

# Lessons from the LEAD-K Campaign for Language Equality for Deaf and Hard of Hearing Children

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## ABSTRACT

*This Article asserts that early intervention under the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) should be amended to recognize the needs of the young child with the disability as primary over the needs of the child's family. This Article contends that certain requirements of the IDEIA cause early intervention professionals to view and treat the child's family, rather than the child herself, as the ultimate recipient of support. In many situations, the needs of the family and the needs of the child may wholly align, but that is an assumption that bears questioning. This Article analyzes groundbreaking legislation efforts in the field of deaf education, the Language Equality & Acquisition for Deaf Kids (LEAD-K) campaign, to illustrate a framework that maintains the focus on the primacy of the child's needs, with support to the family in service of those needs. The LEAD-K campaign has developed model legislation for adoption by states. Since 2016, twelve states have adopted a form of the LEAD-K model bill. There are approximately fifteen more states with LEAD-K teams in various stages of development. This Article highlights LEAD-K for its potential to transform early intervention for deaf and hard of hearing children and uses the LEAD-K model bill to illustrate a flaw in the IDEIA. The IDEIA subsumes the needs of the child within the consideration of the needs of the family, when the child and family should instead be considered as separate (but related) stakeholders. This Article seeks to apply lessons from the LEAD-K campaign to early intervention services under the IDEIA to facilitate more informed decision making by families.*

*While first considering the needs of deaf and hard of hearing children, this Article contends that a framework shift that identifies the needs and goals of the child separately from the needs and goals of her family would*

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*be beneficial to all children receiving early intervention services. This Article therefore calls for an amendment to the IDEIA to require that the child's program of services includes a written statement of the expectations for the child to attain by the end of early intervention. Currently, no such requirement exists. The expectations would be accompanied by a statement of how the measurable goals and outcomes (an existing requirement under the IDEIA) serve these expectations. This Article also suggests an alternative proposal, specifically for deaf and hard of hearing children receiving early intervention services, requiring the early intervention team to consider the child's language needs. This Article addresses anticipated counterarguments to the proposals, including claims that the proposals fail to recognize the importance of family autonomy and authority. This Article contends that the proposals set forth herein would facilitate better information sharing by early intervention professionals, leading to more informed decision making by families of young children with disabilities.*

INTRODUCTION .....	109
I. DEAF EDUCATION IN THE UNITED STATES—PAST AND PRESENT.....	115
A. <i>History of Deaf Education in the United States</i> .....	115
1. Primary paradigms in deaf education.....	115
2. History of deaf education in the United States.....	115
B. <i>Deaf Education Today</i> .....	121
C. <i>Academic Performance of Deaf and Hard of Hearing     Children</i> .....	123
D. <i>Language Deprivation in Deaf and Hard of Hearing     Children</i> .....	125
II. PART C OF THE INDIVIDUALS WITH DISABILITIES EDUCATION IMPROVEMENT ACT.....	129
A. <i>Framework of the IDEIA</i> .....	130
B. <i>Part C of the IDEIA</i> .....	131
1. The Individual Family Services Plan under Part C of IDEIA .....	132
2. Focus on Support to the Family Unit under Part C of the IDEIA.....	134
C. <i>Provisions Unique to Deaf and Hard of Hearing     Children in Part B of the IDEIA</i> .....	135
1. Clarification on “least restrictive environment” for deaf and hard of hearing children .....	136
2. “Special factors” for deaf and hard of hearing children .....	138

<i>D. State Laws: Deaf Children’s Bill of Rights</i> .....	138
III. THE CAMPAIGN: LANGUAGE EQUALITY & ACQUISITION FOR DEAF KIDS .....	139
<i>A. Development of LEAD-K Campaign and the Model Bill</i> .....	140
1. Model bill .....	141
<i>B. State Adoption of the Model Bill</i> .....	143
<i>C. Implications of LEAD-K for Deaf Education</i> .....	146
1. LEAD-K is focused on the child’s language development.....	146
2. LEAD-K is deaf-led and inclusive .....	148
3. LEAD-K as potentially transformative for deaf education.....	149
a. Future issues to be addressed .....	150
IV. LESSONS FROM LEAD-K FOR EARLY INTERVENTION UNDER PART C OF THE IDEIA .....	151
<i>A. LEAD-K Reveals a Flaw in the Structure of Early Intervention</i> .....	151
<i>B. Proposed Amendment to Part C of the IDEIA to Require a Statement of the Family’s Overall Expectations for the Infant or Toddler with a Disability in the IFSP</i> .....	154
1. Alternative proposal limited to deaf and hard of hearing infants and toddlers.....	155
CONCLUSION.....	157

## INTRODUCTION

The Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) is the federal law guaranteeing children with disabilities the right to an education. Services for infants and toddlers (generally birth to age three) with disabilities are governed by Part C of the IDEIA. Under Part C, young children with qualifying developmental delays or certain medical conditions, including deafness or hearing loss, are eligible to receive services under the child’s “individualized family services plan” (IFSP).<sup>1</sup> One of the requirements of the IFSP is that it must include “a statement of the family’s resources, priorities, and concerns relating to enhancing the development of the family’s infant or toddler with a

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1. Individuals with Disabilities Education Improvement Act, 20 U.S.C. § 1436(c) (2017) (“The individualized family service plan shall be developed within a reasonable time after the assessment required by subsection (a)(1) is completed.”).

disability.”<sup>2</sup>

This Article contends that this IFSP requirement leads early intervention professionals to view and treat the family as the ultimate recipient of support, instead of the infant or toddler with the disability. In many situations, the needs of the family and the needs of the child may wholly align, but that is an assumption that bears questioning. This Article analyzes new groundbreaking legislation efforts in the field of deaf education, the Language Equality & Acquisition for Deaf Kids (LEAD-K) campaign, to illustrate a framework that maintains the focus on the primacy of the child’s needs with support to the family in service of those needs. This Article seeks to apply lessons from LEAD-K to early intervention more broadly, to facilitate better informed decision making by all families with children who receive early intervention services.

The overwhelming majority of deaf and hard of hearing children are raised in environments where sign language is not used. Estimates are that approximately 70 percent of families with deaf and hard of hearing children do not sign in the home.<sup>3</sup> Over 90 percent of deaf and hard of hearing babies are born to hearing families who do not know sign language.<sup>4</sup> Families of a baby recently identified as deaf or hard of hearing may repeatedly encounter the statistic that the majority of deaf and hard of hearing students in the United States read at a third or fourth grade level at the time of high school graduation.<sup>5</sup> When these families begin early intervention programs, the early intervention professionals may not be experienced working with deaf and hard of hearing infants and toddlers as deafness is considered a low-incidence disability,

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2. § 1436(d)(2) (requiring that the IFSP contain “a statement of the family’s resources, priorities, and concerns relating to enhancing the development of the family’s infant or toddler with a disability”).

3. GALLAUDET RESEARCH INSTITUTE, REGIONAL AND NATIONAL SUMMARY REPORT OF DATA FROM THE 2009–10 ANNUAL SURVEY OF DEAF AND HARD OF HEARING CHILDREN AND YOUTH 11 tbl.2 (Gallaudet Univ. 2014), [https://research.gallaudet.edu/Demographics/2010\\_National\\_Summary.pdf](https://research.gallaudet.edu/Demographics/2010_National_Summary.pdf) [<https://perma.cc/798W-DA5P>].

4. See *Quick Statistics About Hearing*, U.S. DEP’T HEALTH & HUM. SERVS. NAT’L INSTIT. HEALTH (Dec. 15, 2016), <https://www.nidcd.nih.gov/health/statistics/quick-statistics-hearing> [<https://perma.cc/NLS3-T5BQ>] [hereinafter *Quick Statistics About Hearing*] (“More than 90 percent of deaf children are born to hearing parents.”). Other sources report that over 95 percent of deaf and hard of hearing children are born to hearing parents. See, e.g., Tom Humphries et al., *Avoiding Linguistic Neglect of Deaf Children*, SOC. SERV. REV., 589, 598–99 (2016) (citation omitted) (stating that approximately ninety-six percent of deaf children are born to hearing parents).

5. See, e.g., Iva Hrastinski & Ronnie B. Wilbur, *Academic Achievement of Deaf and Hard-of-Hearing Students in an ASL/English Bilingual Program*, J. DEAF STUD. & DEAF EDUC. 156, 156 (2016) (stating that numerous surveys and studies from last forty years reveal “overall depressed academic achievement” and significantly lower reading comprehension and literacy for deaf and hard of hearing children as compared to hearing peers).

affecting two to three out of every one thousand infants born in the United States.<sup>6</sup> Best practices in early intervention for deaf and hard of hearing children call for an “unbiased” or neutral approach toward language choice and communication modes.<sup>7</sup> For many hearing families, their deaf child may be the first deaf person they have met, and families may feel a lot of uncertainty and pressure to make the best decisions for their child.<sup>8</sup> In these circumstances, familial decision making is heavily weighted in favor of what families already know and are comfortable with, which is typically spoken language-based approaches. This decision may be entirely appropriate for some deaf and hard of hearing children and their families. Most families, however, are not making these high-stakes decisions for their deaf and hard of hearing children in a context in which they are truly informed because of the imbalance in information that families receive. This Article contends that a framework where the child’s needs and goals are identified as primary and the family’s needs as secondary, in support of the child’s needs, would drive more informed decision making by families. This is true regardless of the language choices that families make for their children and ultimately leads to more successful educational outcomes for deaf and hard of hearing children.

Researchers have identified the early years of life as critical for language acquisition and development.<sup>9</sup> Many deaf and hard of hearing children suffer from language deprivation. Language deprivation occurs when children do not have enough exposure to develop a strong foundation in their first language during this critical developmental period, regardless of whether they use hearing assistive devices such as cochlear implants or hearing aids. Even with the use of hearing assistive technologies, deaf and hard of hearing children do not have the same access to spoken language as their hearing peers. Language deprivation leads to poor academic outcomes which then contribute to poor job prospects, as well as feelings of isolation. Issues of language deprivation can be exceptionally acute for deaf and hard of hearing children of color.

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6. *Quick Statistics About Hearing*, *supra* note 4 (“About 2 to 3 out of every 1,000 children in the United States are born with a detectable level of hearing loss in one or both ears.”).

7. Mary Pat Moeller et al., *Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement*, 18 J. DEAF STUD. & DEAF EDUC. 429, 434 (2013).

8. See, e.g., Janet DesGeorges, *Avoiding Assumptions: Communication Decisions Made by Hearing Parents of Deaf Children*, 18 AM. MED. ASS’N J. ETHICS 442, 443 (2016) (stating that “[d]ecision making regarding communication and language choices for children often weighs heavily on parents.”).

9. See *infra* notes 58–59 and accompanying text (explaining a critical time window for children’s language development).

The LEAD-K campaign is a deaf-led grassroots campaign that originated in California and has sprawled nationwide, on a state-by-state basis. The campaign directly targets language deprivation in deaf and hard of hearing children from birth through age five. The campaign's goal is that all deaf and hard of hearing children enter kindergarten with age-appropriate language skills. LEAD-K has a model bill for adoption by state legislatures.<sup>10</sup> Under the model bill, states must adopt language developmental milestones for deaf and hard of hearing children, in both American Sign Language (ASL) and spoken English, and; on an annual basis, states must publicly report the language and literacy progress of deaf and hard of hearing children in the state, compared to their peers who are not deaf or hard of hearing.

This Article explores how LEAD-K is unique in the landscape of deaf education.<sup>11</sup> Specifically, this Article addresses how the accountability required by the LEAD-K bill has the potential to drive change at both the individual child level and more broadly at the state level with respect to

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10. *Model Legislation for States § 1(a)*, LEAD-K, <http://www.lead-k.org/model-legislation-for-states> [<https://perma.cc/MFV5-6QHP>] [hereinafter Model Bill].

11. The terms “deaf” and “Deaf” have different cultural and political connotations. The National Association of the Deaf (NAD)—which is the largest and longest-existing civil rights organization for deaf and hard of hearing people in the United States—quotes extensively from leading scholars of deaf history and culture, Carol Padden and Tom Humphries, in their formative work, *Deaf in America: Voices from a Culture*, to explain the terms “deaf” and “Deaf”:

We use the lowercase deaf when referring to the audiological condition of not hearing, and the uppercase Deaf when referring to a particular group of deaf people who share a language—American Sign Language (ASL)—and a culture. The members of this group have inherited their sign language, use it as a primary means of communication among themselves, and hold a set of beliefs about themselves and their connection to the larger society. We distinguish them from, for example, those who find themselves losing their hearing because of illness, trauma or age; although these people share the condition of not hearing, they do not have access to the knowledge, beliefs, and practices that make up the culture of Deaf people.

CAROL PADDEN & TOM HUMPHRIES, *DEAF IN AMERICA: VOICES FROM A CULTURE 2* (1988). See also *Community and Culture—Frequently Asked Questions*, NAT'L ASS'N DEAF, <https://www.nad.org/resources/american-sign-language/community-and-culture-frequently-asked-questions/> [<https://perma.cc/9PE4-DSDf>] (quoting PADDEN & HUMPHRIES, *supra*). Because (i) the LEAD-K bill uses the term “deaf and hard of hearing;” (ii) this Article discusses language acquisition among children in deaf education in the United States, regardless of their primary language and culture; and (iii) the NAD as well as other advocacy groups generally use “deaf and hard of hearing,” this Article will also use “deaf and hard of hearing” when referring to this population. This is not a comprehensive list; for example, people may also identify as DeafBlind or DeafDisabled, among others. In recognition of people's different lived experiences and identities, some advocacy organizations are shifting to the more inclusive terminology, referring to the community as “DDBDHH” or “DDBDHLLD” (Deaf, DeafBlind, DeafDisabled, Hard of Hearing, Late Deafened). See, e.g., *About Us*, COUNCIL DE MANOS, <https://www.councildemanos.org/about-us.html> [<https://perma.cc/8F9F-YDV4>] (stating its objectives as: “Empowering Latinx Deaf, DeafBlind, Deaf Disabled, Hard of Hearing and Late Deafened . . . through social justice awareness”).

the early intervention services it provides to deaf and hard of hearing children. This Article posits that LEAD-K's focus on language represents a shift by recognizing the child's needs as unique from those of the family unit, and highlights an example of how the IDEIA conflates the two.

Part I of this Article provides a brief overview of the history of the education of deaf and hard of hearing children in the United States through the current state of deaf education. This Part also discusses deaf and hard of hearing children's academic performance and the chronic issue of language deprivation that many deaf and hard of hearing children face.

Part II of this Article discusses Part C of the IDEIA, which governs services to infants and toddlers (birth to age three) with disabilities. This Part also discusses certain provisions of Part B of the IDEIA, which governs services to children with disabilities ages three through twenty-one, that are specific to deaf and hard of hearing children.

Part III analyzes LEAD-K, the grassroots campaign that seeks to end language deprivation for children from birth through age five. In Parts III.A and III.B, this Article discusses the LEAD-K campaign and its model bill as well as the states that have adopted and implemented the model bill. In Part III.C, this Article examines the potential implications of the model LEAD-K bill and the national LEAD-K campaign for deaf education. In Part III.D, this Article highlights that LEAD-K is unique in that it focuses on a deaf or hard of hearing child's *language acquisition*, which represents a new path in the competing paradigms in deaf education. This Part addresses how deaf and hard of hearing children of color are at greater risk for language deprivation, and how LEAD-K's demand for accountability has the potential to devise early intervention approaches to focus on and support those at greatest risk. Currently, while we do not yet have comprehensive data at the level required by LEAD-K, existing research shows that black deaf students fall behind their white deaf peers academically. Given the racial inequities in general education and society at large, this is perhaps not surprising. The adoption of LEAD-K represents an opportunity for state legislatures and education teams to take steps to correct this. Part III explores potential future implications on deaf education as more states adopt LEAD-K bills and the data from those states become public, and also considers how LEAD-K or strategies based on LEAD-K could be expanded to include children who have disabilities in addition to deafness.

In Part IV, this Article explores how LEAD-K unmask a consequence of the IDEIA in which the needs of the child are conflated with the needs of the family. Part IV.A discusses how the "unbiased" approach in early intervention for deaf and hard of hearing children is, in fact, often actually

quite biased against using sign language, given that deafness and hearing loss is a low incidence disability, early intervention professionals may not be sufficiently experienced in working with this population of children and their families, and there is often an information imbalance between early intervention professionals and the families of a newly identified deaf or hard of hearing child. This Article contends that the IFSP requirements set forth in the IDEIA further this imbalance by focusing on services directed toward family support—which means the family’s needs, rather than the child’s needs, become the driver of early intervention programming. This Part considers how the LEAD-K bill separates out the two questions: First, what are the expectations for the deaf or hard of hearing child? Second what services does the family need to support the child in realizing that outcome? This Part considers how such an approach facilitates more informed decision making by families, regardless of the language choices they make for their children.

While there are many situations in which the needs of the child and the needs of the family are in complete alignment, this Article identifies deaf and hard of hearing children as one population for which this assumption may not be true, and posits this discrepancy exists for other populations as well. This Article suggests that a framework that fosters an analysis of the child as an independent stakeholder from the family unit has the potential to yield better decision making for families of all children with disabilities, ultimately leading to better outcomes for these children. In Part IV.B, this Article proposes an amendment to Part C of the IDEIA to require that the first portion of the IFSP for an infant or toddler with a disability to be a statement of the family’s expectations for the child, based on a holistic view of the child, when the child transitions out of early intervention. The proposed amendment would also require the IFSP to include a statement explaining how the measurable goals and outcomes set forth in the IFSP are in service of these expectations. This Article also suggests, as an alternative or in addition to the change to the IFSP requirements, a proposal specific for deaf and hard of hearing children requiring the IFSP team to consider the child’s language needs in development of the IFSP. This Article also addresses several anticipated counterarguments to the proposals, including anticipated claims that the proposals fail to appropriately recognize family autonomy. This Article contends that incorporating these proposals into the IDEIA would be a way to account for an imbalance in information in decision making, and ultimately lead to families making more informed decisions for their children.



## I. DEAF EDUCATION IN THE UNITED STATES—PAST AND PRESENT

This Part presents a summary to provide an overview for readers who may not have previous exposure working in deaf and hard of hearing communities in order to situate the material in this Article in its appropriate context. The issues discussed herein can fill many textbook volumes across a variety of disciplines. In Parts I.A and I.B, this Article provides a brief summary of the history of deaf education in the United States from the 1800s to today. Part I.C discusses the academic performance of deaf and hard of hearing children, with a particular focus on deaf children of color. Part I.D discusses language deprivation as it affects deaf and hard of hearing children.

### A. *History of Deaf Education in the United States*

This Part discusses the history of deaf education in the United States, noting the shift in the paradigms between the spoken language-based approaches and the signed-based approaches.

#### 1. Primary paradigms in deaf education

In “Origins of Deaf Education: From Alphabets to America,” Heather G. Zimmerman and Thomas Horejes, scholars in the field of deaf education, explain that an understanding of deaf education (historically and today) requires a recognition that throughout the history of deaf education in the United States (and more broadly), there have been two main archetypes: sign-based approaches and spoken language-based approaches.<sup>12</sup> Recognizing these two ideologies will further contextualize the brief history of deaf education set forth below in Part II.A.2, as well as some of the issues surrounding the promulgation and adoption of LEAD-K bills, discussed in Part III.

#### 2. History of deaf education in the United States

This Part very broadly summarizes the history of deaf education in the United States.<sup>13</sup> While formal education of deaf and hard of hearing

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12. Heather G. Zimmerman & Thomas Horejes, *Origins of Deaf Education: From Alphabets to America*, in AN INTRODUCTION TO EDUCATING CHILDREN WHO ARE DEAF/HARD OF HEARING ch. 6, at 1–2 (eBook Feb. 7, 2019), <https://www.infantheating.org/ebook-educating-children-dhh/chapters/6%20Chapter%206%202017.pdf> [<https://perma.cc/X2CE-USTQ>]. “For hundreds of years, language philosophies and education of deaf children have been mired in an ‘either-or’ dilemma between sign language-inclusive and spoken-language only approaches.” Wyatt C. Hall, *What You Don’t Know Can Hurt You: The Risk of Language Deprivation by Impairing Sign Language Development in Deaf Children*, 21 MATERNAL CHILD HEALTH J. 961, 961 (2017).

13. For in-depth analysis of the history of deaf education, see, for example, PADDEN & HUMPHRIES, *supra* note 11. See also CAROLYN MCCASKILL ET AL., THE HIDDEN TREASURE OF

children in the United States is generally considered to have begun with the founding of the American School for the Deaf in Connecticut in 1817, black deaf people and other deaf people of color were largely excluded and did not have the same access to deaf schools (including Gallaudet University), prior to the Supreme Court's decision in *Brown v. Board of Education*.<sup>14</sup>

- *Pre-1800s*: Little is known about deaf education during this time, although there was use of sign language. Wealthy colonists sent their deaf children to Europe or hired private tutors.<sup>15</sup>
- *April 15, 1817*: The Connecticut Asylum for the Education and Instruction of Deaf and Dumb Persons (later renamed the American School for the Deaf (ASD)) was founded as the first school for deaf children in the United States.<sup>16</sup> ASD was established by Laurent Clerc, a deaf professor from the Director of the French Institute for the Deaf, and Thomas Hopkins Gallaudet, an American clergyman.<sup>17</sup> American Sign Language developed from French Sign Language (through Clerc's teachings), students' homesigns, Plains Indian Sign Language, as well as other sources.<sup>18</sup> ASD had a strong influence on ASL. ASL was the primary language of education, and ASD served as a model and a training facility for many deaf teachers and for the deaf schools that were subsequently established.
- *Early 1800s*: Deaf schools were established across the country,

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BLACK ASL: ITS HISTORY & STRUCTURE 14–16 (Gallaudet Univ. Press ed., 2011) (explaining the history and structure of ASL in America).

14. *Brown v. Board of Education of Topeka*, 347 U.S. 483, 487 (1954), *supplemented by*, 349 U.S. 294 (1955).

15. Zimmerman & Horejes, *supra* note 12, ch. 6, at 8. Zimmerman and Horejes (among others) cite Martha's Vineyard as a well-known community with a high percentage of deaf people where both hearing and deaf people used signs to communicate. *Id.*

16. *Id.* ch. 6, at 9–11.

17. *Id.* ch. 6, at 9. Gallaudet had traveled to Europe to learn about methods of educating deaf children, at the behest of Mason Fitch Cogswell, a wealthy physician with a young deaf daughter. Through Cogswell's political connections, he developed the financial and political support to establish a school for deaf children in Connecticut. In France, Gallaudet met and studied under Clerc, and persuaded Clerc to travel with him to Connecticut to open the first school for the Deaf in the United States. The school opened with Gallaudet as the school's director, Clerc the first deaf teacher, and Cogswell's daughter, Alice, as one of the school's first seven students. *Id.* ch. 6, at 9–11.

18. For a discussion of the different sources that led to the development of ASL, see JEFFREY E. DAVIS, *HAND TALK: SIGN LANGUAGE AMONG AMERICAN INDIAN NATIONS* (Cambridge Univ. Press 2010).

in what has been called “a golden era of deaf education,” where deaf education flourished, with approximately half of the teachers of deaf students also themselves being deaf.<sup>19</sup> While schools in New York, Pennsylvania, and Ohio had small populations of black deaf students, the majority of the deaf students that were educated were white. Deaf students of color were excluded from school and began developing separate schools.<sup>20</sup>

- *1864*: The Columbia Institution for the Instruction of the Deaf and Dumb and Blind (renamed Gallaudet College in 1894 and now Gallaudet University) was founded as the first institution of higher education for deaf and hard of hearing students.<sup>21</sup>
- *Late 1800s*: After the Civil War, the first oral schools for the deaf were established. These schools used different methods to teach deaf and hard of hearing children spoken language and prohibited sign language. Alexander Graham Bell was a key figure in the oralism movement.<sup>22</sup>
- *1880 The Milan Conference*: The Second International Congress on Education of the Deaf (Milan Conference) was an international meeting of deaf educators from Europe and the United States. The Milan Conference was planned and organized by the Pereire Society, an organization opposed to the use of sign language. Of the 164 delegates, 163 were hearing, and one delegate, James Denison, was deaf. 158 of the 163 delegates voted in favor of a resolution that the oral education was superior to sign language and to ban the use of sign language in schools.<sup>23</sup> The Milan Conference was a game-changer in deaf education. In the wake of the Milan Conference, deaf educators and administrators across the United States were fired from their jobs and replaced with

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19. Zimmerman & Horejes, *supra* note 12, ch. 6, at 11.

20. *Id.* Zimmerman & Horejes note this segregation led to the development of Black American Sign Language. *Id.*; see also MCCASKILL ET AL., *supra* note 13, at 14–16 (illustrating the history of Black deaf education before and after *Brown*).

21. *History of Gallaudet*, GALLAUDET UNIV., <https://www.gallaudet.edu/academic-catalog/about-gallaudet/history-of-gallaudet> [<https://perma.cc/T355-9K5N>]. Edward Miner Gallaudet, the son of Thomas Gallaudet, was the college’s first president. *Id.*

22. Zimmerman & Horejes, *supra* note 12, ch. 6, at 11–12. Bell, among other oralists, promoted a eugenics approach to deafness, and advocated against the intermarriage of deaf people to avoid producing deaf children. *Id.* ch. 6, at 12.

23. *Id.* ch. 6, at 7. The five delegates who opposed the resolution included Mr. Denison, the sole deaf person who was invited, as well as Edward Gallaudet and Thomas Gallaudet. *Id.*

hearing teachers who used oral methods. Students were banned from using sign language (and in some cases, physically punished for signing).<sup>24</sup> By 1900, it was rare for deaf students to have a deaf teacher and for sign language to be taught.<sup>25</sup> Despite the ban on sign language, Gallaudet University continued using ASL as the language of instruction. In response to the Milan Conference, a group of deaf people formed the National Association of the Deaf (NAD), a civil rights and advocacy organization, which among other things, advocated for the right of deaf people to use sign language.<sup>26</sup> Deaf people of color and women (of all races) were excluded from participation in the NAD until 1965.<sup>27</sup>

- *1950s*: In 1952, in *Miller v. D.C. Board of Education*, the United States District Court for the District of Columbia ruled that Kendall School, the elementary school that sits on the campus of Gallaudet University, was required to accept black students.<sup>28</sup> Prior to this decision, black deaf students from the District of Columbia were sent to Maryland for school. Gallaudet University responded by creating a separate facility on campus called Division II School for black deaf elementary school students.<sup>29</sup> The institution did not integrate its lower schools until it was required to do so by the *Brown v. Board of Education* decision. In 1954, Andrew J. Foster became the first black deaf person to graduate from Gallaudet University.<sup>30</sup>

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24. *Id.* ch. 6, at 11–12. In 2010, the board of the twenty-first International Congress on Education of the Deaf issued a formal apology and repudiation of the resolutions of the Milan Conference. See Donald F. Moores, *Partners in Progress: The 21st International Congress on Education of the Deaf and the Repudiation of the 1880 Congress in Milan*, 155 AM. ANNALS DEAF 309, 310 (2010) (stating that the twenty-first congress formally rejected the resolutions of the Milan Conference).

25. Zimmerman & Horejes, *supra* note 12, ch. 6, at 12.

26. *About Us*, NAT'L ASS'N DEAF, <https://www.nad.org/about-us/> [<https://perma.cc/K5BW-WJEZ>].

27. In 2012, the NAD issued a formal apology to black deaf people and deaf women (of all races) for its past discrimination on the basis of race and gender. See *2012 Conference Resolutions*, NAT'L ASS'N DEAF, <https://www.nad.org/about-us/priorities/2012-conference-resolutions/> [<https://perma.cc/2R7L-S332>] (“[L]et it be resolved that the NAD acknowledges and expressed sincere remorse and regret for the detrimental effects of its discriminatory exclusion of deaf women from voting privileges and discriminatory exclusion of deaf black individuals from membership and voting privileges.”).

28. *Miller v. Board of Education of District of Columbia*, 106 F. Supp. 988, 991 (D.D.C. 1952).

29. Sandra Jowers-Barber, *The Struggle to Educate Black Deaf Schoolchildren in Washington, D.C.*, in *A FAIR CHANCE IN THE RACE OF LIFE: THE ROLE OF GALLAUDET UNIVERSITY IN DEAF HISTORY* 113, 124 (Brian H. Greenwald & John Vickrey Van Cleve eds., 2008).

30. *Visionary Leader Andrew Foster*, GALLAUDET UNIV. (May 2014),

- *1980s*: Scholars of black deaf history, Glenn B. Anderson and Lindsay M. Dunn refer to the 1980s as “the beginning of the ‘black Deaf renaissance.’”<sup>31</sup> National Black Deaf Advocates (NBDA) formed in 1982, after a group of black deaf people from the Washington metropolitan area raised concerns with existing deaf advocacy organizations and as a culmination of the groundbreaking Black Deaf Experience conference at Howard University. NBDA is the premiere nationwide advocacy organization for black deaf people.<sup>32</sup> Anderson and Dunn also point to the 1983 release of *Black and Deaf in America: Are We That Different?*, by black deaf scholars Ernest Hairston and Linwood Smith, citing this work as the first publication of its sort to publicize that black deaf people have different ways of signing than white deaf people do.<sup>33</sup>
- *1988 “Deaf President Now” (DPN)*: When the Board of Trustees of Gallaudet, a majority-hearing body, appointed as its seventh president a hearing person over other highly qualified deaf candidates, students protested. As a result of DPN, I. King Jordan was appointed as Gallaudet’s first deaf president.<sup>34</sup> A deaf person, Philip Bravin, was appointed as the first deaf chair of the Board of Trustees, and the Board was reconstituted to require at least a 51 percent majority of deaf members.
- *1990s*: The American with Disabilities Act of 1990 was

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<https://www.gallaudet.edu/about/history-and-traditions/andrew-foster> [https://perma.cc/K529-5AVN]. Foster Auditorium on Gallaudet’s campus is named in Andrew Foster’s honor. *Id.*

31. Glenn B. Anderson & Lindsay M. Dunn, *Assessing Black Deaf History: 1980s to the Present*, 17 SIGN LANGUAGE STUD. 71, 72 (2016).

32. *Id.* at 72–73; see *History*, NAT’L BLACK DEAF ADVOCATES, <https://www.nbda.org/content/history> [https://perma.cc/8UPR-22WP] (stating that the conference “marked an important milestone and provided a model for others to emulate”). The mission statement of the National Black Deaf Advocates (NBDA) “is to promote the leadership development, economic and educational opportunities, social equality, and to safeguard the general health and welfare of Black deaf and hard of hearing people.” *About Us*, NAT’L BLACK DEAF ADVOCATES, <https://www.nbda.org/content/about-us> [https://perma.cc/S9J2-5PUT]. Now there are more than 30 local NDBA chapters. *Id.*

33. Anderson & Dunn, *supra* note 31, at 72 (citing ERNEST HAIRSTON & LINWOOD SMITH, *BLACK AND DEAF IN AMERICA: ARE WE THAT DIFFERENT?* 55 (T.J. Publishers 1983)).

34. *Deaf President Now*, GALLAUDET UNIV., <https://www.gallaudet.edu/about/history-and-traditions/deaf-president-now> [https://perma.cc/8WVY-RCRY]. In the wake of the DPN protests, Gallaudet’s first deaf president, I. King Jordan, made his famous declaration: “[D]eaf people can do anything hearing people can do except hear.” *I. King Jordan*, GALLAUDET UNIV., <https://www.gallaudet.edu/about/history-and-traditions/deaf-president-now/profiles-and-viewpoints/i-king-jordan> [https://perma.cc/99CX-6RM7].

passed, prohibiting discrimination on the basis of disability. Anderson and Dunn highlight the 1990s as a significant time period in black deaf history, with the advancement of black deaf people to leadership positions, including at Gallaudet University.<sup>35</sup> Anderson and Dunn also note Gallaudet University's acknowledgement of its history of segregation as a significant event in this period. The university placed a plaque recognizing and commemorating the education of black Deaf students near the entrance of the Gallaudet University Kellogg Conference Hotel, which had formerly been the site of the segregated elementary school on campus for black deaf children.<sup>36</sup>

- *2000s*: Anderson and Dunn point to the 2000s as the period of the ascension of black deaf scholarship.<sup>37</sup> A groundbreaking work in this period was the publication in 2011 of *The Hidden Treasure of Black ASL: Its History and Structure* by Carolyn McCaskill, Ceil Lucas, Robert Bayley, and Joseph Hill.<sup>38</sup> Deaf

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35. Anderson & Dunn, *supra* note 31, at 73–74. Anderson and Dunn themselves are among the black deaf individuals that advanced to key leadership positions within Gallaudet University during this time period. Anderson became the first black deaf person elected as chair of the Board of Trustees of Gallaudet University, and Dunn was the first person appointed as special assistant to the president for diversity and community relations. *Id.* at 73.

36. *Id.* at 73. Gallaudet University, in partnership with NBDA, is in the process of creating a Kendall School Division II Memorial as a way to examine “its fraught racial legacy and participate in a national reckoning with the destructive legacy of segregation.” *Kendall School Division II Memorial*, GALLAUDET UNIV., [https://www.gallaudet.edu/office-of-development/kendall-school-division-ii-memorial](https://www.gallaudet.edu/office-of-development/kendall-school-division-ii-memorial-project-fund/kendall-school-division-ii-memorial) [https://perma.cc/LE65-9DWH].

37. Anderson & Dunn, *supra* note 31, at 74–76; *cf.* Lindsay Dunn, *The Burden of Racism and Audism*, in *OPEN YOUR EYES: DEAF STUDIES TALKING* 235, 241 (H-Dirksen L. Bauman ed., Univ. Minn. Press 2008) (noting that “much research and literature on deafness has been from a Eurocentric perspective and mainly based on the European-American experience”).

38. See MCCASKILL ET AL., *supra* note 13, at 14 (explaining the history and structure of ASL in America). Carolyn McCaskill, one of the authors of *The Hidden Treasures of Black ASL*, was the second black deaf woman to earn a doctorate from Gallaudet University in 2005, with her younger sister, Angela McCaskill, being the first in 2004. See *Black Deaf History Month*, NAT'L BLACK DEAF ADVOCATES, <https://www.nbda.org/content/black-deaf-history-month> [https://perma.cc/G9HE-GRRU] (“Notable Black Deaf Americans with Ph.D.s . . . Dr. Angela McCaskill & Dr. Carolyn McCaskill (Deaf Sisters with Ph.D.s at Gallaudet University, 2004 & 2005 respectively)”). Estimates are that there are *fourteen* black deaf people in the United States who have earned doctoral degrees, including the McCaskills. B.R.J. O'Donnell, *We Have 14 Black Deaf Americans with Ph.D.s—14*, THE ATLANTIC (Aug. 16, 2017), <https://www.theatlantic.com/business/archive/2017/08/gallaudet-franklin-jones-carolyn-mccaskill/536949/> [https://perma.cc/D9J2-AHUM]. Glenn B. Anderson, whose work is cited in this Article, was the first black deaf person to earn a doctoral degree. Anderson earned his PhD from New York University in 1982. *Visionary Leader Glenn B. Anderson*, GALLAUDET UNIV. (Feb. 2014), <https://www.gallaudet.edu/about/history-and-traditions/glenn-anderson> [https://perma.cc/62M7-ANDT]. Laurene Simms, also cited in this

education began to change in the 1990s and more so in the 2000s with the availability of the cochlear implant for children as young as 12 months of age.<sup>39</sup> As hearing assistive technology continues to become increasingly sophisticated, children with a wider range of hearing levels are eligible candidates for implantation, leading to a broader array of decisions for families of a newly-identified deaf or hard of hearing child.<sup>40</sup>

### B. Deaf Education Today

Currently, there are a variety of approaches used to educate deaf and hard of hearing children. This Part explains the different approaches and where services may take place. Generally, services for deaf and hard of hearing infants and toddlers take place in the family home, while children ages 3 and older receive services in a host of centers.

There are several languages and communication approaches used with deaf and hard of hearing children. The National Association of State Directors of Special Education (NASDSE) discusses these approaches in *Optimizing Outcomes for Students who are Deaf or Hard of Hearing: Educational Service Guidelines (Educational Service Guidelines)*, which was developed by deaf educators across a range of modalities and deaf education scholars.<sup>41</sup> NASDSE's *Educational Service Guidelines* lists the

Article, earned her doctorate in 2000 from the University of Arizona. *Laurene Simms*, GALLAUDET UNIV., <https://my.gallaudet.edu/laurene-simms> [<https://perma.cc/7595-9ZZR>].

39. *Cochlear Implants*, U.S. DEP'T HEALTH & HUM. SERVS.: NIH FACT SHEETS, <https://report.nih.gov/NIHfactsheets/ViewFactSheet.aspx?csid=83> [<https://perma.cc/4NB5-JKBP>].

40. See Deborah Vickers, Leo De Raeye & John Graham, *International Survey of Cochlear Implant Candidacy*, 17 COCHLEAR IMPLANTS INT'L 36, 36 (2016) (noting, for example, that innovations in technology and surgical techniques have made cochlear implants a possible intervention for individuals with low frequency residual hearing); *Technical Report: Cochlear Implants*, AM. SPEECH-LANGUAGE-HEARING ASS'N (Mar. 2003), <https://www.asha.org/policy/tr2004-00041/> [<https://perma.cc/U24D-4EQU>] (describing how the current cochlear implant system works as well as briefly summarizing the history of the devices). Hearing aids are amplification devices that deliver sounds to the brain via the auditory system. Hearing aids are external devices that the user can remove at her will. Cochlear implants have an internal component (implanted under general anesthesia) as well as an external component, called the speech processor. The speech processor detects sound and sends it via electrical signal to the implant, which then sends signals to the auditory nerve. See Joseph P. Roche, *How Improved Cochlear Implant Technology Benefits More Patients*, U. WIS. SCH. MED. & PUB. HEALTH: DEP'T SURGERY (Oct. 5, 2017), <https://www.surgery.wisc.edu/2017/10/05/how-improved-cochlear-implant-technology-benefits-more-patients/> [<https://perma.cc/KAL3-VDW6>] (describing ways to improve cochlear implants to increase the number of people who are eligible for implantation).

41. NAT'L ASS'N OF STATE DIRECTORS OF SPEC. EDUC., *OPTIMIZING OUTCOMES FOR STUDENTS WHO ARE DEAF OR HARD OF HEARING: EDUCATIONAL SERVICE GUIDELINES* 17–18 tbl.3.2 (3d ed. 2018) [hereinafter NASDSE, EDUCATIONAL SERVICE GUIDELINES].

following as communication approaches currently used with deaf and hard of hearing children: ASL/English Bilingualism, Cued Speech, Listening and Spoken Language, Signed English/Pidgin Signed English, Sign Supported Speech, and Simultaneous Communication.<sup>42</sup>

Importantly, NASDSE notes that of these options, “Signed English, simultaneous communication, sign-supported speech, and Pidgin Signed English are not recommended for infants and toddlers who are developing language because they are not complete languages.”<sup>43</sup>

For school-aged children who receive services under the IEP, the child’s placement is the “least restrictive environment” (LRE) as discussed in Part I.C. NASDSE’s *Educational Service Guidelines* identified the following principles for educating deaf children, regardless of the language, communication mode, or school placement:

1. Each student is unique.
2. High expectations drive educational programming and future employment opportunities.
3. Families are critical partners.
4. Early language development is critical to cognition, literacy and academic achievement.
5. Specially designed instruction is individualized.
6. Least restrictive environment (LRE) is student-based.
7. Educational progress must be carefully monitored.

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42. *Id.* NASDSE defines these approaches as follows:

- ASL/English bilingualism “[i]ncorporates the separate use of two languages, one visual and one spoken. . . . Spoken and signed languages are used in the same environment, with intentional times and roles. The two languages are given equal value and equal representation.” *Id.* at 17 tbl.3.2.
- Cued speech is a “system of eight hand shapes placed in one of four positions near the face that visually presents a phonetic representation of syllables used in spoken English. Cued speech systems . . . make visual the phonemes that are spoken that cannot be visually distinguished through lipreading.” *Id.* at 18 tbl.3.2.
- Listening and spoken language uses “primarily listening to understand spoken language and using spoken language to interact and communicate with others.” *Id.*
- Signed English/Pidgin Signed English is “[u]sed when native English speakers are learning ASL and use ASL signs without using appropriate ASL grammar and sign in an incomplete way. [It is u]sed as a bridge to link spoken and signed language and is not seen as a true representation of either language.” *Id.*
- In sign supported speech, “[s]igns are used to clarify and support the use of spoken language. [It is p]rimarily used when children rely on mostly audition and spoken language to communicate but may need visual support to understand spoken language in loud settings or for new information.” *Id.*
- Simultaneous communication is when “spoken language is used simultaneously with a system of signs (not a true visual language) that borrow from ASL but are put in English order and then said and signed simultaneously.” *Id.*

43. *Id.* at 17 tbl.3.2.



8. Access to peers and adults who are deaf or hard of hearing is critical.
9. Qualified providers are critical to a child's success.
10. State leadership and collaboration is essential.<sup>44</sup>

Deafness and hearing loss is considered a low-incidence disability. Each year, two to three out of every one thousand children are born in the United States with a detectable level of hearing loss in one or both ears—representing approximately 1 percent of the children receiving special education services.<sup>45</sup> Thus, absent a “critical mass” of deaf and hard of hearing students it may be difficult for schools to justify appropriate staffing, support, and programming aligned with the above principles.<sup>46</sup>

### *C. Academic Performance of Deaf and Hard of Hearing Children*

Numerous studies have found that deaf and hard of hearing children under-perform academically. In calling for a change in the training of teachers of deaf and hard of hearing children,<sup>47</sup> scholars Laurene Simms and Helen Thumann of Gallaudet University list several of these studies showing that deaf and hard of hearing students have low levels of reading achievement, mathematics performance, oral language, as well as low employment and low earnings rates.<sup>48</sup> Educational researchers Iva Hrastinski and Ronnie B. Wilbur cite a largely different set of studies with the same results—deaf and hard of hearing children have significantly poorer reading comprehension and literacy skills and decreased enrollment in postsecondary institutions compared to their hearing peers.<sup>49</sup> According to studies cited by Hrastinski and Wilbur,

44. *Id.* at 2–3.

45. *Quick Statistics About Hearing*, *supra* note 4 (stating that 2 to 3 of every 1,000 children in the United States are born with some detectable level of hearing loss); Nat'l Center for Educ. Statistics, *Children and Youth with Disabilities*, THE CONDITION OF EDUC. 1, at 1 (May 2019), [https://nces.ed.gov/programs/coe/pdf/coe\\_cgg.pdf](https://nces.ed.gov/programs/coe/pdf/coe_cgg.pdf) [<https://perma.cc/6Q6J-68P7>] (showing that 1 percent of children ages 3–21 receiving services under the IDEA were identified as having a “hearing impairment” for school year 2017–18).

46. Zimmerman & Horejes, *supra* note 12, ch. 6, at 13.

47. Laurene Simms & Helen Thumann, *In Search of a New, Linguistically and Culturally Sensitive Paradigm in Deaf Education*, 152 AM. ANNALS DEAF 302, 302 (2007) (“Throughout the history of deaf education in America, researchers have produced a staggering amount of information regarding its ‘failure.’ Although many reasons for this failure have been reported, we suggest that school systems and ultimately college and university teacher training programs have not fully addressed issues related to the teaching of prekindergarten through 12 (P-12) deaf and hard of hearing students who are visual learners.”); *see also* Humphries et al., *supra* note 4, at 597 (“If the deaf child has deficits, it is assumed [by society] that these are due to the condition of deafness rather than to the lack of action on the part of caregivers.”).

48. Simms & Thumann, *supra* note 47, at 303.

49. Hrastinski & Wilbur, *supra* note 5, at 156; *see also, e.g.*, Candace Myers et al., *Black Deaf*

half of deaf and hard of hearing students in the United States graduate from high school with less than a fourth-grade reading level, with only seven to ten percent of graduates reading at a seventh-grade level or above.<sup>50</sup>

These numbers have remained static for decades.<sup>51</sup> While this appears bleak, it also necessarily masks certain issues. Deaf and hard of hearing children are a diverse group and certain populations of deaf and hard of hearing children may face greater marginalization than others. While research data is sparse on black deaf children and other children of color, a 2010 study done at Gallaudet University comparing the reading skills of black deaf adults and white deaf adults found major differences between the groups. It found first, that black deaf participants had, on average, a fourth-grade reading level, whereas white deaf participants had, on average, an eighth-grade reading level; and second, that black deaf participants had significantly lower ASL scores than the white Deaf participants.<sup>52</sup>

The authors of this study attributed these differences in results to several factors. Black and white deaf individuals typically learned ASL at different ages—nine years of age for black deaf individuals and three years of age for white deaf individuals—meaning that black deaf

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*Individuals' Reading Skills: Influence of ASL, Culture, Family Characteristics, Reading Experience, and Education*, 155 AM. ANNALS DEAF 449, 450 (2010) (showing that the deaf population's average reading level drops off around the fourth grade in studies from the past thirty years).

50. Hrastinski & Wilbur, *supra* note 5, at 156.

51. Hrastinski and Wilbur cite studies from 1975 to 2015 finding poorer literacy skills and academic achievement of deaf and hard of hearing children compared to their hearing peers. *Id.* at 156. For example, see Ronnie Bring Wilbur & Stephen P. Quigley, *Syntactic Structures in the Written Language of Deaf Students*, 77 VOLTA REV. 194, 199–201 (1975) (comparing academic achievement of deaf and hard of hearing children to hearing children); Carol Bloomquist Traxler, *The Stanford Achievement Test, 9th Edition: National Norming and Performance Standards for Deaf and Hard-of-Hearing Students*, 5 J. DEAF STUD. & DEAF EDUC. 337, 337 (2000) (explaining how the Stanford Achievement Test allows a test user to examine a student's performance over time); Ross E. Mitchell, *Academic Achievement of Deaf Students*, in TESTING DEAF STUDENTS IN AN AGE OF ACCOUNTABILITY 38, 44 (Robert C. Johnson & Ross E. Mitchell eds., Gallaudet Univ. Press 2008) (describing how the academic achievement gap between deaf students and hearing students remains large and unchanged in the last three decades); Marc Marschark et al., *Predicting the Academic Achievement of Deaf and Hard-of-Hearing Students from Individual, Household, Communication, and Educational Factors*, 81 EXCEPTIONAL CHILD. 350, 350–51 (2015) (describing research explaining reasons why deaf children are behind their hearing peers for academic achievement).

52. Myers et al., *supra* note 49, at 454–55; *see also id.* at 450 (citing Judith A. Holt, *Stanford Achievement Test—8th Edition: Reading Comprehension Subgroup Results*, 138 AM. ANNALS DEAF 172, 172–75 (1993)) (comparing reading achievement of white and Black deaf individuals, researchers found that 77% of white deaf student college students read at least at the fourth-grade level, 12% of black deaf students, and 7% of Hispanic (Latinx) deaf students).

individuals are typically not native ASL signers. “[T]his later acquisition implies that the critical period for language development has likely passed before these individuals have full exposure to visual language.”<sup>53</sup> The authors also cite frequency of parent-child reading interactions as a cause of the difference in literacy rates between the black deaf and white deaf individuals, based on the reporting by the individuals in the study.<sup>54</sup> They also found a significant difference with respect to maternal college education levels between the black deaf and white deaf individuals.<sup>55</sup>

While this study was on adults, there is evidence that these gaps apply to academic achievement in black deaf children as well. In a 2008 article, Professor Laurene Simms et al. identified several factors that can seriously affect the academic performance of black deaf school children. They found a near-absence of black deaf people in positions that could serve as role models, such as teachers; and noted that hearing loss in black deaf children is often identified later than in white peers (particularly so before every state mandated newborn infant screenings), thereby leading to delayed identification until the child demonstrated speech and language delays in the early school years.<sup>56</sup> Professor Simms et al. stated that these children are more likely to have missed opportunities for critical early intervention services and are often misdiagnosed with learning or behavioral disorders.<sup>57</sup>

#### *D. Language Deprivation in Deaf and Hard of Hearing Children*

Researchers have identified a critical period of language development, from birth to approximately age five,<sup>58</sup> where there is a high degree of brain plasticity and elevated neurological sensitivity necessary for

53. Myers et al., *supra* note 49, at 455 (citing KAREN EMMOREY, LANGUAGE, COGNITION, AND THE BRAIN 218 (Lawrence Erlbaum Associates 2002)).

54. Myers et al., *supra* note 49, at 455.

55. *Id.* The authors also cite differences in the use of ASL between black deaf and white deaf people as a possible contributing factor to the differences in test results, citing the work of Carolyn McCaskill. *Id.* at 451 (citing MCCASKILL ET AL., *supra* note 13, at 14–19).

56. Laurene Simms et al., *Apartheid in Deaf Education: Examining Workforce Diversity*, 153 AM. ANNALS DEAF 384, 385–87 (2008).

57. *Id.* at 385–86.

58. Hall, *supra* note 12, at 962; *see also* Humphries et al., *supra* note 4, at 593 (citations omitted) (“All children need regular and frequent exposure to an accessible language during the critical (or sensitive) period between birth and 3 or 4 years old . . . or they risk linguistic deprivation—a biological state that interferes with the development of neurolinguistic structures in the brain . . .”); *Position Statement on Early Cognitive and Language Development and Education of Deaf and Hard of Hearing Children*, NAT’L ASS’N DEAF (June 18, 2014), <https://www.nad.org/about-us/position-statements/position-statement-on-early-cognitive-and-language-development-and-education-of-deaf-and-hard-of-hearing-children/> [<https://perma.cc/X7XA-GMGV>] (referring to period of birth to two years of age as the critical time period for language acquisition).

language development. “Language delays affect development of neuro-linguistic structures in the brain, especially those related to developing grammar and second language acquisition.”<sup>59</sup> Language deprivation occurs where there is insufficient linguistic stimuli necessary for the language acquisition process. There are stories of “feral” children or other cases of seriously neglected children who did not have the opportunity to develop a first language. These instances are extreme, tragic, and rare.<sup>60</sup> For deaf and hard of hearing children, by contrast, language deprivation (or “linguistic deprivation”)<sup>61</sup> is a well-documented frequent occurrence.<sup>62</sup>

Language deprivation occurs in deaf and hard of hearing children due to a lack of access to a natural language.<sup>63</sup> A “natural language” means a spoken or signed language used by the community in which the child lives. A natural language has evolved naturally through human use and has its own grammatical rules and structures, syntax, and other features that make it unique from other languages. ASL is a natural language, as is English, Spanish, Arabic, and the many other language used by people

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59. Hall, *supra* note 12, at 962 (citing Nils Skotara et al., *The Influence of Language Deprivation in Early Childhood on L2 Processing: An ERP Comparison of Deaf Native Signers and Deaf Signers with a Delayed Language Acquisition*, 13 BMC NEUROSCIENCE, no. 44, 2012).

60. See Wyatt C. Hall, Leonard L. Levin & Melissa L. Anderson, *Language Deprivation Syndrome: A Possible Neurodevelopmental Disorder with Sociocultural Origins*, 52 SOC. PSYCHIATRY & PSYCHOL. EPIDEMIOLOGY 761, 768 (2017) (stating that for hearing children to experience language deprivation in the way that many deaf children do “requires extreme situations of neglect and/or abuse”).

61. See Humphries et al., *supra* note 4, at 593-96 (describing harm caused to deaf children by lack of “appropriate input at critical points”).

62. See, e.g., Neil Glickman, *Blog: Language Deprivation and Deaf Mental Health: Introduction to a Webinar*, NAT’L ASS’N ST. MENTAL HEALTH PROGRAM DIRECTORS 3, [https://www.nasmhpd.org/sites/default/files/Glickman\\_Language%20Deprivation%20Article.pdf](https://www.nasmhpd.org/sites/default/files/Glickman_Language%20Deprivation%20Article.pdf) [<https://perma.cc/8XVA-KS68>] (“At the extreme end of the language deprivation continuum are a-lingual deaf people—people with no or minimal formal language skills. Hearing people have usually never met such people and may find it hard to believe that human beings with normal intelligence can be, essentially, language-less. Inside the Deaf Community, however, the problem of language deprivation is well-known. Programs and specialists that serve D/deaf people usually know some a-lingual or semi-lingual deaf people.”).

63. “Language deprivation occurs due to a chronic lack of full access to a natural language during the critical period of language acquisition (where there is an elevated neurological sensitivity for language development), approximately the first 5 years of a child’s life. Language deprivation during the critical period appears to have permanent consequences for long-term neurological development. Neurological development can be altered to the extent that a deaf child ‘may be unable to develop language skills sufficient to support fluent communication or serve as a basis for further learning.’”

Hall, Levin, & Anderson, *supra* note 60, at 761–62 (citing Amy R. Lederberg et al., *Language and Literacy Development of Deaf and Hard-of-Hearing Children: Successes and Challenges*, 49 DEVELOPMENTAL PSYCHOL. 15 (2013)).

across the globe. Importantly, “speech” itself is not a language—speech is a modality in which language may be expressed.<sup>64</sup> Also important is that communication systems used to facilitate the development of language are not themselves language. Cued speech or simultaneous communication (often called “sim-com”) are not languages—they are systems to facilitate the learning of English (in the case of cued speech) or to facilitate interpersonal communication with signers who are not fluent (in the case of sim-com).<sup>65</sup>

Thus, children need *access* to a language.

What makes a language accessible to a child? If a child is exposed regularly and frequently to a language and picks up that language naturally without explicit training and exercise (as generally happens with hearing children in a speech environment and with deaf children in a signing environment), the language qualifies as accessible to that child. On the other hand, if a child is exposed regularly and frequently to a language but does not pick it up even after explicit training and exercise (as can happen with deaf children in a speech environment), the language is arguably inaccessible to that child. *Between those two ends lied a gray area in which decisions by caregivers and professionals have as much bearing on the lack of access as the fact of the hearing loss.*<sup>66</sup>

The effects of language deprivation can be profound. Psychologist Neil Glickman, who specializes in cognitive behavior psychotherapy and Deaf mental health care states: “People with significant language deprivation are unlikely to be literate, even at an elementary level, and they are also likely to have impaired abstract reasoning abilities and difficulty

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64. The American Speech-Language-Hearing Association (ASHA) defines speech as the way sounds and words are pronounced, including articulation, voice and fluency. ASHA defines language as the words used and how they are used to share ideas and information. *What Is Speech? What Is Language?*, AM. SPEECH-LANGUAGE-HEARING ASS’N, [https://www.asha.org/public/speech/development/language\\_speech.htm](https://www.asha.org/public/speech/development/language_speech.htm) [<https://perma.cc/9MV4-PCW5>]; see also Humphries et al., *supra* note 4, at 597 (“Language is a cognitive faculty that can be manifested in more than one modality: oral-aural, realized as speech, and manual-visual, realized as sign. . . . [L]anguage development is modality-independent and people can express themselves fully in either modality.”).

65. NASDSE, EDUCATIONAL SERVICE GUIDELINES, *supra* note 41, at 42–43 tbl.6.1. NASDSE states:

Regardless of the language, approach or approaches used, children are highly vulnerable to the “Swiss cheese” effect. That is, the holes or gaps that arise when the message expressed is incomplete, or when all parts of the message are not received due to visual or auditory interruptions. Young children do not have the language foundation to fill in what they do not receive, leading to receptive and expressive language deficits and subsequent literacy gaps.

*Id.* at 18.

66. Humphries et al., *supra* note 4, at 595 (emphasis added).

learning.”<sup>67</sup> Language deprivation affects psychosocial development and interpersonal skills.<sup>68</sup> Hrastinski and Wilbur state:

Many deaf children do not reach conversational proficiency in either a spoken or signed language, which means that they lack appropriate vocabulary size, sentence formation, skills, and world knowledge that hearing children already possess by the time they start learning how to read. In contrast to their hearing peers, who learn to read and write in a language they already know, many deaf beginning readers have to cope with acquiring complex English language structures while being tasked to learn how to read in another language.<sup>69</sup>

With respect to deaf and hard of hearing children, studies show that a strong foundation in ASL promotes English literacy skills.<sup>70</sup> This is a lightning rod issue among the stakeholders, revealing the ongoing competing paradigms in deaf education.<sup>71</sup> An analysis of these paradigms and the incentives underlying them is beyond the scope of this Article.

For purposes of understanding the effect of language deprivation on deaf and hard of hearing children, it is worth noting the potential

67. Glickman, *supra* note 62, at 3.

68. *Id.* at 4 (citations omitted); *see also* Hall, *supra* note 12, at 962 (“Altogether, a fundamental and irreversible biological impact—on the brain and on healthy development—appears to occur when an accessible language is not provided by a certain *early* time period in brain development.”); *id.* at 963 (“The lifelong consequences of language deprivation are too far-reaching, from early childhood to adulthood, to limit a deaf child’s time-sensitive language acquisition opportunities.”); Humphries et al., *supra* note 4, at 593–94 (citations omitted) (“Linguistic deprivation inhibits fluency in any language and correlates with a range of poor cognitive and academic outcomes . . .”).

69. Hrastinski & Wilbur, *supra* note 5, at 157 (citing John L. Luckner et al., *An Examination of the Evidence-Based Literacy Research in Deaf Education*, 150 AM. ANNALS DEAF 443 (2005)).

70. *See* Hrastinski & Wilbur, *supra* note 5, at 157 (citing Charlene Chamberlain & R.I. Mayberry, *Theorizing About the Relationship Between ASL and Reading*, in LANGUAGE ACQUISITION BY EYE 221, 221 (Charlene Chamberlain et al. eds., 2000)) (explaining the results of early research studies); R.J. Hoffmeister, *A Piece of the Puzzle: ASL and Reading Comprehension in Deaf Children*, in LANGUAGE ACQUISITION BY EYE 143, 143 (Charlene Chamberlain et al. eds., 2000) (citation omitted) (“[T]here are many Deaf individuals who are able to attain excellent mastery of reading English even without oral knowledge of English. Many of these individuals are well versed in both ASL and English . . .”); Carol Padden & Claire Ramsey, *Reading Ability in Signing Deaf Children*, 18 TOPICS IN LANGUAGE DISORDERS 30, 30–31 (1998) (discussing various studies of the relationship between ASL proficiency at a young age and English literacy); Michael Strong & Philip M. Prinz, *A Study of the Relationship Between American Sign Language and English Literacy*, 2 J. DEAF STUD. & DEAF EDUC. 37, 37 (1997)) (discussing the findings of a study among 160 deaf children). *But see* Ann E. Geers et al., *Early Sign Language Exposure and Cochlear Implantation Benefits*, 140 PEDIATRICS, no. 1, July 2017, at 6 (explaining findings that suggest that the long-term use of sign-language could delay speech and reading skills of children who use cochlear implants).

71. *See* Zimmerman & Horejes, *supra* note 12, ch. 6, at 2, and accompanying text (discussing the history of signed based approaches and spoken language-based approaches in deaf education).

outcomes that can occur in the event that using a spoken language approach with a deaf or hard of hearing infant does not have the results the parents expected. According to clinical psychologist and scholar Wyatt C. Hall, “[t]he common recommendation of using sign language as a ‘last resort,’ only after noticeable failure to develop speech skills, creates the possibility for language deprivation to occur given that there is only one time-sensitive language acquisition window regardless of visual or auditory modalities.”<sup>72</sup> In other words, relying on spoken language approach only, which may be wholly appropriate for some deaf and hard of hearing children, is in some ways a gamble with potentially developmentally serious ramifications for deaf and hard of hearing children who are not successful with this approach.

## II. PART C OF THE INDIVIDUALS WITH DISABILITIES EDUCATION IMPROVEMENT ACT

This Part addresses services to children and families under Part C of the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA), which governs services for children with disabilities from birth to age three. This Part also addresses specific provisions found within Part B of the IDEIA (which governs services for children ages three through twenty-one) that are specific to deaf and hard of hearing children

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72. Hall, *supra* note 12, at 963. Numerous deaf educators and deaf education scholars cite this grave concern. For example, see CAL. ASS’N OF THE DEAF, *THE ROAD TO KINDERGARTEN READINESS: LANGUAGE POLICY FOR DEAF CHILDREN AGES 0-5*, at 6 (2017) (“By the time families recognize that their Deaf child is not hearing and/or speaking as promised, they have missed critical language development milestones.”); Tom Humphries et al., *Ensuring Language Acquisition for Deaf Children: What Linguists Can Do*, 90 LANG. & PUB. POL., no. 2, June 2014, at e31–32 (referring to deaf children who “experience little to no success in language acquisition with a CI, and only turn to sign language after the early critical period. Unfortunately, these children run the risk of never having completely fluent use of either a spoken or a sign language.”); Poorna Kushalnagar et al., *Infants and Children with Hearing Loss Need Early Language Access*, 20 J. CLIN. ETHICS 143, 145 (2010) (stating that if children do not acquire their first language before the critical time period, they “may well have difficulties becoming fluent in any language”). See also Tom Humphries et al., *Bilingualism: A Pearl to Overcome Certain Perils of Cochlear Implants*, 21 J. MED. SPEECH-LANGUAGE PATHOLOGY 107, 114 (2014) (citation omitted) (“Exposure of deaf children to a sign language at a very early age is a guaranteed way of ensuring healthy formation of the language faculty; in contrast, giving the child sign language at a later age (in response to lack of progress in spoken language) does not ameliorate language difficulties due to lack of accessible language before that.”). Interestingly, using sign language (or “baby sign”) is often encouraged with hearing children to help foster their language skills before they begin to speak. See, e.g., Jay L. Hoecker, *Is Baby Sign Language Worthwhile?*, MAYO CLINIC (Mar. 6, 2019), <https://www.mayoclinic.org/healthy-lifestyle/infant-and-toddler-health/expert-answers/baby-sign-language/faq-20057980> [<https://perma.cc/M4T3-3ES5>] (stating that “baby sign language might give a typically developing child a way to communicate several months earlier than those who only use vocal communication”).

and recognize their specific communication needs. At the state level, several states have passed a “Deaf Child’s Bill of Rights,” codifying a deaf or hard of hearing child’s fundamental human right of communication. This Part will briefly address the Deaf Child’s Bill of Rights in Part II.D.

#### A. Framework of the IDEIA

The IDEIA is the federal special education law. The IDEIA provides the right to a “free appropriate public education” to eligible children with disabilities from birth through age twenty-one.<sup>73</sup> The IDEIA provides specific rights and safeguards to children with disabilities and their parents. The purpose of special education, as set forth in the IDEIA, is “to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living” and “to ensure that the rights of children with disabilities and parents of such children are protected.”<sup>74</sup> The IDEIA was originally passed in 1975 as the Education for All Handicapped Children Act.<sup>75</sup> The passage of the IDEIA was a crucial advancement in civil rights for children with disabilities. Prior to the passage of the IDEIA, children with disabilities, many of whom were institutionalized or otherwise isolated from their communities and families, did not have access to a public school education.

The IDEIA is comprised of four parts: Part A provides for the general provisions of the law, Part B addresses services for children from ages three through twenty-one, Part C addresses services for children from birth to age three, and Part D deals with national support programs that are administered at the federal level.

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73. 20 U.S.C. § 1400(d) (2017).

74. §§ 1400(d)(1)(A)–(B).

75. Education for All Handicapped Children Act, Pub. L. No. 94-142 (1975). In the wake of the Supreme Court’s 1954 decision in *Brown v. Board of Education*, 347 U.S. 483, parents of children with disabilities initiated lawsuits against their children’s school districts claiming that by excluding and segregating children with disabilities from the general education classroom, schools were discriminating against these children based on their disabilities. See Pa. Ass’n for Retarded Children v. Commonwealth, 343 F. Supp. 279 (E.D. Pa. 1972) (challenging the exclusion from public school children with disabilities); Mills v. Bd. of Educ., 348 F. Supp. 866 (D.D.C. 1972) (challenging the expulsion from public school children with disabilities). Congress subsequently initiated an investigation into the education of children with disabilities, which found that millions of children with disabilities were not receiving an appropriate education. Following the investigation, Congress enacted the Education for All Handicapped Children Act.



*B. Part C of the IDEIA*

In the 1986 reauthorization of the IDEIA, Congress established early intervention services for children from birth to age three by adding Part H to the IDEIA in recognition of

an urgent and substantial need (1) to enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay; (2) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after handicapped infants and toddlers reach school age; (3) to minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society; and (4) enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps.<sup>76</sup>

The IDEIA's 1997 reauthorization moved the early intervention program to Part C. Part C requires that states have policies and programs to identify and provide services to infants and toddlers with disabilities.<sup>77</sup> Congress's findings supporting the establishment of the early intervention program remain largely the same as when they were first set forth in the 1986 reauthorization of the IDEIA,<sup>78</sup> though Congress added additional findings regarding a need "to enhance the capacity of State and local agencies and service providers to identify, evaluate, and meet the needs of all children, particularly minority, low-income, inner city, and rural children, and infants and toddlers in foster care."<sup>79</sup> The 2004 reauthorization of the IDEIA also included a recognition of "the significant brain development that occurs during a child's first 3 years of life."<sup>80</sup>

Part C of the IDEIA governs services for an "infant or toddler with a disability," and the services must be designed to meet the child's developmental needs.<sup>81</sup> These needs may be physical, cognitive, communicative, social, emotional, and/or adaptive. Early intervention services are typically provided by the state at no charge to the family.<sup>82</sup>

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76. Education of the Handicapped Act Amendments of 1986, Publ. L. No. 99-457, § 671(a), 100 Stat. 1145, 1145 (1986) (codified as amended at 20 U.S.C. § 1471 (2017)).

77. 20 U.S.C. § 1431(b) (2017).

78. See Education of the Handicapped Act § 671(a).

79. § 1431(a). The 2004 reauthorization also removed the term "handicapped" and references to institutionalization.

80. § 1431(a)(1).

81. 20 U.S.C. § 1435(b) (2017).

82. 20 U.S.C. § 1432(4)(B) (2017) (stating that early intervention services "are provided at no cost except where Federal or State law provides for a system of payments by families, including a schedule of sliding fees"); 34 C.F.R. § 303.521(b) (2018) (listing the functions under Part C of the IDEIA that must be carried out at public expense).

To qualify for early intervention services under Part C, the child must be an “infant or toddler with a disability” as defined in Section 1432 of Part 20 of the United States Code:

The term ‘infant or toddler with a disability’ - (A) means an individual under 3 years of age who needs early intervention services because the individual (i) is experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development; or (ii) has a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay.<sup>83</sup>

The statute provides that the term “infant or toddler with a disability” may also include, at the discretion of the state, at-risk infants and toddlers and children in certain preschool programs.<sup>84</sup> While early intervention services under Part C generally terminate on a child’s third birthday, the IDEIA preserves flexibility so that states may elect to permit the continuation of early intervention services under Part C until the child enters kindergarten or is eligible do so.<sup>85</sup>

#### 1. The Individual Family Services Plan under Part C of IDEIA

Under Part C of the IDEIA, children receive services according to their Individual Family Services Plan (IFSP). An IFSP under Part C must include:

- A statement of the child’s present levels of physical, cognitive, communication, social or emotional, and adaptive development based on objective criteria;
- A statement of the family’s resources, priorities, and concerns as they relate to enhancing the development of the child with a disability;
- A statement of the measurable results or outcomes expected to be achieved by the child and the family, “including pre-literacy and language skills, as developmentally appropriate for the child, and the criteria, procedures, and timelines used to determine the degree to which progress toward achieving the results is being made and whether modifications or revisions of the results or outcomes or services are necessary;”
- A statement of the specific early intervention services “necessary to meet the unique needs of the infant or toddler and the family;”

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83. § 1432(5)(A).

84. § 1432(5)(B).

85. § 1435(c)(1).

- A statement of the natural environment in which early intervention services will take place and a justification to which any services will not be provided in a natural environment;
- The expected start date for services and their anticipated length, duration, and frequency;
- The identification of the service coordinator who will be responsible for implementation of the IFSP; and
- The steps to support the transition of the toddler with a disability to preschool or other appropriate services.<sup>86</sup>

The IFSP is reviewed every six months with a reevaluation every year (or more often based on the needs of the child and family).<sup>87</sup> Participation in any stage of early intervention is optional. Families must give informed written consent prior to the provision of early intervention services.<sup>88</sup> The Department of Education includes on its website a model IFSP that contains the required components.<sup>89</sup> States are free to add additional requirements to the IFSP, so the IFSP document will include requirements that vary state-to-state.

To assess the child's present level of development and progress toward meeting her measurable results or outcomes, the IDEIA requires a "multidisciplinary assessment of the unique strengths and needs of the infant or toddler and the identification of services appropriate to meet such needs."<sup>90</sup> The IDEIA defined an assessment as "the ongoing procedures used by qualified personnel to identify the child's unique strengths and needs and early intervention service."<sup>91</sup> The IDEIA does not mandate the use of specific assessments for the IFSP. It instead requires that "assessment[s] . . . must be conducted by qualified personnel in order to identify the child's unique strengths and needs and the early intervention services appropriate to meet those needs."<sup>92</sup> Assessments will typically be done through a family interview to collect information on how the child functions within everyday routines in order to develop

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86. 20 U.S.C. § 1436(d) (2017).

87. § 1436(b).

88. § 1436(e).

89. U.S. DEP'T OF EDUC., THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA) REGULATIONS, MODEL FORM: INDIVIDUALIZED FAMILY SERVICE PLAN (ISFP), <https://www2.ed.gov/policy/speced/reg/idea/part-c/model-form-ifsp.pdf> [<https://perma.cc/3NWM-LLN2>] (last modified Sept. 2, 2011) [hereinafter ISFP MODEL FORM].

90. § 1436(a)(1).

91. 34 C.F.R. § 303.321(2)(ii) (2018).

92. 34 C.F.R. § 303.321(c)(i) (2018).

meaningful and functional outcomes and results for the IFSP.<sup>93</sup> Assessment information may also include observations, medical records, review of any evaluation results, checklists, and criterion-based assessment tools.

## 2. Focus on Support to the Family Unit under Part C of the IDEIA

One of the central principles under Part C of the IDEIA is that a young child's needs are closely tied to the needs of her family. To determine whether a child qualifies as an "infant or toddler with a disability" eligible for services under Part C, the IDEIA and the regulations thereunder state: "A family-directed assessment must be conducted by qualified personnel in order to identify the family's resources, priorities, and concerns and the supports and services necessary to enhance the family's capacity to meet the development needs of the family's infant or toddler with a disability."<sup>94</sup> The family-directed assessment "[i]nclude[s] the family's description of its resources, priorities, and concerns related to the child's development."<sup>95</sup>

Thus, the IFSP is a whole family plan, with the family as major contributors in its development. The IDEIA sets forth the requirements of the IFSP, one of which is: "A statement of the family's resources, priorities, and concerns as they relate to enhancing the development of the child with a disability."<sup>96</sup> This requirement appears second on the list set forth in the statute immediately following the requirement to list a statement of the child's present level of development, before any statement of the goals for the child or the services that the child will receive. While the IFSP requirements are not listed in order of priority (all are required components of the IFSP), listing this element second helps underscore its importance in developing the IFSP. The Model Form: Individualized Family Service Plan, available on the website of the United States Department of Education,<sup>97</sup> lists this family resource statement third, after the name of the family service coordinator and the

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93. See, e.g., *Family Assessment: Gathering Information From Families*, EARLY CHILDHOOD TECHNICAL ASSISTANCE CENTER, <https://ectacenter.org/topics/families/famassess.asp> [<https://perma.cc/NUU5-5AWW>] (explaining common processes in family assessments).

94. 34 C.F.R. § 303.321(c)(2); see also 20 U.S.C. § 1436(a)(2) (stating that the development of the IFSP program requires "a family-directed assessment of the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family's capacity to meet the developmental needs of the infant or toddler").

95. 34 C.F.R. § 303.321(c)(2)(iii).

96. 20 U.S.C. § 1436(d)(2).

97. ISFP MODEL FORM, *supra* note 89, at 1.

statement of the child’s present level of development.<sup>98</sup>

From the outset, the early intervention component of the IDEIA addressed needs of the family as part of and alongside of addressing the needs of the infant or toddler with a disability. One of the four purposes Congress initially listed as the rationale for early intervention explicitly addresses family supports: “an urgent and substantial need . . . to enhance the capacity of families to meet the special needs of their infants and toddlers.”<sup>99</sup> The third original purpose—“an urgent and substantial need . . . to minimize the likelihood of institutionalization”—also goes directly to the issue of family supports.<sup>100</sup> According to a 2005 publication by the United States Office of Special Education Programs of the United States Department of Education, early intervention addresses the needs of both the child and the family because “[f]amilies play critical roles in their child’s development; thus helping families has direct implications for the extent to which children benefit from [early intervention]” and “[f]amily members themselves can be affected by having a child with a disability, and programs can promote positive adaptation and reduce potential negative impacts.”<sup>101</sup>

Thus, Part C is structured to recognize the importance of the family unit in supporting the child’s development.

### *C. Provisions Unique to Deaf and Hard of Hearing Children in Part B of the IDEIA*

Once children reach age three, to continue to qualify for services under the IDEIA, they must have a disability that falls within thirteen enumerated categories, and need special education services because of that disability.<sup>102</sup> Children ages three through twenty-one receive special

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98. *Id.*

99. Education of the Handicapped Act § 671(a)(4).

100. Education of the Handicapped Act § 671(a)(3).

101. DON BAILEY & MARY BETH BRUDER, EARLY CHILDHOOD OUTCOMES CENTER, FAMILY OUTCOMES OF EARLY INTERVENTION AND EARLY CHILDHOOD SPECIAL EDUCATION: ISSUES AND CONSIDERATIONS 1–2 (2005), [http://ectacenter.org/~pdfs/eco/Family\\_Outcomes\\_Issues\\_01-17-05.pdf](http://ectacenter.org/~pdfs/eco/Family_Outcomes_Issues_01-17-05.pdf) [<https://perma.cc/FAD6-DPPF>].

102. Deaf and hard of hearing children generally qualify for early intervention services under Part C, because they fall under the category of having “a diagnosed physical or mental condition that has a high probability or resulting in developmental delay.” 20 U.S.C. § 1432(5)(a)(ii). Each state will determine specific eligibility requirements. Deaf and hard of hearing children generally qualify for early intervention services under Part C, because they fall under the category of having “a diagnosed physical or mental condition that has a high probability or resulting in developmental delay.” *Id.*; see, e.g., N.Y. PUB. HEALTH LAW § 2541(5) (McKinney 2019) (providing, for example, in New York, a disability for early intervention purposes is defined as a developmental delay or “a diagnosed physical or mental condition with a high probability of resulting in developmental delay, such as down syndrome or other chromosomal abnormalities, sensory impairments, or fetal alcohol

education services according to their “individualized education program” (IEP). An IEP is similar to an IFSP in many ways. For example, like the IFSP, the IEP must include a statement of the child’s present level of development and a statement of the measurable results or outcomes expected.<sup>103</sup> The IEP must also state the projected dates for the start of services and the anticipated length, duration, and frequency of the services.<sup>104</sup> The IEP is reviewed at least annually with a full re-evaluation every three years, or more frequently at the request of a member of the IEP team.<sup>105</sup> In developing the IEP, the IEP team is required to consider the child’s strengths, the parents’ concerns for enhancing their children’s education, the child’s evaluation results, and the academic, developmental, and functional needs of the child.<sup>106</sup> IEPs are designed for school-aged children, so the stated focus is on services to the child, not the child and family as with the IFSP. Parents, however, are a member of the IEP team, and parental consent is required for the initiation of services under the IEP.

As with the IFSP, states and local school systems may add requirements that must be included in the IEP. Thus, there is variation in IEPs across different school systems.

#### 1. Clarification on “least restrictive environment” for deaf and hard of hearing children

Two core components for services under Part B are that the child receives a “free appropriate public education” (FAPE) in the “least restrictive environment” (LRE). Generally, the IDEA requires that “[a] free appropriate public education is available to all children with disabilities residing in the State between the ages of three and twenty-one, inclusive, including children with disabilities who have been suspended or expelled from school.”<sup>107</sup>

LRE is defined as:

To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, special schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular

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syndrome”).

103. 20 U.S.C. §§ 1414(d)(1)(A)(I)–(II) (2017).

104. § 1414(d)(1)(A)(i)(VII).

105. §§ 1414(d)(4)–(5).

106. § 1414(d)(3)(A).

107. 20 U.S.C. § 1412(a)(1)(A) (2017).

classes with the use of supplementary aids and services cannot be achieved satisfactorily.<sup>108</sup>

A child's IEP is required to include "an explanation of the extent, if any, to which the child will not participate with nondisabled children in the regular class and in [extracurricular and other nonacademic activities] with nondisabled children."<sup>109</sup> The LRE requirement is based on disability inclusion principles, which mandate that to the extent possible, a child with disabilities is educated with her peers.

For deaf and hard of hearing children, the United States Department of Education has clarified "the consideration of LRE as part of the placement decision must always be in the context in which appropriate services can be provided. Any setting which does not meet the communication and related needs of a child who is deaf, and therefore does not allow for the provision of FAPE, cannot be considered the LRE for the child."<sup>110</sup>

Just as placement in the regular education setting is required when it is appropriate for the unique needs of a child who is deaf, so is removal from the regular education setting required when the child's needs cannot be met in that setting with the use of supplementary aids and services.<sup>111</sup>

Thus, LRE for a deaf or hard of hearing child may be in schools designed specifically for the education of deaf and hard of hearing children (these schools may use ASL or spoken English); in deaf and hard of hearing programs housed within general education schools; or in the general education classroom (called "mainstreaming"), with or without an ASL interpreter and/or technological aids, including the use of hearing aids, cochlear implants, and/or FM systems; or some combination of the above.<sup>112</sup>

108. § 1412(a)(5)(A).

109. § 1414(d)(1)(A)(i)(V).

110. Deaf Students Education Services; Policy Guidance, 57 Fed. Reg. 49,274, 49,275 (Oct. 30, 1992) [hereinafter Notice of Policy Guidance]; see also *Position Statement on Inclusion*, NAT'L ASS'N DEAF, <https://www.nad.org/about-us/position-statements/position-statement-on-inclusion/> [<https://perma.cc/A7JU-HAKH>] (explaining the factors to consider when an IEP team determines the least restrictive environment for a deaf or hard of hearing child).

111. Notice of Policy Guidance, *supra* note 110, at 49,275.

112. School placement is determined by the child's IEP team, based on the child's present level of performance, the child's IEP goals, and the supports and services required for the child to achieve those goals. NASDSE, EDUCATIONAL SERVICE GUIDELINES, *supra* note 41, at 33–34. NASDSE's *Educational Service Guidelines*, *id.* at 36, lists the following as possible placements for a deaf or hard of hearing child:

a local/neighborhood school with consultation or itinerant support from teacher of the deaf; a district or state regional program for students who are deaf or hard of hearing; a special day school (public, including charter school, or private) for students who are deaf

## 2. “Special factors” for deaf and hard of hearing children

Part B, and the regulations thereunder, identify “special factors” that must be considered in developing an IEP for deaf and hard of hearing children.

(B) Consideration of Special Factors. The IEP Team shall—

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consider the communication needs of the child, and in the case of a child who is deaf or hard of hearing, consider the child’s language and communication needs, opportunities for direct communication with peers and professional personnel in the child’s language and communication mode, academic level, and full range of needs, including opportunities for direct instruction in the child’s language and communication mode.<sup>113</sup>

Identical language appears in the regulation thereunder.<sup>114</sup> This provision also considers behavior intervention, limited English proficiency, and blindness or visually impairments to be special factors in the development of an IEP.

The special factors provision was added to the IDEIA in its 1997 reauthorization.<sup>115</sup> One of the reasons for the addition of special factors to the IDEIA was that LRE was often inappropriately applied to deaf and hard of hearing children and other populations.<sup>116</sup> Based on this “special factors” provision, some states require communication plans for deaf and hard of hearing children. These communication plans identify the child’s primary language or communication mode and what the school will do to support the child’s language development and communication access.<sup>117</sup>

### *D. State Laws: Deaf Children’s Bill of Rights*

A handful of states, including California, Colorado, Connecticut, Georgia, and New Mexico, have passed a bill of rights for deaf and hard

or hard of hearing; a state-supported school for the deaf; a residential facility; or a combination of the above.

113. 20 U.S.C. § 1414(d)(3)(B)(iv).

114. 34 C.F.R. § 300.324(a)(2)(iv) (2018).

115. Individuals with Disabilities Education Act Amendments of 1997, Pub. L. No. 105-17 (1997), § 614(d)(3)(B), 111 Stat. 37, 86 (1997) (codified as amended at 20 U.S.C. § 1414 (2017)).

116. See Assistance to States for the Education of Children With Disabilities and the Early Intervention Program for Infants and Toddlers With Disabilities, 64 Fed. Reg. 12,406, 12,590 (Mar. 12, 1999) (to be codified at 34 C.F.R. pt. 300, 303) (citing Notice of Policy Guidance, *supra* note 110, at 49,275 (“The Secretary is concerned that the least restrictive environment provisions of the IDEA . . . are interpreted incorrectly to require the placement of some children who are deaf in programs that may not meet the individual student’s educational needs.”)).

117. See NASDSE, EDUCATIONAL SERVICE GUIDELINES, *supra* note 41, at 30, 104 (listing state communication plans).



of hearing children. These bills of rights emphasize a child's basic human right to communicate freely with others. While these bills vary from state-to-state, typically the bill of rights will state that the purpose of the bill is to promote an understanding of communication needs and not to favor any one particular language or communication mode over any other. For example, in 1994, California adopted "The Deaf Children's Bill of Rights," which, among other things, acknowledges the importance of deaf and hard of hearing children being able to socialize with each other.<sup>118</sup> These bill of rights also may require the IEP team to use a communication plan for deaf and hard of hearing students, in recognition of the "special factors" provision described previously.<sup>119</sup> In this sense, a Deaf Children's Bill of Rights is generally more useful at the IEP, rather than the IFSP, stage.

### III. THE CAMPAIGN: LANGUAGE EQUALITY & ACQUISITION FOR DEAF KIDS

The Language Equality & Acquisition for Deaf Kids (LEAD-K) campaign is a kindergarten-readiness grassroots campaign that seeks to promote language acquisition for deaf and hard of hearing children from birth through age five.<sup>120</sup> LEAD-K seeks to end language deprivation via a two-pronged approach: first, by providing information to families about language milestones and giving assessments that measure the child's progress toward these milestones; and second, by using this assessment data to hold state education systems accountable for deaf and hard of hearing children's failure to meet the milestones.<sup>121</sup>

LEAD-K is a national campaign which provides model legislation for adoption by states. The national LEAD-K team is led by Julie Rems-Smario, Public Relations Director, and Sheri Farinha, Campaign Director. Together, Rems-Smario and Farinha serve as the co-chairs of

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118. CAL. EDUC. CODE § 56000.5 (West 2019).

119. *See, e.g.*, H.B. 96-1041, 60th Gen. Assemb., Reg. Sess. (Co. 1996), 1996 Colo. Sess. Laws 39-42. Colorado provides the following special factors:

(I) The child's individual communication mode or language; (II) The availability to the child of a sufficient number of age, cognitive, and language peers of similar abilities; (III) The availability to the child of deaf or hard-of-hearing adult models of the child's communication mode or language; (IV) The provision of appropriate, direct, and ongoing language access to teachers of the deaf and hard of hearing and interpreters and other specialists who are proficient in the child's primary communication mode or language; and (V) The provision of communication-accessible academic instruction, school services, and extracurricular activities.

*Id.*

120. *About LEAD-K*, LEAD-K, <http://www.lead-k.org/about/> [<https://perma.cc/7W4U-5K39>].

121. *Id.*

the national LEAD-K campaign.<sup>122</sup> The campaign began in 2012 in California with the launch of California Senate Bill 210 and spread nationwide.<sup>123</sup> To date, twelve states have passed LEAD-K bills, and approximately fifteen other states have LEAD-K teams in various stages of development.

The philosophy behind LEAD-K is that addressing the issue of language deprivation in deaf and hard of hearing children is crucial to children's academic and social development. To that end, the focus of the campaign is language acquisition, regardless of the language(s) that is used. The goal of the LEAD-K campaign is that all deaf and hard of hearing children enter kindergarten with age-appropriate language and literacy skills.<sup>124</sup>

This Part discusses the development of the LEAD-K campaign and its model bill as well as the states that have adopted LEAD-K bills. This Part then considers how LEAD-K represents a new path in deaf education.

#### *A. Development of LEAD-K Campaign and the Model Bill*

The national campaign, chaired by Rems-Smario and Farinha, works with state-level LEAD-K teams to provide tools and support to pass LEAD-K legislation in their states.<sup>125</sup> The national LEAD-K campaign partners and collaborates with several organizations, including the Nyle DiMarco Foundation, the National Association of the Deaf, the American Society for Deaf Children, Dawn Sign Press, CueSign, and a host of other organizations representing a broad and diverse range of stakeholders.<sup>126</sup> The national campaign also embarked on a new partnership with the Alexander Graham Bell Association for the Deaf and Hard of Hearing (AGB), announced on October 26, 2018.<sup>127</sup> In LEAD-K's announcement

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122. See *Meet Our Team!*, LEAD-K, <http://www.lead-k.org/team/> [https://perma.cc/CZ85-KD2B] (providing a complete list of LEAD-K's "Advocates"); *Media*, LEAD-K, <http://www.lead-k.org/media/> [https://perma.cc/V7WH-Z5TR] (listing Julie Rems-Smario and Farinha as the public relations director and campaign director, respectively of LEAD-K, as well as the co-chairs of the national team).

123. S.B. 210, 2015 Sen. Reg. Sess. (Cal. 2015).

124. *About LEAD-K*, *supra* note 120.

125. See *LEAD-K Response to R.O.A.R.*, LEAD-K, (Feb 2, 2019), <http://www.lead-k.org/posts/lead-k-response-to-roar/> [https://perma.cc/MJ5L-FGT8] (describing how the national LEAD-K team works with and invests in the state teams).

126. *Meet Our Team!*, *supra* note 122.

127. See *LEAD-K and AG Bell Reach Historic Agreement*, LEAD-K (Oct. 26, 2018), <http://www.lead-k.org/posts/lead-k-and-ag-bell-reach-historic-agreement/> [https://perma.cc/ZW9M-QX5K] (announcing the meeting held between representatives of the national LEAD-K team and AGB "to discuss shared goals related to language acquisition and literacy"). In the announcement, Farinha stated:

It's an exciting time to see two otherwise polarized groups come together to focus and

of this partnership, it recognized how historic and unique its relationship is with AGB. AGB's express mission is to ensure that deaf and hard of hearing people hear and speak.<sup>128</sup> AGB focuses on developing listening and spoken language and has long been at odds with many in the deaf community who view AGB's methods as oppressive and discriminatory. LEAD-K's arrangement with AGB has not been without controversy.<sup>129</sup>

### 1. Model bill

Under the LEAD-K model bill, the state's entity with responsibility for the education of deaf and hard of hearing children selects developmental language milestones, based on existing standardized norms.<sup>130</sup> These

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support a legislative initiative aimed at changing the landscape of Deaf children's language acquisition rights in ASL and English. All stakeholders are now at the table to get the LEAD-K bill passed in their states. With language acquisition accountability and data in place, we can now develop resources for each Deaf child to arrive at kindergarten ready for literacy, reading, and writing. Meeting the language acquisition and development for all Deaf babies is a basic human right.

*Id.*; see also *AG Bell and LEAD-K Reach Historic Agreement*, A.G. BELL ASS'N DEAF & HARD HEARING (Oct. 26, 2018), <https://www.agbell.org/Resources/Articles-Documents/View/AG-Bell-and-LEAD-K-Reach-Historic-Agreement> [<https://perma.cc/6GY5-NRHJ>] (making an identical announcement to the one LEAD-K posted).

128. *Our Mission*, A.G. BELL ASSOCIATION DEAF & HARD HEARING, <https://www.agbell.org/> [<https://perma.cc/QH63-FDL3>] ("Our Mission: Working globally to ensure that people who are deaf and hard of hearing can hear and talk.").

129. For a poignant example, Laurene Simms, a black deaf woman and professor of education at Gallaudet University, said with respect to LEAD-K's partnership with AGB, "[f]or me, it feels like the NAACP partnered with the Ku Klux Klan." Laurene Simms, *Beyond the LEAD-K: Core Values*, YOUTUBE (Nov. 22, 2018), [https://www.youtube.com/watch?v=FwCzCFR\\_920](https://www.youtube.com/watch?v=FwCzCFR_920) [<https://perma.cc/TCV5-QDK7>] (English transcript available at [https://docs.wixstatic.com/ugd/1d9bc6\\_1011ee7ee5fa48d9a8f92228b57e5992.pdf](https://docs.wixstatic.com/ugd/1d9bc6_1011ee7ee5fa48d9a8f92228b57e5992.pdf) [<https://perma.cc/2N86-RMDL>]). As another example, a deaf and ASL advocacy group called R.O.A.R. ("Reclaiming Our ASL Rights") sent an open letter to LEAD-K, demanding LEAD-K withdraw from the partnership with AGB, to which LEAD-K publicly responded. *LEAD-K Response to R.O.A.R.*, *supra* note 125. After outcry from the deaf community, LEAD-K published an announcement, apologizing for the "triggers that the announcement about the agreement with AGB created," further explaining its agreement with AGB, and emphasizing that LEAD-K did not retreat on any of its core principles in the meeting with AGB. *LEAD-K Statement*, LEAD-K (Nov. 13, 2018), <http://www.lead-k.org/posts/lead-k-statement/> [<https://perma.cc/H26Y-JTU9>]. In the subsequent announcement, LEAD-K explained that the reason it requested the meeting with the national AGB team was because some of the state AGB chapters had successfully blocked state-level LEAD-K legislation. The agreement with AGB led to a revised model bill, which LEAD-K reports is stronger because AGB is actively supporting/sponsoring a bill that recognizes ASL and English as *language* options that must be shared with parents. *Id.* AGB also received pushback from its constituents, and in response, on November 21, 2018, it published FAQs addressing the LEAD-K bill. *AG Bell FAQs on Recent LEAD-K Agreement*, A.G. BELL ASS'N DEAF & HARD HEARING (Nov. 21, 2018), <https://www.agbell.org/Resources/Articles-Documents/View/ag-bell-frequently-asked-questions-faqs-on-revised-lead-k-model-bill-and-related-agreement> [<https://perma.cc/BXP9-G584>].

130. Model Bill, *supra* note 10, § 1(a).

milestones are selected for purposes of developing a parent resource guide that will present the developmental milestones in terms of typical development of all children based on their age.<sup>131</sup> The parent resource guide will be aligned with the state's existing guidelines and instruments used to assess the development of children with disabilities under federal law, as well as state standards with respect to English language arts. The model bill specifies that parents have the right to select the language ("ASL, English or both") for their child's language acquisition and developmental milestones.<sup>132</sup>

The model bill also requires the state to select existing tools or assessments for educators that can be used to assess the language and literacy development of deaf and hard of hearing children.<sup>133</sup> These tools for educators are required to be in a format that shows stages of language development and shall be selected to track the development of deaf and hard of hearing children's expressive and receptive language acquisition and developmental stages toward English literacy.<sup>134</sup> The model bill states that these assessments "[m]ay be used, in addition to the assessment required by federal law, by the child's IFSP or IEP team, as applicable, to track deaf and hard-of-hearing children's progress, and to establish or modify IFSP or IEP plans."<sup>135</sup>

Under the model bill, if the deaf or hard of hearing child does not demonstrate progress, the IEP or IFSP team is required to explain in detail the reasons why, and recommend specific strategies and programs "that shall be provided to assist the child's success toward English literacy."<sup>136</sup> The model bill includes timeframes for recommending, selecting, and adopting the language development milestones.<sup>137</sup>

The bill establishes an "ad hoc advisory committee" for the purposes of developing the language development milestones for children who are deaf or hard of hearing.<sup>138</sup> The advisory committee shall be comprised of thirteen members, a majority of whom are deaf or hard of hearing. The model bill also calls for the advisory committee to be comprised of a balance of members who "personally, professionally or parentally use the dual languages of ASL and English and members who personally,

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131. *Id.*

132. *Id.*

133. *Id.* § 1(b).

134. *Id.*

135. *Id.*

136. *Id.* § 1(c)(2).

137. *Id.* § 1(d).

138. *Id.*

professionally or parentally use only spoken English.”<sup>139</sup>

The model bill requires the state department to annually produce a publicly available report reporting on the language and literacy development of deaf or hard of hearing children from birth to age five and show it relative to peers who are not deaf or hard of hearing.<sup>140</sup> The bill states that all activities shall be consistent with federal law regarding the education of children with disabilities and regarding the privacy of student information.<sup>141</sup> The term “language” is explicitly defined to include both American Sign Language and English.<sup>142</sup>

### *B. State Adoption of the Model Bill*

As of this writing, twelve states have adopted LEAD-K legislation. The LEAD-K model bill was based on California’s Senate Bill 210. As described below, thus far, the adopting states have adopted the following variations of the model bill: either requiring the statewide adoption of language development milestones via recommendations of an advisory committee or working group but *not* at this stage including a requirement to publicly report on an annual basis the language and literacy development of deaf and hard of hearing children compared to their hearing peers (Variation I); or generally the same requirements as the model bill but extending the ages of applicability from birth through age eight instead of through age five (Variation II). In the case of Variation I, the LEAD-K teams are generally seeking to introduce the bill in a two-step process. The first step is to secure statewide adoption of the language development milestones and develop the advisory board, with the plan to introduce the publicly available reporting requirement in a subsequent legislative session.<sup>143</sup>

- *California*: Senate Bill 210 adopted as Section 56326.5 to the Education Code in 2016.<sup>144</sup> The California LEAD-K bill is the bill that was used as LEAD-K’s model bill.
- *Kansas*: Senate Bill 444 adopted as Section 75-5397e of the Kansas Statutes Annotated in 2016.<sup>145</sup> The Kansas LEAD-K

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139. *Id.* § 1(e).

140. *Id.* § 1(g).

141. *Id.* § 1(h).

142. *Id.* § 1(j).

143. *See, e.g., Oregon Became 4th State to Have LEAD-K*, OR. ASS’N DEAF, <https://oad1921.org/article/oregon-became-4th-state-have-lead-k> [<https://perma.cc/R9AA-UQNO>] (“This act established a task force to study the IDEIA behind LEAD-K. This act is not the actual LEAD-K bill, the actual one will be introduced in [the] 2019 legislative section.”).

144. CAL. EDUC. CODE § 56326.5 (West 2016).

145. KAN. STAT. ANN. § 75-5397e (2016).

law is Variation II of the model bill. The publicly available report was projected to be released January 31, 2019, and on each January 31 thereafter.

- *Hawaii*: Senate Bill 2476 Act 177 adopted as Section 321-352.2 of the Hawaii Revised Statutes in 2016.<sup>146</sup> The Hawaii LEAD-K law is Variation I of the model bill.
- *Oregon*: House Bill 3412 adopted as Section 326.111 of the Oregon Revised Statutes in 2017.<sup>147</sup> The Oregon LEAD-K law is Variation I of the model bill.
- *South Dakota*: House Bill 1155 adopted as Section 13-33B-1 of the South Dakota Consolidated Law in 2018.<sup>148</sup> The South Dakota LEAD-K law is Variation I of the model bill.
- *Georgia*: House Bill 844 adopted as Section 30-1-5 of the Georgia Code Annotated in 2018.<sup>149</sup> The Georgia LEAD-K law is Variation II of the model bill. The publicly available report was projected to be released September 1, 2019, and on each September 1 thereafter.
- *Louisiana*: House Bill 199 adopted as Section 17:1960.1 of the Louisiana Revised Statutes in 2018.<sup>150</sup> The Louisiana LEAD-K law is Variation I of the model bill.
- *Indiana*: House Enrolled Act No. 1484 adopted as Section 20-35-12 of the Indiana Code.<sup>151</sup> The Indiana LEAD-K law is Variation I of the model bill.
- *Texas*: House Bill 548 adopted as Section 29.316 to the Education Code.<sup>152</sup> The Texas LEAD-K law is Variation II of the model bill.
- *Maine*: Senate Bill No. 642 was signed by the governor on June 20, 2019.<sup>153</sup> The Maine LEAD-K bill is Variation I of the model bill.
- *Connecticut*: Substitute House Bill No. 7353 was signed into law by the governor on July 12, 2019.<sup>154</sup> The Connecticut LEAD-K bill requires the Department of Education to

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146. HAW REV. ST. § 321-352.2 (2016).

147. OR. REV. ST. § 326.111 (2017).

148. S.D. CODIFIED LAWS § 13-33B-1 (2018).

149. GA. CODE ANN. § 30-1-5 (2018).

150. LA. STAT. ANN. § 17:1960.1 (2018).

151. IND. CODE § 20-35-12 (2019).

152. TEX. EDUC. CODE ANN. § 29.316 (West 2019).

153. ME. STAT. tit. 20-A, § 7204.8 (2019).

154. H.B. 19-184, 2019 Leg., Reg. Sess. (Conn. 2019).

establish a working group to “develop guidelines concerning appropriate language assessments, practices and programs and the provision of immediate interventions” for deaf and hard of hearing children.<sup>155</sup>

- *New Jersey*: Senate Bill No. 2045 was signed into law by the governor on August 5, 2019.<sup>156</sup> The New Jersey LEAD-K bill is Variation I of the model bill.

In several states, LEAD-K bills have been introduced but have failed to pass.<sup>157</sup> Still other states have LEAD-K teams at various stages in the process of developing and introducing bills to their legislatures. LEAD-K is truly a grassroots campaign made up of volunteers across the United States. Many state-level LEAD-K teams exist via Facebook groups and other forms of social media. Currently, there are LEAD-K teams in various stages of development in Arizona, Colorado, Delaware, Idaho, Illinois, Iowa, Massachusetts, Nevada, New York, Ohio, Pennsylvania, Utah, and Washington.<sup>158</sup>

As of this writing, the only states projected to have released statewide data as part of its LEAD-K bill are California (as of July 31, 2017, July 31, 2018, and July 31, 2019), Kansas (as of January 31, 2019), and Georgia (as of September 1, 2019). At this point, it is still very early to have or make sense of any data. For example, Kansas is instituting a comprehensive set of assessments for its deaf and hard of hearing children on a rolling basis, where fifty children ages birth to three will be tested in its first year.<sup>159</sup>

California, whose Senate Bill 210 formed the basis of the model LEAD-K bill, is the only state to have begun full implementation of

155. *Id.*

156. S.B. 2045, 218th Sen. Reg. Sess. (N.J. 2019).

157. The Texas Office of Deaf and Hard of Hearing Services tracks the progress of state-wide LEAD-K bills. See Susie Tiggs, LANGUAGE ACQUISITION BILLS AND DEAF CHILD BILL OF RIGHTS, <https://www.livebinders.com/play/play?id=2106355> [<https://perma.cc/PN9Q-CV5M>] (showing LEAD-K bills introduced but not passed in Iowa, New York, Virginia, Michigan, Rhode Island, Mississippi, New Hampshire, West Virginia, Missouri, and Alabama).

158. See, e.g., LEAD-K Arizona (@www.leadkarizona.org), FACEBOOK, <https://www.facebook.com/www.leadkarizona.org/> [<https://perma.cc/2SYH-A2Q6>] (illustrating one of the various examples of LEAD-K Facebook groups); see also LEAD-K Illinois (@LeadKillinois), FACEBOOK, <https://www.facebook.com/LeadKillinois/> [<https://perma.cc/88HQ-FC3D>] (showing another example of a state LEAD-K team Facebook group).

159. See K.S.A. 75-5397E ADVISORY COMMITTEE, THE LANGUAGE ASSESSMENT OF CHILDREN WHO ARE DEAF/HARD OF HEARING AGES BIRTH THROUGH 8 YEARS, K.S.A. 75-5397E ADVISORY COMMITTEE FINAL REPORT 10 (Jan. 31, 2018), [http://images.pcmac.org/SiSFiles/Schools/KS/KansasStateSchools/SchoolForTheDeaf/Uploads/DocumentsCategories/Documents/KSA\\_75-5397e\\_FINAL\\_REPORT\\_%7BSIS03087858BEF8%7D.pdf](http://images.pcmac.org/SiSFiles/Schools/KS/KansasStateSchools/SchoolForTheDeaf/Uploads/DocumentsCategories/Documents/KSA_75-5397e_FINAL_REPORT_%7BSIS03087858BEF8%7D.pdf) [<https://perma.cc/54KC-ULJP>] (explaining Kansas’s process of phasing in language assessments over a five-year period).

LEAD-K. California's LEAD-K language milestones are publicly available on its website.<sup>160</sup>

At this point, reports were required to have been released by January 31, 2017, January 31, 2018, and January 31, 2019. The "Senate Bill 210 Report 2017" is available on the website of the California Department of Education.<sup>161</sup> The report identifies assessments of infants, toddlers, and preschool age children according to the following groups: "Deaf Children," "Hard of Hearing Children," and "Total Children with IFSPs and IEPs" (which includes all of the first and second groups).<sup>162</sup> Because it is still early in the implementation of Senate Bill 210, the report is based on existing state-wide assessments, which were not created for the explicit purpose of tracking language acquisition or literacy development for deaf and hard of hearing children as compared to hearing peers. California has adopted the SKI-HI Language Development Scale as its assessment for language development.<sup>163</sup>

### C. Implications of LEAD-K for Deaf Education

This Part IV.C discusses the implications of LEAD-K for the education of deaf and hard of hearing children. LEAD-K's focus on tracking a child's language development is important for families to have an accessible way to monitor their child's language development. LEAD-K is deaf-led, bringing together people's professional and lived experience. LEAD-K's focus on accountability means it has the potential to truly transform deaf education for the next generation of deaf and hard of hearing children.

#### 1. LEAD-K is focused on the child's language development

LEAD-K's dual focus on language development and accountability drives attention to how and what deaf and hard of hearing children are learning rather than the methods by which they are being taught. LEAD-K's focus on language acquisition and development is pedagogically

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160. *Senate Bill 210 Language Milestones*, CAL. DEP'T EDUC., <https://www.cde.ca.gov/sp/ss/dh/sb210langmilestones.asp> [<https://perma.cc/X2JN-2LUF>] (last updated Oct. 13, 2017).

161. SENATE BILL 210 REPORT 2017, CAL. DEP'T OF EDUC.: DESIRED RESULTS ACCESS PROJECT (2017) (listed as *Desired Results Developmental Profile Report for Children who are Deaf or Hard of Hearing* at <https://www.cde.ca.gov/sp/ss/dh/>).

162. *Id.*

163. *See SB210 - LEAD-K Language Assessments*, CAL. SCH. FOR THE DEAF: EARLY START RESOURCES, <https://sites.google.com/csdeagles.net/es-teachers/home/assessments/sb-210-lead-k> [<https://perma.cc/TTT9-ZBF5>] (stating that the committee of stakeholders has selected the SKI-HI Language Development Scale as the language assessment instrument for deaf and hard of hearing children in California).



sound. According to researchers Hall, Levin, and Anderson, an “early assessment of language access is crucial; this would increase the likelihood of deaf children reaching appropriate language milestones to maintain a healthy developmental path.”<sup>164</sup> The language assessment is consistent with best practices as set forth by NASDSE’s *Educational Service Guidelines*, which specifically states that “[e]arly language development is critical to cognition, literacy and academic achievement,” and that “[f]amilies are critical partners.”<sup>165</sup> Further, the focus on language helps families of deaf and hard of children understand that difference between *language* and *speech*, which often may become conflated with deaf and hard of hearing children. Speech is one modality in which language can be expressed.<sup>166</sup>

LEAD-K’s focus on language also represents a paradigm shift away from the medicalization of deafness and also away from the spoken versus signed language paradigm. By focusing instead on the *outcomes* that adherents of both paradigms seek—which is language acquisition for deaf and hard of hearing children—LEAD-K is deliberately not engaging in the traditional ideological split between spoken and signed languages.

At LEAD-K, we believe that Deaf children benefit from American Sign Language (ASL), a natural visual language, however our goal is language acquisition regardless of the language used, whether ASL or English or both. We cannot afford to lose another generation of Deaf children by engaging in a[n] ideological war. Deaf children who have language are Kindergarten-ready.<sup>167</sup>

LEAD-K takes nothing away from families who decide that their deaf and hard of hearing children will use hearing aids, cochlear implants, and be taught primarily or exclusively via listening and spoken language methods.<sup>168</sup> In fact, as further discussed in Part IV, LEAD-K represents something of a course-correction in terms of the resources and options made available to parents of deaf and hard of hearing children. This is consistent with Zimmerman and Horejes’s imperative that “[w]hile understanding and recognizing these ideologies is important, [a]t the same time, it is imperative to examine avenues to transcend these

164. Hall, Levin, & Anderson, *supra* note 60, at 767.

165. NASDSE, EDUCATIONAL SERVICE GUIDELINES, *supra* note 41, at 2–3.

166. See AM. SPEECH-LANGUAGE-HEARING ASS’N, *supra* note 64 and accompanying text (distinguishing speech from language).

167. *About LEAD-K*, *supra* note 120.

168. See *Mythbusters*, LEAD-K, <http://www.lead-k.org/leadkfaq/> [<https://perma.cc/42SZ-YT4Q>] (“The LEAD-K bill does not and will not interfere with a family’s decision to have their deaf child learn to listen and speak. Again, the assessments are conducted in *one* or *both* languages, American Sign Language and English. Language is the family’s decision.”).

polarizing either/or paradigms when it comes to cultural and linguistic choices within deaf education.”<sup>169</sup>

## 2. LEAD-K is deaf-led and inclusive

The LEAD-K campaign was started by and is run by deaf people, and it includes a host of sponsors, partners, and collaborators, including AGB, which has drawn push back from some deaf rights advocacy groups, because of members of the deaf community’s past experiences and trauma with AGB.<sup>170</sup> In addition to these challenges from within the deaf community, press abounds about the LEAD-K bill reigniting deaf culture wars—much of it replete with misinformation, such as the LEAD-K bill requiring that all deaf and hard of hearing children use ASL.<sup>171</sup> In addition to misinformation in the popular press, there have also been challenges from certain stakeholder industry groups, including the American Speech-Language Hearing Association and the American Cochlear Implant Alliance.<sup>172</sup>

A core-tenant of LEAD-K is that it is “Deaf-run” and “Deaf-centric.”<sup>173</sup> Even with these growing pains from within and outside of the deaf community, LEAD-K’s potential impact is significant. By adopting the model LEAD-K bill, states are formally recognizing ASL as a language by and for deaf and hard of hearing people. The LEAD-K team

169. Zimmerman & Horejcs, *supra* note 12, ch. 6, at 2.

170. See *supra* notes 127–129 and accompanying text (discussing some of the reported reactions to the announcement of LEAD-K’s collaboration with AGB).

171. See, e.g., Hanno van der Bijl, *Alabama Bill Highlights Latest Battle in Deaf Culture Wars*, AL.COM (Mar. 28, 2017), [https://www.al.com/news/index.ssf/2017/03/alabama\\_debate\\_highlights\\_late.html](https://www.al.com/news/index.ssf/2017/03/alabama_debate_highlights_late.html) [<https://perma.cc/RD4S-6NV3>] (distinguishing between “deaf culture” advocates who support HB 253 and the “hearing deaf” community that uses listening and spoken language); see also, e.g., Jane Madell, *The Spoken Language vs ASL Debate is Back*, HEARING HEALTH & TECH. MATTERS (June 14, 2016), <https://hearinghealthmatters.org/hearingandkids/2016/spoken-language-vs-asl-debate-back/> [<https://perma.cc/FA6V-QMCT>] (“As there always has been, there are people pushing for ASL for all children with hearing loss. Now there is a group (LEAD-K), which is pushing for sign language for all deaf kids and calling it language equality.”). The LEAD-K campaign released a four-page document called “Mythbusters” to address some of the misinformation surrounding the Model Bill. *Mythbusters*, *supra* note 168.

172. LEAD-K has released public statements challenging information released by these groups. See *OPEN LETTER to American Speech-Language-Hearing Association (ASHA)*, LEAD-K (Feb. 27, 2019), <http://www.lead-k.org/posts/open-letter-to-asha/> [<https://perma.cc/SP6M-9BBG>] (objecting to, among other things, ASHA’s assertion that LEAD-K restricts consumer choice and supports ASL over other language choices); *AN OPEN LETTER: To Donna Sorkin, Executive Director, American Cochlear Implant Alliance (ACIA)*, LEAD-K (Mar. 8, 2019), <http://www.lead-k.org/posts/an-open-letter-to-donna-sorkin-executive-director-american-cochlear-implant-alliance-acia/> [<https://perma.cc/XVK4-QPHX>] (countering ACIA’s assertion that the LEAD-K bill requires every child who is deaf or hard of hearing to learn ASL).

173. *LEAD-K Statement*, *supra* note 129.

stated: “What is extremely important and groundbreaking about LEAD-K is that it expressly states ASL as one of the languages used by Deaf children in the United States in addition to English.”<sup>174</sup> This represents a more inclusive approach to the education of deaf and hard of hearing children, and an opportunity to lead to increased levels of family awareness and understanding of language choices for their deaf and hard of hearing children.<sup>175</sup>

### 3. LEAD-K as potentially transformative for deaf education

LEAD-K has enormous potential for the education of deaf and hard of hearing children. This Part IV.C.3 discusses how the adoption of LEAD-K can drive change at the individual level of a deaf or hard of hearing child and at the broader level of early intervention programming across the state. This Part also considers future implications for LEAD-K, referring to the work of Professor Laurene Simms.

The LEAD-K model bill requires states to adopt language development milestones and assessments for educators to use to track deaf and hard of hearing children’s progress along those milestones.<sup>176</sup> The IDEIA currently requires the use of assessments to determine the child’s level of performance and educational needs but does not require a specific assessment of a child’s language development. Moreover, the language milestones selected under LEAD-K will be used across the state in assessments of deaf and hard of hearing children. This is a new level of accountability for IEP and IFSP teams and can drive programming and remediation programming for deaf and hard of hearing children as soon as they enter early intervention. The adoption of language milestones will give the IFSP or IEP team information needed to intervene early, rather than when a child enters school and is behind.

The milestones then become an accountability tool that families can use to drive programming in the IFSP or IEP meeting. The LEAD-K founders crafted this deliberately. Rems-Smario poignantly explained that in the critical short term, for the deaf and hard of hearing children that we are raising and teaching today, data from that individual child’s language assessment can be used as leverage in her IFSP or IEP team meeting.<sup>177</sup>

As we see more data from states that have adopted a model bill or will do so in the future, other states can identify groups at greatest risk and target resources appropriately. Under IDEIA, states can require more (but

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174. *Id.*

175. CAL. ASS’N OF THE DEAF, *supra* note 72, at 6.

176. Model Bill, *supra* note 10, at § 1(a).

177. *LEAD-K Response to R.O.A.R.*, *supra* note 125.

not less) than the federal law requires. States can add to their IFSP and IEP requirements to account for groups who are at greatest risk. Ultimately, this could lead to a conclusion that change is warranted at the federal level, and to IDEIA itself, based on the data from the LEAD-K reporting states.

In addition, Rems-Smario believes that in the long-term, tracking children's progress according to language milestones will validate the importance of ASL in deaf education.<sup>178</sup>

a. Future issues to be addressed

While LEAD-K's focus on language access is crucial, Professor Laurene Simms urges the community to go further. In the popular and educational Facebook group she runs, "3R: Revisit, Rethink, Re-educate," while congratulating and honoring the LEAD-K teams for passing the bills in their states, Professor Simms noted the model LEAD-K bill uses ASL as a language to be used to develop the language skills necessary to acquire English literacy skills.<sup>179</sup> In other words, the bill views ASL as a tool to acquire command of English reading and writing skills, with literacy skills in English as the ultimate goal of the bill.<sup>180</sup> Professor Simms questions the equity with which the languages are viewed and asks where the encouragement is to acquire ASL for the ultimate goal of developing fluency in ASL.<sup>181</sup> Professor Simms also raised concerns about the disparity in current expectations for licensure and credentialing of professionals who are qualified to assess language development milestones in ASL versus in English, as well as the issue of the dire need for deaf children of color to see themselves represented in their role models, as teachers of deaf students are predominantly white women.<sup>182</sup>

These are critically important issues, and as the model LEAD-K bill is adopted in more states and states report data year-to-year, it will be a way to address and focus the issues that Professor Simms raises. Potentially,

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178. *Id.*

179. Simms, *supra* note 129.

180. *See, e.g.*, Model Bill, *supra* note 10, at § 1(b)(2) ("These educator tools or assessments . . . [s]hall be selected for use by educators to track the development off deaf and hard-of-hearing children's expressive and receptive language acquisition and developmental stages toward English literacy."); *id.* at § 1(c)(2) ("If a deaf or hard-of-hearing child does not demonstrate progress in expressive or receptive language skills, . . . the child's IFSP or IEP team . . . shall recommend specific strategies, services, and programs that shall be provided to assist the child's success toward English literacy.").

181. Simms, *supra* note 129 ("[I]t's important to not strive for equality, but rather equity. It's not about hearing and Deaf people being equal. Instead, look at the whole person or being.").

182. *Id.*

the promulgation of LEAD-K across the nation can serve as a platform to leverage concerns of equity throughout deaf education.

Another area of consideration is the extent to which the LEAD-K bill is inclusive of the greater deaf, deaf blind, and deaf disabled community. With respect to the annual reporting, the model bill specifies that the annual reporting of deaf and hard of hearing children's language and literacy rates "include[s] those who are deaf or hard of hearing and have other disabilities, relative to their peers who are not deaf or hard of hearing."<sup>183</sup> The model bill does not otherwise specifically refer to children who have disabilities in addition to deafness, so this may be an area for future consideration.

#### IV. LESSONS FROM LEAD-K FOR EARLY INTERVENTION UNDER PART C OF THE IDEIA

This Part discusses how LEAD-K's focus on outcomes highlights the failure of the early intervention framework under the IDEIA, which focuses on the family's needs, to sufficiently address the primary question of what it is that the child with a disability needs to do. The focus revolves around the services needed to support the family of the child rather than the more fundamental question of what the child with a disability needs to achieve. In the context of early intervention services for deaf and hard of hearing children, this Article contends that the child should be viewed as a unique stakeholder from the family unit.

Part IV.A explores how LEAD-K recognizes the child as a unique stakeholder from the family. In Part IV.B, this Article presents a proposed amendment to the IDEIA that would require all IFSPs to include a statement of the overall goals that the family has for the child and the steps the IFSP team will take in that year to work toward those goals. Part IV.B also presents an alternative proposal limited to the population of deaf and hard of hearing children and addresses several anticipated counterarguments to the proposals.

##### *A. LEAD-K Reveals a Flaw in the Structure of Early Intervention*

Early intervention services focus on what services the family needs to support the child. This makes sense in a lot of ways. Consider, for example, a child with an insulin pump. Certainly, family services should include teaching the family members how to properly monitor and use the pump, how to clean it, and that sort of thing. This family-centered approach to early intervention reflects societal views on inclusion, as

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183. Model Bill, *supra* note 10, at § 1(g).

reflected in the law and policy shift away from isolating children with disabilities.<sup>184</sup> This shift in view has been critically important for the lives and rights of children with disabilities and their families. We no longer institutionalize and isolate children with disabilities. Instead, society recognizes children with disabilities and their families as full community members.

This Article contends that now, this framework of what the family needs in order to support the child conflates two important questions into one. First, before the issue of family services is addressed, the fundamental question of what it is that we expect the infant or a toddler with a disability to achieve needs to be addressed. After that first question is answered, then the second question can be addressed: what supports does the family need to help the child achieve that outcome. These questions are related and overlap, but it should be recognized that while the child is a part of the family unit, she is also distinct from it. Instead, these questions tend to be conflated with a determination of what is best for the family.

Early intervention service providers emphasize parental autonomy in making decisions that are best for the family. Best practices in early intervention for deaf and hard of hearing children endorse an “unbiased” approach, meaning that the early intervention provider does not advocate one approach over another when the family is making language and communication decisions for their deaf and hard of hearing child.<sup>185</sup> Families (most of whom are hearing and not familiar with sign language) are provided information in a neutral manner about the languages and communication methods that can be used with deaf and hard of hearing children. Assuming that the information provided to families itself is unbiased, and its delivery is unbiased, this approach is weighted heavily

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184. *Early Childhood Inclusion: A Joint Position Statement of the Division for Early Childhood (DEC) and the National Association for the Education of Young Children (NAEYC)*, NAT'L ASS'N EDUC. YOUNG CHILDREN (Apr. 2009), [https://www.naeyc.org/sites/default/files/globally-shared/downloads/PDFs/resources/position-statements/DEC\\_NAEYC\\_EC\\_updatedKS.pdf](https://www.naeyc.org/sites/default/files/globally-shared/downloads/PDFs/resources/position-statements/DEC_NAEYC_EC_updatedKS.pdf) [<https://perma.cc/7KSQ-XHPU>].

185. Moeller et al., *supra* note 7, at 434 (stating that early intervention service providers should “[s]hare information and experiences from a variety of sources that are comprehensive, meaningful, relevant, and unbiased to enable informed decision making.”); *see, e.g.*, EARLY HEARING DETECTION & INTERVENTION PARENT TO PARENT COMMITTEE, A PARENT’S GUIDE TO DEAF AND HARD OF HEARING EARLY INTERVENTION RECOMMENDATIONS 4 (2017) (“Information should be [c]onveyed in an unbiased/culturally sensitive manner”); *see also, e.g.*, Christine Yoshinaga-Itano, *Principles and Guidelines for Early Intervention After Confirmation that a Child Is Deaf or Hard of Hearing*, 19 J. DEAF STUD. & DEAF EDUC. 143, 146 (2014) (best practices recommendations include: “Develop and implement guidelines that address family-to-family support. These guidelines should . . . include[e] the importance of objective, unbiased information”).

against using sign language. The environment within which a family first makes these language and communication decisions is generally shortly after their child's hearing loss has been confirmed, which often is a high-pressure and emotional time. Janet DesGeorges, co-founder and Executive Director of Hands & Voices,<sup>186</sup> a nationwide support group for families of deaf and hard of hearing children, referred to the time frame following the identification of a child as deaf or hard of hearing as “a time of intense vulnerability for parents, as ‘experts’ in the field . . . hold strong opinions about what the ‘best’ path for D/HH children might be in terms of language and communication acquisition.”<sup>187</sup>

When presented essentially equally-weighted options—again, assuming that to be the case—it is not surprising that hearing families tend not to choose sign language, given it is likely that families have never met a signing deaf person. Perhaps they see only that scary statistic about fourth-grade reading levels, or in those early moments, have feelings similar to grief about the baby's deafness and the now different and unknown future they may be envisioning for their child. While families are processing different emotions, a so-called “unbiased” approach about the language options for children does not allow room for consideration that hearing families typically do not have the level of comfort and familiarity with sign language as they do with spoken language.<sup>188</sup> Some jurisdictions are countering this information imbalance by having a deaf mentor program as part of the early intervention team as a source of support for the child and the family.<sup>189</sup>

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186. *Mission*, HANDS & VOICES, <https://www.handsandvoices.org/about/mission.htm> [<https://perma.cc/WQ5Y-AQK7>].

187. DesGeorges, *supra* note 8, at 444; *see also* Merv Hyde et al., *Coming to a Decision About Cochlear Implantation: Parents Making Choices for their Deaf Children*, 15 J. DEAF STUD. & DEAF EDUC. 162, 163 (2010) (“Hearing parents with a recently diagnosed deaf child generally find themselves negotiating a world previously unknown to them. After the diagnosis of their child's deafness, parents may be presented with, or need to seek out, a great deal of information about deafness and the educational, communication, and technological options for deaf children. Given the need to assimilate so much information at a time when they are likely to be experiencing heightened emotions, making decisions about cochlear implantation is often difficult and stressful for parents.”).

188. *See* Moeller et al., *supra* note 7, at 434 (noting that with respect to the best practice principle of “Informed Choice and Decision Making,” early intervention professionals should “[k]eep in mind that ‘informed choice’ is not synonymous with information that is neutral or functionally descriptive. Rather, evaluative information is essential in that it draws attention to the various risks, benefits, and uncertainties related to particular options.”); *see also* Kushalnagar et al., *supra* note 72, at 144 (explaining the problems with the recommendations that families receive unbiased information).

189. *See, e.g.*, *SKI HI Deaf Mentor Program*, SKI HI INSTIT., <http://deaf-mentor.skihi.org/> [<https://perma.cc/DH4F-AHBJ>] (explaining the role of deaf mentors); *see also, e.g.*, Stephanie Olson, *Deaf and Hard of Hearing Mentors & Role Models*, HANDS & VOICES,

With its focus on language acquisition outcomes, the LEAD-K campaign embraces all languages that lead to language acquisition for deaf and hard of hearing children. By focusing on language outcomes (and demanding accountability for those outcomes), LEAD-K charts a path where families receive balanced and comprehensive information about languages and communication options for their deaf and hard of hearing child. Families are free to decide that their child will learn English via listening and spoken language techniques, but they will be making that decision on a more informed basis.

LEAD-K's focus on the child's language acquisition and development shifts to a framework that considers the child as a stakeholder, separate from the family. At first blush, this may seem an odd statement, as the very purpose of the IDEIA is to provide the right to an appropriate education to the *child* with a disability. Yet, early intervention services under Part C of the IDEIA are focused on services to the child *and* the family. LEAD-K's focus on the child's language acquisition helps keep the primary focus on the deaf and hard of hearing child, who will grow up to be a deaf or hard of hearing adult.

*B. Proposed Amendment to Part C of the IDEIA to Require a Statement of the Family's Overall Expectations for the Infant or Toddler with a Disability in the IFSP*

This Article proposes to amend Part C of the IDEIA to require all IFSPs to include a statement of the family's longer-term holistic expectations for the child when the child transitions out of early intervention, and the steps the IFSP team will take in that year in service of those overall goals (the Proposed Amendment). The purpose of the Proposed Amendment is to recognize the primacy of the child's needs in developing the IFSP by focusing on the expectations for the child. The Proposed Amendment seeks to draw from LEAD-K's focus on outcomes to shift focus to the child's needs, recognizing them as unique from the needs of the family.

This statement should be the first part of the IFSP. This requirement should not be confused with the existing IFSP requirement to provide "a statement of the measurable results or outcomes expected to be achieved by the child and the family." The existing requirement is professional-driven, as it requires such things as identifying measurable results and criteria for determining those results. Generally, while families are involved in the decision of which of these to include, the information is



in the knowledge base of the professionals.

The Proposed Amendment, in contrast, would require the IFSP to begin with a family-driven statement of the family's holistic expectations for the child when the child transitions out of early intervention. Including such a statement would facilitate more informed information sharing with families to enable them to craft the statement. Requiring the IFSP team to identify steps to work toward the family's goal would further facilitate information sharing and also provide a mechanism of accountability if those steps are not met. The Proposed Amendment would clarify the role of the child and the child's needs as the ultimate driver in early intervention services. This would essentially serve as the "child statement" counterpart to the existing requirement that the IFSP must contain "a statement of the family's resources, priorities, and concerns relating to enhancing the development of the family's infant or toddler with a disability."<sup>190</sup>

1. Alternative proposal limited to deaf and hard of hearing infants and toddlers

In addition to or instead of the Proposed Amendment, this Article also suggests a separate amendment to the IDEIA that would require an IFSP for a deaf or hard of hearing infant or toddler to consider the infant or toddler's language or communication needs, and the support opportunities for families to develop familiarity, comfort, and skills in the infant or toddler's language and/or communication mode (the "Alternative Proposal"). This more limited Alternative Proposal is essentially the Part C counterpart to the provision in Part B regarding the consideration of "special factors" for children who are deaf and hard of hearing, which mandates that the child's language and communication needs be taken into consideration in developing the child's IEP.<sup>191</sup>

The Alternative Proposal would help maintain the primacy of the child's needs in the analysis of the family's needs by recognizing the need for the analysis of the two separate questions of the child's needs and the family supports needed in service of the child's needs.

This Article set forth this Alternative Proposal as a different way to address the problem of a children's needs being potentially inappropriately subsumed in an analysis of the needs of the family unit. Given the politics and competing paradigms in deaf education, it may be that one of the two proposals is more politically viable at a given time. While neither the Proposed Amendment nor the Alternative Proposal is a

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190. 20 U.S.C. § 1436(2)(d) (2018).

191. 20 U.S.C. § 1414(d)(5)(iv).

perfect fix, the adoption of either (or both) proposals would represent an improvement in the baseline protections provided by the IDEIA by recognizing the infant or toddler with a disability as unique from the family unit.

Short of an amendment to the IDEIA, additional alternatives to either the Proposed Amendment or the Alternative Proposal could include promulgating regulations or interpretive guidance to this effect or updating the model IFSP available on the Department of Education's website.

This Article contemplates several counterarguments that may be levied against the Proposal and/or the Alternative Proposal. One anticipated counterargument is that the proposals fail to respect family autonomy as decision makers.

In the deaf education space, this argument tends to come from opponents of children using sign language who claim that such a proposal reduces family autonomy in making decisions for their children. These claims are similar in spirit to flawed arguments that are often levied against LEAD-K, such as claims that LEAD-K removes parent choice by requiring sign language or prohibits parents from allowing their deaf or hard of hearing child to use spoken language.<sup>192</sup> These claims fail for the same reasons. This is somewhat of a straw argument, as it is apparent from the face of the proposals that neither do anything to reduce family choices or options. They instead are both geared toward empowering families with more information to make decisions for their child. Further, all early intervention services under the IDEIA are optional.

Somewhat at the other end of the spectrum is the potential counterargument that the proposals do not go far enough for deaf and hard of hearing children. Certainly, there could be a degree of redundancy in states that have adopted a LEAD-K bill, because the LEAD-K bill demands much greater accountability than either of the proposals set forth in this Article. However, the IDEIA is a federal law that provides a baseline of protections to which states can always add. Right now, there are thirty-eight states (plus the District of Columbia and other jurisdictions in the United States) that have not adopted the LEAD-K bill.<sup>193</sup>

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192. *See supra* note 171 (showing examples of claims that LEAD-K removes parent choice).

193. As part of its arrangement with AGB, LEAD-K was asked why in its collaboration it did not address concerns of AGB's audism. LEAD-K answered that question as follows:

The LEAD-K bill provides for the measurement and reporting of language development outcomes. By doing this, the LEAD-K bill supplements the implementation of current federal IDEIA law by different states. As a consequence, LEAD-K is limited to the focus

A similar charge may be leveled that the Alternative Proposal is too narrow in addressing only the needs of deaf and hard of hearing children. For example, the “special factors” provision of Part B of the IDEIA also recognizes students with limited English proficiency, students with behavior issues, and other populations, as having unique considerations.<sup>194</sup> This Article recognizes this limitation, which is why the Proposed Amendment is intended to apply to all infants and toddlers who receive early intervention services under Part C.

A more significant potential challenge to the Proposal is possible unintended consequences of the Proposal on other populations. While this Article viewed the Proposal in the context of deaf and hard of hearing children, the Article’s thesis—that early intervention services need to recognize the primacy of the child as a stakeholder with unique needs before addressing the necessary family supports—should ring true for all children. However, future study on other populations may be warranted to further substantiate this claim.

#### CONCLUSION

Part C of the IDEIA conflates the needs of the infant or toddler with a disability with the needs of the child’s family. In early intervention, there are two separate questions that need to be answered in order of priority: First, what is it that the infant or toddler with a disability needs to achieve? Second, what services and supports does the family need to help the child achieve the outcome identified in the first question? Instead, the first question gets overlooked, with the focus going to how best to support the family, without considering the child as a separate stakeholder.

This Article examines LEAD-K, the grassroots campaign to end language deprivation in deaf and hard of hearing children, and analyzes how LEAD-K’s focus on a child’s language acquisition outcomes as an example of an approach where due focus is given to the *a priori* question of identifying the child’s needs before moving on to the family supports in service of the child’s needs. This Article argues that such an approach can drive better information sharing by early intervention professionals, leading to more informed decision making by the child’s parents with respect to selecting services for the infant or toddler with a disability.

This Article proposes an amendment to Part C of the IDEIA to include as a mandatory requirement of a child’s IFSP a statement of what the

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and scope of IDEIA law. The broader civil rights issues of audism and linguisticism are not addressed within IDEIA law and will require different kind of legislation and legislative efforts.

LEAD-K Statement, *supra* note 129.

194. 20 U.S.C. § 1414(d)(3)(B).

infant or toddler with a disability needs to be able to achieve. Then the statements of services and supports for the family will be considered in service of this *a priori* statement.

In many settings and under ideal circumstances, this may be an innocuous change as the needs of the child and the needs of the family to support the child in meeting those needs will be one and the same. This Article looks at these questions in the context of deaf and hard of hearing infants and toddlers and argues that this conflation of questions is inappropriate for this population, particularly given the imbalance in information provided to families on the different languages and communication systems and supports that can help deaf and hard of hearing children thrive. There is the saying, “You don’t know what you don’t know,” which bears itself out in early intervention.

This Article also suggests an alternative proposal in the form of an amendment to the IDEIA providing that, for a deaf or hard of hearing child, the IFSP team must consider her unique language and communication needs in developing her IFSP. This provision would be the Part C counterpart to the “special factors” provision for deaf and hard of hearing children that exists under Part B. Requiring IFSP teams to recognize the language and communication needs of deaf and hard of hearing children would facilitate more informed decision making by families of deaf and hard of hearing children.

While this Article is focused on early intervention services provided to deaf and hard of hearing infants and toddlers, it bears questioning whether and to what extent there are other populations for which the needs of the child and the needs of the family may not wholly overlap. There may be populations for which the proposals set forth in this Article have little to no effect. For example, one could imagine a situation where a pediatrician and parents have concerns about a toddler’s potential delays in gross motor development. In developing an IFSP, the early intervention professional may ask, “what is it that you need her to do so that she can fully participate in family activities?” In this context, the space between the two may be negligible. But it also may be that by subsuming the question of the child’s needs into the question of the family’s needs, families are missing an opportunity to receive all information they would want to make the best decisions for their children.

For populations where there is minimal or negligible space between these questions, this proposal has no effect. At worst, it changes nothing. For other populations of children, the proposals set forth in this Article create more informed decision making by parents and therefore better outcomes for children. For deaf and hard of hearing children, the conflation of these questions is troubling given the weight and biases of

the information that families are given. For this population, adding a provision where the IFSP team must consider the language and communication needs of the child, in addition to isolating the question of what the family expects the child do to, would facilitate more informed family involvement and decision making. Where families are given more complete information about the options available to their child, families will have more agency to make informed decisions about the language choices for their deaf or hard of hearing child.