hearing screening and improved early identification of hearing loss, children are obtaining language skills in the average range (Kennedy, McCann, Campbell, Law, Mullee, et al. 2006; Vehaert, Williams, Van Kerschaver & Desloovere, 2008). With this realization of improved language outcomes, we should be compelled to recognize when children are not making appropriate progress.

It is appropriate to consider key questions when determining next steps if a child is not making appropriate language progress such as: What is the impact of hearing on language development? Do our interventions allow access to language development? Is the communication environment able to support the child's language needs? These questions provide guidance related to amplification, effectiveness of communication approach, and sufficiency of the language environment. In addition to these questions, one should consider whether there are unexplained or atypical patterns of language development. When a child has good comprehension but poor speech, consideration of an expressive language or speech sound disorder may be appropriate. Some children also have considerable language processing challenges. Monitoring development of non-verbal communication, gestures, and pragmatic language is also important and can be a red flag for broader social-communication problems. It is reasonable to expect that a child's language level should approach their non-verbal cognitive capacity. However, if we are unaware of a child's potential, our interventions could under-estimate appropriate goals for progress.

Appropriate Goals and Functional Skill Development

Unfortunately, children who are deaf/HH plus are often compared to typically developing children who are deaf/HH. This comparison may not provide meaningful information to guide interventions and expectations. It may be more helpful to consider what hearing children with similar developmental abilities can achieve to assist in goal-setting and monitoring of progress. Most importantly, we should guide intervention for individual

growth and not over-estimate or under-estimate a child's capacity to learn.

The role of functional skill development and quality of life may be particularly relevant for this group of children. Functional auditory skills have been highlighted in children who are deaf/HH, but broader functional skill development has been largely ignored. Functional skills focus on broad-based whole child needs and are defined as a child's ability to perform essential daily tasks in the areas of self-care (eating, dressing, bathing), mobility (changing positions, movement in space at home and community), and social cognition or social function (communicating basic needs, problem solving, social interaction with peers) (Msall, 1996).

This perspective can broaden our understanding of a child's strengths and needs and help determine next areas for focusing intervention. Partnering with families to prioritize a child's needs is important in children with complexities. The number of different interventions and therapies which may be suggested by professionals can be unrealistic and become overwhelming to families. This may detract from the family's most pressing needs.

Partnerships and Team Building

Children who are deaf/HH plus benefit greatly from strong team collaboration. There can be barriers to effective team work, particularly if professionals work within different systems of care (educational settings, private therapy practices, hospital-based services). Strong collaboration can bring the team members in alignment and improve knowledge across disciplines.

Based on a focus group on the needs of children who are deaf/HH with autism spectrum disorders, participating professionals indicated a number of strategies which they found helpful in building a collaborative team across settings (Wiley, Meinzen-Derr, & Gustafsen, 2013). Although, they recognized that having time to spend in team meetings or in communication with other professionals is not a "billable service," it is important to determine ways to effectively communicate among professionals and with families and include family participation in this communication system. Technology may serve as one mechanism to enhance communication, such as through a communication notebook, blog, or internet group. Families have also indicated their desire for strong and consistent communication from those working with their child (Wiley, Gustafson & Rozniak, 2013). Professionals also indicated they look for specific characteristics in team members, such as willingness

to share information, flexibility, respect and sensitivity, awareness of limits, ability to think outside the box and be open-minded, and showing a commitment to follow-through.

Based on these results as well as the philosophy helpful to strive towards common goals, use active listening strategies, communicate effectively, and be open to trying new ideas and strategies. When thinking outside the box, if we recognize the limitations in knowledge and expertise, and are open to new ideas, we can enhance the care and interventions for these children with complex needs.

Conclusion

With the high rate of additional disabilities in children who are deaf/HH, it is important to recognize the developmental patterns that children exhibit over time. As development is ever-changing due to on-going brain development, monitoring progress and discussing concerns if development seems to be progressing at a different rate or atypical pattern than most children can help expand the services and strategies important for children to achieve their maximal capabilities. Partnering with families to identify supports and adaptations is particularly important for this complex group of children.

The quote from Candace Lindow-Davies, from the Minnesota Hands and Voices chapter, is an appropriate concluding reflection:

Deaf/hh Plus is meant to be a positive term, not in any way negative or insensitive to the child who has medical issues along with hearing loss. In fact, I see it as an "A+" or "B+," meaning the child carries additional positive qualities. But it is a gift that needs to be carefully unwrapped. And it may not appear to be a gift when you first receive it. Time helps you appreciate, understand and unfold the possibilities. And the "Plus" most often means the child and family has added responsibilities and requires additional expertise. (<http://www.cohandsandvoices.org/plus/index.html> accessed 12/28/13)

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