

## **Implications of Language Deprivation for Young Deaf, DeafBlind, DeafDisabled, and Hard of Hearing Children**

**\*Note:** This paper will use the term “deaf” as a shorthand term to refer to people who may identify as Deaf, DeafBlind, DeafDisabled, and Hard of Hearing.

### **Leading Issue**

Based on existing research literature, “many deaf children - perhaps as many as 70% - are deprived of language.”<sup>1</sup> Such deprivation is more prevalent among deaf children from Black, Indigenous, and Persons of Color (BIPOC) families and communities<sup>2</sup>. Language deprivation is a devastating reality for many deaf children, and must be addressed as a serious and urgent health crisis.

Parents and families of deaf children are often misguided by medical professionals about the process of language development as it pertains to spoken and signed languages. The misguidance from medical professionals often convinces parents and families of deaf children that they must select one form of language to ensure efficient language development and communication. However, this is incorrect, especially when many people around the world thrive educationally and intellectually when they are educated in or exposed to two or more languages from birth. Despite the benefits of providing children with multiple language input, medical professionals with no training in the language development of deaf children often tell parents and families that providing these children with spoken language is their only hope. Due to this incorrect information from their doctors, parents and families often end up selecting a spoken language to teach their children. The decision of families to only use spoken language with deaf children too often results in language deprivation for these children.

It is imperative to prevent language deprivation in all deaf children, and this requires addressing the usual reliance on auditory input for language acquisition. As a result, it is important to utilize “active prevention” to mitigate any possibility of language deprivation in each deaf child. “Active prevention” is defined here as the systematic structures used to ensure that deaf children are exposed to language in all forms necessary to avoid language deprivation. Parents, families and professionals need to actively prevent language deprivation within deaf children starting at birth, particularly through the newborn hearing screening process. The responsibility of active prevention continues well after that initial experience in infancy, meaning that every provider, professional, advocate, organization, and program who comes in contact with the family then becomes equally responsible to actively work toward preventing language deprivation for each deaf child.

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<sup>1</sup> Dougherty, E. (2019). Getting the word in. *The Brink*. <https://www.bu.edu/articles/2017/asl-language-acquisition/>.

<sup>2</sup> Murray J, J., Hall, W. C., & Snoddon, K. (2019). Education and health of children with hearing loss: The necessity of signed languages. *Bulletin of the World Health Organization*, 97(10), 711-716. doi: 10.2471/BLT.19.229427.

The purpose of this document is to outline a foundation on which systematic policy can be altered to better ensure the prevention of language deprivation in a deaf child, from birth to adulthood. This document focuses on providing language exposure and acquisition to young deaf children from birth to five years old. For more information about K-12 education for school-aged deaf children, please look through the NAD's [various resources](#) for this age population.

## Examining Language Deprivation

### Background

The term “language deprivation” is used in different ways by different stakeholders, which can lead to confusion and misunderstanding. This document adopts and adapts a conceptual framework proposed by Dr. Matt Hall, which aims to distinguish language deprivation itself from its consequences and from its causes (both proximal and distal)<sup>3</sup> (Hall, M., 2022).

***Defining language deprivation.*** “Language deprivation” can be defined as the lack of developmentally-appropriate proficiency in any natural language. “Developmentally-appropriate” refers to achieving milestones commensurate with chronological age combined with any other factors that would be expected to influence language acquisition. Such lack of developmentally-appropriate proficiency in any language can range from mild to extreme.

***Consequences of language deprivation.*** The lack of strong language skills acquired by children within the first five years of their life typically has adverse consequences in many domains across the lifespan. In young children between birth and five years of age, this often manifests as delays in cognitive development (including executive function & theory of mind), social-emotional development, and school readiness. In school-age children, weak first-language skills compromise the development of literacy and numeracy, which can limit educational achievement. The related delays in cognitive and social-emotional development can hinder the formation of strong relationships with family members and peers, and even self-identity and self-esteem. According to modern day interpretations of the Erikson model of development, the development of relationships during early years, otherwise referred to as the sensitive periods of development, shape the growth of identity and social-emotional regulation.<sup>4</sup> The inhibition to fully develop language at earlier stages of life hinders the domain-general learning trajectory. In adulthood, the cumulative impact of these factors contributes to disparities in physical and mental health outcomes and quality of life. Here again, the impact can range from mild to

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<sup>3</sup> Hall, M. (2022, March 14). Accurate and unbiased information about language outcomes: How would we know? [Conference Presentation]. EHDI 2022 Conference, Virtual.

<sup>4</sup> Tayler, C. and N. Sebastian-Galles (2007), "The Brain, Development and Learning in Early Childhood", in *Understanding the Brain: The Birth of a Learning Science*, OECD Publishing, Paris, <https://doi-org.ezp-prod1.hul.harvard.edu/10.1787/9789264029132-12-en>.

extreme, with more serious cases meeting emerging diagnostic criteria for Language Deprivation Syndrome.<sup>5</sup>

***Proximal cause of language deprivation.*** It is important to distinguish proximal and distal causes. The proximal cause of language deprivation is a lack of accessible linguistic input in the child's environment during early childhood. Although a deaf child may be immersed in an environment where spoken language is plentiful, their hearing levels may not be sufficient to support access to that spoken input, even when combined with early and consistent use of appropriate hearing technologies. As a result, children with varying hearing levels (including minor or unilateral levels) can still struggle in an auditory-only environment.<sup>6</sup> Deaf children whose environment contains little to no visual input are likely to experience language deprivation.

***Distal causes of language deprivation.*** It is important to examine why there is a lack of accessible language input in the child's environment. There are many possible answers. Despite the implications of the phrase "language deprivation" (including one common American Sign Language translation), most parents do not intentionally deprive their children of language. While many parents do intentionally decide to *not* include sign language as part of their child's experience, this is usually because they have been led to believe that using only spoken language will provide their child with accessible and adequate input. Data shows that this belief is incorrect and many deaf children who receive only spoken language input are actually deprived of language acquisition.<sup>7,8</sup> This misguided belief is a result of various factors including but not limited to the perspectives held and expressed by professionals, family-based organizations, other families with deaf children, public health systems, and the predominantly negative attitudes that society espouses toward disability in general (ableism) and deafness in particular (audism). These perspectives hold that it is better to prioritize learning to hear and speak over learning a language that is neither heard nor spoken. As such, spoken language outcomes are typically the top priority; even when sign languages are included, they are often viewed as merely a tool for supporting the development of spoken language as the ultimate goal. The NAD views these systemic issues as the root cause of language deprivation within deaf children across the United States.

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<sup>5</sup> Hall, W. C., Levin, L. L., & Anderson, M. L. (2017). Language deprivation syndrome: a possible neurodevelopmental disorder with sociocultural origins. *Social psychiatry and psychiatric epidemiology*, 52(6), 761–776. <https://doi.org/10.1007/s00127-017-1351-7>.

<sup>6</sup> Nassrallah, F., Tang, K., Whittingham, J., Sun, H., & Fitzpatrick, E. M. (2020). Auditory, social, and behavioral skills of children with unilateral/mild hearing loss. *The Journal of Deaf Studies and Deaf Education*, 25(2), 167–177. <https://doi.org/10.1093/deafed/enz041>

<sup>7</sup> Hall, W. C. (2017). What you don't know can hurt you: The risk of language deprivation by impairing sign language development in deaf children. *Maternal Child Health Journal*, 21(5), 961–965. doi: 10.1007/s10995-017-2287-y.

<sup>8</sup> Hall, W. C., Levin, L. L., & Anderson M. L. (2017). Language Deprivation Syndrome: A possible neurodevelopmental disorder with sociocultural origins. *Sociology, Psychiatry, Psychology, Epidemiology*, 52(6), 761-776. doi: 10.1007/s00127-017-1351-7.

## Factors and Impacts of Language Deprivation

There are many contributing factors to language deprivation that currently exist within early childhood and early intervention systems, and all of them greatly impact deaf children. It is critical to address each factor to mitigate language deprivation and thereby ensure every deaf child has successful education and language acquisition.

***Issue: Language acquisition of deaf children is not being appropriately tracked in accordance with current EHDI requirements.***

The EHDI 2017 reauthorization legislation includes language requiring state agencies that oversee EHDI “to develop, maintain, and improve data collection systems related to newborn, infant, and young child hearing screening, evaluation (including audiologic, medical, and *language acquisition evaluations*), diagnosis, and intervention services” (Section 399M(b)(1), emphasis added).<sup>9</sup> Currently only a few states appropriately track language acquisition by deaf infants and toddlers, which makes it more difficult to address the systemic failure as well as to properly research the progress of language acquisition within this population. The emphasis on data collection pursuant to EHDI is on the rates of identification of hearing status, levels of hearing status, and rates of EI enrollment, rather than the much needed data on language acquisition. This is not an appropriate substitution, for reasons already outlined above, including the lack of qualified service providers, lack of balanced information sharing, and the lack of a timely system for access to information.

To comply with the EHDI 2017 reauthorization legislation, all states should implement systems for tracking data on language acquisition by young deaf children. The information documented should include:

- A. Level of language acquisition in any language to which a deaf child is exposed;
- B. Which languages are being used by deaf children and their families; and
- C. Level and extent of services provided to support acquisition in each and any language exposed to deaf children and used by their families.

***Issue: While there is research related to language acquisition by deaf children, families are not provided this information in an appropriate manner.***

A preliminary search for information on the oral method or listening and spoken language (LSL) shows that it is more visible and prevalent than sign language resources on many state department websites, EHDI websites and large family-based organizations. When a child is identified with low hearing levels soon after birth, the bulk of information shared with families emphasizes spoken language and surgeries, and very little or no information about visual

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<sup>9</sup> Early Detection, Diagnosis, and Treatment Regarding Deaf and Hard-of-Hearing Newborns, Infants, and Young Children. 42 USC 280g-1. (2017). <https://www.scribbr.com/apa-examples/law/#:~:text=To%20cite%20federal%20laws%20>

language and deaf culture. Families are then referred to organizations, programs, or into systems that prioritize spoken language and the expertise of medical professions over the lived experiences of deaf adults and experts on sign language education. The current system of sharing information, resources, and making referrals is inequitable for families as they do not receive balanced information, and are then led to believe that they must choose only one option instead of pursuing several approaches. Families are not being empowered to make fully informed decisions about their family and deaf child's future.

States and EHDI programs should be held accountable for providing balanced information about language opportunities and a variety of resources, per the requirements of the 2017 EHDI reauthorization legislation. For state and federal departments, more oversight and follow through with enforcing federal legislation is necessary. Some specific ways that states and EHDI agencies should provide balanced information include:

- A. Providing information about visual language and sign language immediately at referral after the initial hearing screening, so that families are able to take steps that support any child (regardless of hearing level) while waiting for confirmation of hearing levels;
- B. Ensuring that any program or organization providing services to deaf children and their families, including state EHDI agencies and family to family organization, presents information on their website in a balanced and accessible way, where families are able to find information and resources about a variety of language opportunities, without emphasis on LSL approaches;
- C. Adjusting referral processes for families with deaf children to include access to programs or services that support visual language and sign language acquisition in addition to LSL, and that families are informed all opportunities for services at the same time; and
- D. Ensuring that contracted services include a variety of providers and approaches. At least 50% of contracts through any EHDI funds should be deaf-led, visual language based, and diversity-oriented.

***Issue: There is inadequate access to information, resources, and opportunities for services to families from marginalized communities.***

Data from the Gallaudet Research Institute (GRI) shows that about 35% of deaf or hard of hearing children are from homes where languages other than English or American Sign Language (ASL) are used.<sup>10</sup> Studies on the decision making processes of families who use languages other than English or ASL have shown that cultural and language differences between families and providers influenced and even limited what information these families received.<sup>11</sup> Bowen (2016) discussed findings relevant to Spanish-speaking families that reported barriers to

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<sup>10</sup> Gallaudet Research Institute. (2013). 2013-2014 Regional and National Survey. [https://www.gallaudet.edu/documents/Research-Support-and-International-Affairs/Intl%20Affairs/Demographics/AS14\\_RegNat.pdf](https://www.gallaudet.edu/documents/Research-Support-and-International-Affairs/Intl%20Affairs/Demographics/AS14_RegNat.pdf).

<sup>11</sup> Crowe, K., McLeod, S., McKinnon, D. H., & Ching, T. Y. (2014). Speech, sign, or multilingualism for children with hearing loss: quantitative insights into caregivers' decision making. *Language, Speech, and Hearing Services in Schools, 45*(3), 234–247. [https://doi.org/10.1044/2014\\_LSHSS-12-0106](https://doi.org/10.1044/2014_LSHSS-12-0106).

services for these families, including a lack of qualified interpreters and a lack of materials appropriately translated to Spanish.<sup>12</sup>

The Joint Committee on Infant Hearing (JCIH) published in 2007 a position statement that provides guidance on quality early hearing detection and intervention programs. Since 2007, the JCIH has released several supplements and additional statements, all which address culturally sensitive services for families with deaf children.<sup>13</sup> Some examples of cultural considerations in services from the JCIH 2019 Position Statement include<sup>14</sup>:

- a) providing culturally and linguistically appropriate interpretation services for families whose primary language is not English or ASL (JCIH, p. 6),
- b) providing information about the screening and diagnostic processes are shared appropriately with culturally and linguistically diverse families (JCIH, p. 10),
- c) training providers to collaborate with families and become aware of cultural influences on decision making by families (JCIH, pp. 26 & 36), and
- d) ensuring that assessments and evaluations properly include cultural considerations. (p. 28)

To ensure that all families with deaf children (including BIPOC families and families where English is not the home language) have appropriate access to information, resources, and opportunities for services, providers should be required to implement these recommendations when serving deaf children and their families.

***Issue: The Newborn Hearing Screening process has many flaws, from gaps in timely and appropriate services to provision of unbalanced and heavily biased information.***

Current screening practices do not include provision of any information to the family after the referral from the initial screening. Families are left in the dark until their follow up visit, which is often more than a month later. Any amount of delay, let alone more than a month, is precious time lost in the sharing of information or resources with families with a child with potentially low hearing levels. Research has shown that such a gap in provision of services can be exacerbated as the result of maternal depression or resistance in parents' acceptance of the child having low hearing levels. However, this can be mitigated by social supports, defined by Gross & Howard (2001) as a "variety of social support systems within their community,"<sup>15</sup> [and t]his might include educational programs during prenatal classes and discussions during hospital

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<sup>12</sup> Bowen, S. K. (2016). Early Intervention: A multicultural perspective on d/Deaf and hard of hearing multilingual learners. *American Annals of the Deaf*, 161(1), 33–40. <https://doi.org/10.1353/aad.2016.0009>.

<sup>13</sup> Joint Committee on Infant Hearing. (n.d.). *Position Statements from the Joint Committee on Infant Hearing*. <http://www.jcih.org/posstatements.htm>.

Crowe, K., McLeod, S., Y.C. Ching, T., The Cultural and Linguistic Diversity of 3-Year-Old Children with Hearing Loss, *The Journal of Deaf Studies and Deaf Education*, Volume 17, Issue 4, Fall 2012, Pages 421–438, <https://doi.org/10.1093/deafed/ens028>

<sup>14</sup> Joint Committee on Infant Hearing. (2019). Year 2019 position statement: Principles and guidelines for Early Hearing Detection and Intervention programs. *Journal of Early Hearing Detection and Intervention*, 4(2), 1–44. DOI: <https://doi.org/10.15142/fptk-b748>.

<sup>15</sup> Gross G. J., & Howard M. (2001). Mothers' decision making processes regarding health care for their children. *Public Health Nursing*, 18(3), 157–168. DOI: [10.1046/j.1525-1446.2001.00157.x](https://doi.org/10.1046/j.1525-1446.2001.00157.x).

discharge or physician office visitation” (p. 167).<sup>16</sup> However, many of these social supports are not available to all families, particularly families from marginalized communities.

Black mothers of children who are identified as deaf or hard of hearing are the most impacted by a lack of equitable access to information at the early stages of identification. Research has shown that children born to non-Hispanic Black mothers who did not pass the initial hearing screening had the highest risk of being lost to follow up (LTF) within the Early Hearing Detection and Intervention (EHDI) system.<sup>17</sup> “When controlling for all other covariates, mothers who identified as non-Hispanic Black and had previous live births and obesity were at increased risk for being LTF. Compared with non-Hispanic Whites, being non-Hispanic Black increased the odds of being LTF by 55 percent.”<sup>18</sup> Moreover, there is evidence that Black, Indigenous, or Persons of Color (BIPOC) parents experience serious equity issues in accessing information that would support future development of their deaf or hard of hearing child.

Newborn Intensive Care Unit (NICU) infants are also at severe risk for delays because of the flaws found in the EHDI system. NICU infants experience documented delays in access to timely EHDI services as well as inadequate oversight due to their longer stays within clinical settings. “On average, NICU infants received the initial screening at 22 days of life (compared to 1 day of life in non-NICU infants), had their first diagnostic assessment at 110 days (compared to 75 days), and enrolled in early intervention at 189 days (compared to 174 days).”<sup>19</sup> NICU infants are most at risk of developmental delays, which means timely service delivery of EHDI activities is critically important for this at-risk population. Their early stay within the clinical setting means that NICU infants are not being directly interacted with through either sign language or speech at the same rate as infants in a home setting and, as a result, their linguistic stimulation and environment is poor for more of their early childhood and leads to an increased risk of language deprivation.<sup>20</sup>

A crucial issue in nearly all early intervention scenarios is that medical providers who serve families with deaf or hard of hearing children often are not trained in the unique language acquisition needs of these children and do not have knowledge about deaf culture and/or resources available for families that support identity development. These medical providers have

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<sup>16</sup> Gross G. J., & Howard M. (2001). Mothers’ decision making processes regarding health care for their children. *Public Health Nursing*, 18(3), 157–168. DOI:[10.1046/j.1525-1446.2001.00157.x](https://doi.org/10.1046/j.1525-1446.2001.00157.x).

<sup>17</sup> Zeitlin, W., McInerney, M., Aveni, K., Schepeler, R., & DeCristofano, A. (2021). Maternal factors predicting loss to follow-up from Newborn Hearing Screenings in New Jersey. *Health & Social Work*, 46(2), 115–124. <https://doi.org/10.1093/hsw/hlab012>.

<sup>18</sup> Zeitlin, W., McInerney, M., Aveni, K., Schepeler, R., & DeCristofano, A. (2021). Maternal factors predicting loss to follow-up from Newborn Hearing Screenings in New Jersey. *Health & Social Work*, 46(2), 115–124. <https://doi.org/10.1093/hsw/hlab012>.

<sup>19</sup> Sapp, C., O’Hollearn, T., & Walker, E. A. (2020). Timeliness of EHDI benchmarks in infants with a NICU admission greater than five days: Analysis from a retrospective cohort. *Journal of Early Hearing Detection and Intervention*, 5(2), 47-56. <https://doi.org/10.26077/35b4-dcf0>.

<sup>20</sup> Rand, K., & Lahav, A. (2013). Impact of the NICU environment on language deprivation in preterm infants. *ACTA Paediatrica*, 103(3), 243-248. DOI: [10.1111/apa.12481](https://doi.org/10.1111/apa.12481).

an implicit bias towards speaking norms leading them to share information that is heavily skewed toward auditory access, listening and spoken language. Moreover, there is undue bias and influence from many professionals providing advice and guidance to families with deaf children, and this is due in part to the type of data being collected regarding language acquisition within deaf children. The data and research on language acquisition is inherently biased by adopting ableist norms such as speaking and hearing as the superior form of communication. The amount of data produced about spoken language acquisition leads to the misconception that it is optimal and superior without appropriate objective analysis of true language acquisition including through visual means and visual language.

For most families who have just learned that their child is deaf, there is little discussion of visual language, language acquisition, or the long term impacts of language deprivation. Rather, the discussion tends to focus on normalizing the deaf child by forcing language through sound. However, infants and toddlers who are deaf may not be able to access oral language through amplification and/or listening and spoken language (LSL) approaches during this critical period in acquisition of language.

Pediatric audiologist Dr. Mallorie Evans (2021) determined from research that “linguistic bias is particularly entrenched in pediatric audiology, especially in those who work with children ages 0-3 years.”<sup>21</sup> Evans further discusses that “the specific inherent language and modality bias we encounter in audiology is the preference for spoken language and auditory input as the primary way for the brain to receive and process the world around us, which implies that if the auditory system is not optimized, a child’s brain will not effectively receive and process the world around them. As audiologists, we focus on how the function of the auditory system affects communication.”<sup>22</sup> The medical team that typically surrounds the family in the earliest months of their infant’s life is already primed for the auditory verbal approach, which results in sharing with the family biased and inequitable access to information while denying them the full range of communication opportunities for their young infant.

Families should be enrolled in Early Intervention (EI) by the time their deaf children turn six months. At that time, the family should have a support team that includes EI providers. However, the reality is that many EI providers are not qualified or trained in working with deaf children beyond superficial introductory training in their professional development. The lack of qualified personnel is particularly apparent in EI deaf education,<sup>23</sup> and has been exacerbated in recent years by the increase in the size of the population needing services identified by the newborn hearing screening program and other services under the Early Hearing Detection and Intervention system mandated by the federal government. Lack of qualified EI personnel is the

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<sup>21</sup> Evans, M. (2021). Implicit bias in audiology: How does it affect families of deaf children? *The Hearing Journal*, 74(10), 16-17. doi: 10.1097/01.HJ.0000795664.84062.33.

<sup>22</sup> Evans, M. (2021). Implicit bias in audiology: How does it affect families of deaf children? *The Hearing Journal*, 74(10), 16-17. doi: 10.1097/01.HJ.0000795664.84062.33.

<sup>23</sup> Houston T., & Stredler-Brown, A. (2012). A model of early intervention for children with hearing loss provided through telepractice. *Volta Review*, 112(3), 283-296 .DOI: [10.17955/tyr.112.3.m.710](https://doi.org/10.17955/tyr.112.3.m.710).



most frequently cited reason for failure to provide children and families with timely EI services.<sup>24,25</sup>

EI services recommended and/or provided by EI programs may not be specialized and/or appropriate for deaf children right away which continues to exacerbate the issues in regards to the critical time frames of Early Intervention as related to identification, services, service provision, expertise and decision making windows that families must grapple with as part of the prevention of language deprivation for the deaf child. In order to address these flaws within the system, the following solutions are offered:

- A. *Introducing the family to deaf people, including those from diverse backgrounds, immediately after identifying that a child is deaf after the birth.* Connecting deaf adults to families that learn they have a deaf child allows families to begin to learn about deaf culture, and is essential to address the gaps in the current newborn screening process. Emphasis must be placed on ensuring that BIPOC families have access to deaf adults who share similar cultures, backgrounds, and life experiences. At the newborn hearing screening, it benefits the families to have deaf people (including those from diverse backgrounds) visible and present, and the families also will receive important resources and information.
- B. *Providing balanced information and resources before discharge from the hospital or upon referral if screened outside of the hospital.* These balanced information and resources empower families to support their deaf child's development within the first few weeks of life. Waiting for the formal identification process before providing accessible language to deaf infants is detrimental to the educational and linguistic development of these infants. Visual language at birth needs to be reframed as beneficial for all infants, regardless of hearing status, especially by medical professionals. When families receive balanced information about language acquisition and resources for implementing visual language in their homes at birth, all of their children would then fully benefit from language, regardless of hearing status. Ultimately, providing balanced information right away when a family is referred for follow-up after the newborn hearing screening becomes a protective factor for all infants' language acquisition, regardless of hearing status. Provision of balanced information at the referral of the newborn hearing screening needs to become the norm.
- C. *Giving families access to one set of balanced information across all points of entries into the EHDI system.* Current practices of sharing information vary state by state. Some states have multiple agencies providing information, while others have a single agency providing this information. Families become confused and overwhelmed when multiple agencies are sharing information, especially when the information shared contradicts

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<sup>24</sup> Jackson, R. L. W., Ammerman, S. B., & Trautwein, B. A. (2015). Deafness and diversity: Early Intervention. *American Annals of the Deaf*, 160(4), 356–367. <http://www.jstor.org/stable/26235227>.

<sup>25</sup> Early Childhood TA Center. (2015). A System Framework for Building High-Quality Early Intervention and Preschool Special Education Programs. Retrieved from <https://ectacenter.org/sysframe/>.

each other. To reduce such confusion and prevent overwhelming the families, agencies should work together to create one point of entry into the EHDI system and provide one set of balanced information to share with families. Providers need to work together with the family to review all the information shared, and provide additional resources and information as needed to empower families to make informed decisions.

***Issue: There are not enough deaf professionals in EHDI and the field of Early Intervention.***

The vast majority of Early Intervention or EHDI professionals are hearing-centered with a severe lack of professionals who have lived and shared experiences with the deaf children that are to be served. However, there are barriers for many deaf professionals to enter the EI/EHDI field, make a living, and become successful in the field. Some barriers include a) lack of support for the provision of interpreters in EI, b) lack of access to certification programs, c) lack of coverage by insurance companies for deaf services which leads to fewer paid opportunities for deaf specialists, and d) lack of active recruitment of deaf professionals, including those who are BIPOC.

Agencies and programs serving deaf children and their families need to make a more concerted effort to increase the number of deaf professionals in the field, particularly those who also are members of other marginalized, underrepresented groups including from BIPOC communities. This representation needs to be within not only direct service providers but also within leadership roles at the local, state, and federal levels. Specific strategies that can be done to increase opportunities for and visibility of deaf professionals include:

- A. Hiring more deaf professionals within EHDI programs, family to family organizations, and EI agencies for both direct service and leadership/administration positions; and
- B. Requiring insurance companies to cover services by qualified service providers for visual language acquisition in the same manner that Speech and Language Pathology services are covered.

When EHDI agencies, family to family organizations, and EI agencies commit to these strategies, more career opportunities for deaf professionals becomes a reality, leading to authentic inclusion and more relatable resources for families with deaf children.

***Issue: EI professionals too often encourage families to make limited and misinformed choices.***

Many Early Intervention professionals have not received adequate training or preparation to support families with providing a balanced approach to navigating the many resources and opportunities available related to language acquisition. Most audiology or speech and language pathology training programs do not include a full course requirement for deaf culture for learning ASL or visual language, yet these same professionals are considered experts on supporting families in navigating the EI and EHDI system. Because of limited professional development on crucial skills such as understanding and supporting balanced language opportunities and resources, families are receiving misinformation and heavily biased resources from these providers. Too many of these EI professionals frame language acquisition as a binary choice of

extremes, which limits deaf children and families to very narrow and potentially harmful approaches that set them up for failure. EI professionals need to be able to offer a range of approaches and even a combination of different approaches that fit the needs of each family with deaf children. Moreover, it is also important for there to be professionals who are BIPOC that fully understand the distinct needs and traditions of BIPOC families that have deaf children.

Deaf children and families' access to resources and information should be framed as opportunities, where multiple approaches and resources can be used and structured to support lifetime success with multiple tools, and should include the following:

- A. Require professional development and course materials of all professionals working in EI and EHDI settings to include material on deaf culture and language acquisition in both visual and auditory modes.
- B. Ensure that EI professionals provide families of deaf children with balanced and appropriate information on all available approaches including visual and auditory modes.

***Issue: Families of deaf children experience considerable confusion in entering the EHDI and EI system.***

Families of deaf children access the EHDI and EI systems in many different ways, depending on the particular organization(s) with which they are connected upon identification. The information conveyed by many of these organizations to families of newly identified deaf infants may be one-sided and imbalanced. Further, there is a great disparity in how some of these organizations are able to reach out to families that have just learned their child is deaf. Some organizations with specific self-interest purposes have greater access to families' information than others, which enables them to more widely share unbalanced information and resources. These organizations effectively act as gatekeepers to biased information for families by restricting the resources shared based on their own views, rather than providing the full range of language and communication options supported by research.

When there are too many points of entries into the EI/EHDI system, many families of deaf children are approached by biased organizations or groups to influence them into adopting their philosophies rather than ensuring that they have complete access to the full information needed to support their deaf children. Moreover, the multiple entry points into the EHDI and EI system along with a lack of accountability have led to some of these families becoming lost to follow up. This means that those families, after identifying that their child may be deaf or hard of hearing, do not receive sufficient information to navigate and complete the early intervention process.

State EHDI programs and/or federal programs supporting EHDI activities should be required to regulate how information is shared with families of deaf children at birth once they are identified and referred to the EI system. These regulations should include standardization of:

- A. Agreements or memorandum of understandings with programs/organizations providing services;

- B. The script used with families upon referral after the newborn hearing screening and at the diagnostic meeting;
- C. The Child Find process for supporting families of deaf children; and
- D. The process of qualifying deaf children for EI services

***Issue: EI and EHDI professionals should not conflate language and modality in the course of providing services to deaf children and their families.***

Language acquisition, regardless of mode, must be the focus of EHDI/EI professionals. The EHDI/EI systems tend to narrowly focus on the mode of communication, which ignores and overlooks the importance of language milestones, acquisition skills, and overall development of the deaf children. Instead of focusing on these important metrics, a significant number of deaf children leave the EI system with severe delays in language milestones. In California, 2019 statistics show that only 57.3% of deaf children at age 3 leave the EI system and enter preschool having met age-appropriate language milestones, compared to 94.1% of deaf infants meeting age-appropriate milestones at one year old.<sup>26</sup> Such a substantial drop can be attributed to many factors, such as the unnecessary battle over modes of communication. Rather, the real focus must be on language support and acquisition.

Professionals in the EI/EHDI field must focus on appropriate and thorough assessments, tracking, and documentation systems that focus on acquisition of language by young deaf children, and not on the modes of communication. This language acquisition assessment should not be limited to ASL or English, but any other spoken or visual language that the child and family may use in their home or community. Through a proper focus on assessing how much language has been acquired by young deaf children, we are better able to collect data and design interventions and services that are appropriate and based on each deaf child and family's unique journey.

### **Summary**

There are many factors that contribute to language deprivation for young deaf children, while at the same time, there are also many factors that support successful language acquisition for these children. This review outlined many gaps in the system of early screening, identification, and service delivery that young deaf children and their families experience. This review also identified potential solutions that lead to systemic change and better outcomes for young deaf children and their families. The NAD hopes this document supports future research and policy implementation efforts to address these identified weaknesses in the current EHDI system for young deaf children and their families.

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<sup>26</sup> Taylor, M. (2016). *Improving education for Deaf and Hard of Hearing students in California*. Legislative Analyst Office, [www.lao.ca.gov](http://www.lao.ca.gov). Retrieved from <https://lao.ca.gov/reports/2016/3498/education-DHH-students-092116.pdf>.