iejee

International Electronic Journal of Elementary Education
September 2020, Volume 13, Issue 1, 1-19

# Determining Language and Inclusion for Deaf-Plus Children

Steven James Singer[*,a], Kimberly Cacciato[b], Julianna Kamenakis[c], Allison Shapiro[d]

Received : 25 August 2019
Revised : 2 July 2020
Accepted : 23 September 2020
DOI : 10.26822/iejee.2020.169

[*,a]**Corresponding Author:** Steven James Singer. The College of New JerseyNew Jersey, USA.
E-mail: singers@ tcnj.edu
ORCID: http://orcid.org/0000-0003-0580-1547

[b]Kimberly Cacciato. The College of New Jersey, New Jersey, USA.
E-mail: cacciak2@tcnj.edu
ORCID: http://orcid.org/0000-0001-5462-2268

[c]Julianna Kamenakis. The College of New Jersey, New Jersey, USA.
E-mail: kamenaj1@tcnj.edu
ORCID: http://orcid.org/0000-0001-5437-0662

[d]Allison Shapiro. The College of New Jersey, New Jersey, USA.
E-mail: Shapira2@tcnj.edu
ORCID: http://orcid.org/0000-0002-9834-5108



## Abstract

Educators have long argued about the best ways for Deaf children to communicate and how they should be educated. The two notions are inseparable for Deaf students who most often learn language at school. Since the passing of IDEA, most Deaf students have moved from segregated schools to their neighborhood schools where all students might benefit from learning and socializing together—the foundations of inclusion. Might inclusion for Deaf students with multiple disabilities mean something different? In this ethnography, the authors examined the experiences of six families that had school-aged children who were Deaf-Plus and used signed language to communicate. Research questions included: 1) What were the experiences of parents navigating communication and education for their children and 2) What did inclusion mean for their children? Data collection included: Semi-structured interviews, participant observations, and focus groups. The team developed three themes: 1) External Influences on Parent's Decision-Making Regarding Language and Communication, 2) Language and Communication Varies Among Deaf-Plus Children and Their Family Members, and 3) Struggling to Determine and Secure an Inclusive and Productive Learning Environment for Their Deaf-Plus Children. It behooves educators to consider how students' individual characteristics might benefit learning and create improved inclusive experiences.

**Keywords:**

Parents; Deaf With Disabilities; Inclusion; Language

## Introduction

For most parents who have Deaf[1] children, it is likely their first significant encounter with this population. After all, approximately 90% of Deaf children are born to hearing parents (Mitchell & Karchmer, 2004). It is not surprising that, especially during the early years of their children's lives, that parents feel confused and overwhelmed by all the decisions they must make about their Deaf child's communication, technology use, and education (Young, Jones, Starmer, & Sutherland, 2005). They must manage pressures from familial, educational, cultural, and medical sources about these decisions and the messages they receive from these sources often conflict with one another (Mauldin, 2016).

However, parents also may feel a sense of fulfillment and pride over the communication journey they take with their children (Calderon & Greenberg, 2000).

The prevalence of disability in the Deaf population is between 35% and 50% (Mitchell & Karchmer, 2006). Comparatively little is known about the Deaf-Plus[2] population and particularly about the experiences of parents as they navigate the many decisions they must make while determining communication for their children and families or their children's educational placements. These decisions are inextricably linked because language use varies greatly across types of Deaf educational placements and Deaf children most often arrive to school in need of additional language or communication support (Lederberg, Schick, & Spencer, 2013; Schick, Marschark & Spencer, 2006; Svirksy et al., 2000). In this ethnographic study of six families, the authors sought to unearth the unique features of parental decision-making about communication and education for their Deaf children with multiple and complex disabilities. Secondly, the authors wondered how parents conceptualized inclusion and the least restrictive environment (LRE) for their Deaf-Plus children.

*Communication Options for Deaf Children*

It is common to distinguish between different interpretations of what being Deaf means. The medical model emphasizes the importance of assimilation into the hearing world by using hearing aids, cochlear implants, and speech (Foss, 2014; Lane, 1999). For some Deaf people, the combination of their identity, ASL (American Sign Language) use, and shared experiences with other members of Deaf culture determine an individual's membership status in the Deaf community, rather than the severity of one's hearing loss (Holcomb, 2012; Padden & Humphries, 2005). Therefore, individuals who identify as members of the Deaf community (which includes some hearing individuals) value Deafhood as a shared cultural experience rather than a medical condition.

The topic of Deaf children and their language use is one wrought with contention both regarding how it influences academic achievement and sociocultural engagement (Knoors & Marschark, 2013; Moores, 2011; Spencer & Marschark, 2011). Deaf/Hard-of-Hearing (HOH) children often lag behind their hearing peers in academic achievement (Helfand et al., 2001; Marschark et al., 2004; Szymanski et al., 2013, Thierfelder & Stapleton, 2016). Consequently, most Deaf students leave school with literacy and other academic achievement levels below those of their hearing peers, though scholastic achievement varies greatly due to various factors including educational placement, use of technology and age of access to language (see Antia et al., 2009; Marschark et al., 2015; Qi & Mitchell, 2011; Traxler, 2000). The reasons for these education disparities include late exposure to language (Mason et al., 2010), poor language models (Lederberg et al., 2013; Marschark & Spencer, 2010), teachers who are unprepared to instruct Deaf/HOH students (Sass-Lehrer et al., 2016), and educational assessments that do not consider the unique needs of the population (Cawthon et al., 2007).

Most Deaf/HOH children learn to speak and use hearing aids or cochlear implants. Only 15% of Deaf/HOH children learn ASL and have teachers who instruct them using some form of signed language (U.S. Department of Education, 2016). Deaf/HOH students spend 80% or more of their school day in a general education setting, with only 3.1% of students instructed in separate schools (Gallaudet Research Institute, 2011; U.S. Department of Education, National Center for Education Statistics, 2016). Proponents of Deaf/HOH children learning ASL claim that signing gives children both immediate and reliable access to language as well as aids in the development of their Deaf identities, both of which lead to social and scholastic benefits later in life (Allen et al., 2007; Holcomb, 2012; Marschark & Spencer, 2006; Napoli et al., 2015; Shmick et al., 2004). Proponents of oral/aural education claim that Deaf students develop better reading skills and gain access to improved opportunities in a vastly hearing world (Moog, 2000; Mussleman & Kircaali-Iftar, 1996). However, contemporary Deaf scholars are quick to point out that variations in residual hearing, technology use, family background and involvement, school resources, teacher preparation, peer relationships, age of onset, presence of disabilities, and assessment techniques affect academic and social outcomes so drastically that each Deaf child must be considered individually (Cawthon, 2010; Marschark & Hauser, 2011; NASDSE, 2018; Marschark & Spencer, 2010).

*Inclusion and Deaf Education*

Since the passing of the Education for All Handicapped Children Act (1975), which later became the Individuals with Disabilities Education Improvement Act (IDEIA, 2004), children with disabilities have moved away from residential or specialized schools and entered mainstream settings. The IDEIA (2004) states that all students with disabilities must be provided free and appropriate public education in the least restrictive environment (LRE). However, Deaf advocates raise questions regarding what LRE really is for Deaf

students. According to the Special Factors section of the 1997 IDEA amendments, an Individualized Education Program (IEP) team must:

> *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. (IDEA, Part B, Section 614(d)(3)(B)(iv))*

With this in mind, Deaf students a general education placement may not be the most inclusive, especially if they struggle with communication access, academic content, and forming and maintaining social relationships, because may be more restrictive (Singer & Vroman, 2019). Deaf students who attend public schools may lack confidence in their ability to communicate, feel as though they do not fit in with their hearing peers, and experience difficulty developing their Deaf identity (Kent, 2003; Leigh, 1999). Additionally, for students with complex support needs, schools continue to view more restrictive educational placements as appropriate to meet students' academic and social needs (Sauer & Jorgensen, 2012; Strieker et al., 2001). Therefore, rather than focusing on what environment is least restrictive for Deaf students, Singer & Vroman (2019) suggest to instead consider the environment that is the most supportive, most liberating, and most culturally-sustaining.

*Deaf-Plus Children*

The conditions that cause deafness in some children may also contribute to the presence of a disability (Das, 1996; Marschark, 2011). In fact, between 40-50% of Deaf children have a disability (Gallaudet Research Institute, 2012). The general and communication related support needs of Deaf-Plus children are different than those of children who are only Deaf, but they are sometimes overlooked (Knoors & Vervloed, 2003; Whicker et al., 2019). In these cases, preferred communication modes vary based on what is most useful for the child. For example, sign language might be an effective means of communication for some Deaf children with Autism (Szymanski & Brice, 2008), but not for all (Jure et al., 1991). In other cases, Deaf children who have difficulties with motor skills or language processing might use modified forms of signed language with or without Augmentative and Alternative Communication (Lee et al., 2013; van Dijk et al., 2012). McCracken and Turner (2012) found that even if not used for language, cochlear implants may benefit Deaf children with additional complex needs because access to environmental sounds may bring them comfort.

For most families with Deaf children, making decisions about communication, locating and accessing resources, and developing communication skills is a long and evolving process. Chapman et al. (2011) found that newborn Deaf children with other disabilities were screened for hearing loss and diagnosed at a significantly later date compared to children who were only Deaf. Furthermore, it is common that for these children, significant health needs will take priority over hearing loss (McCracken & Turner, 2012), leading to delays in making decisions and implementing plans for communication. Deaf-Plus children and their families typically find that they don't quite fit in traditional social support programs developed for Deaf children, because of their unique communication needs and the demands on their time to attend various treatments and therapies (Borders et al., 2018; McCracken & Turner, 2012). Consequently, children may feel isolated and discourse about them becomes unbalanced, focusing primarily on care needs and what they cannot do rather than what they can or want to do (Wiley et al., 2019).

*Parents' Decisions about Communication and Education for Their Children*

Parents of Deaf/HOH children face difficult decisions regarding language for their child. Many of these decisions are made when parents are still learning how to be parents (Tattersall, 2007). A significant body of scholarship touts the importance of Deaf children accessing some form of complete language (e.g. effective hearing assistive technology or ASL) as early as possible in their lives to support their language learning (Decker et al., 2012; Kushalnagar et al., 2010; Napoli et al., 2015; Young, 2018). During this early time in Deaf children's lives, parents often become overwhelmed when they must evaluate information and possible outcomes regarding technology, communication options, education, and habilitation at a time when they are emotionally vulnerable (DesGeorges, 2003; Kirk et al., 2005; Kurtzer-White & Luterman, 2003). After a diagnosis of hearing loss, which typically occurs very early in a child's life, parents are primarily exposed to medical discourses on how to reduce the effects of that loss (Burke et al., 2011; Hyde & Power 2000). These messages they receive from practitioners are not always substantiated. For example, it is common that parents are told that learning a signed language will impede speech development, which has been frequently debunked (Bailes et al., 2009; Mauldin, 2016).

Another persistent misrepresentation used to promote speaking and listening is that the average Deaf person has a reading ability equivalent to a fourth grade student without mentioning that the average hearing person reads at a 7th grade level and that the moniker Deaf is so broad that these findings may be misleading (see Helfand et al., 2001; Walsh & Volsko, 2008). While parents may receive information about Deaf people and various options for communication and education from social services or medical practitioners, it may be difficult for parents to fairly assess their circumstances given the pervasiveness of oral/aural ideologies in their lives (Gascon-Ramos et al., 2010; Mauldin, 2016). Mauldin (2016) showed that parents reported feeling substantial pressure from the Deaf community to pursue ASL for their children too, suggesting that the discourse parents must negotiate is not one-sided. Furthermore, and understandably, parents often want their children to be similar to them and therefore, make decisions about their communication or cultural affiliations to match this desire (Mauldin, 2016; Napoli et al., 2015; Pitts-Taylor, 2010).

Since 90% of Deaf children are born to hearing parents (Mitchell & Karchmer, 2004), it is unsurprising that these parents tend to have little understanding of ASL or Deaf people. When these parents do choose manual communication to use with their child, it is not long before they realize they are unequipped to supply an ASL-rich environment in which the child could best learn and use the language (Bailes et al., 2009; Napoli et al., 2015). When parents and other members of the family decide to learn a signed language along with their Deaf child, they often struggle to develop fluency because they have limited access to an appropriate language model and learn manually coded English rather than ASL (Weaver & Starner, 2011).

While education and social engagement are important factors in the decisions parents make about how their Deaf children will communicate, they also focus on developing loving and communicative relationships with their children. Young (2003) found that the difficulties parents endured when trying to access vital information after discovering their child was Deaf had significantly affected their parenting experience, including their ability to support their child's development and to adapt to their child's Deafness. When parents are either unable to sign proficiently or the child is not capable of utilizing listening and spoken language, the child and his/her parents may drift apart (Most et al., 2007). However, parent commitment to making a communication plan for the whole family has been found to positively relate to better parental communication exchanges with their children (Calderon et al., 1998; Knoors & Marschark, 2012).

## Methods

### *Research Design*

This research sought to document the experiences of parents of Deaf-Plus children. The researchers wished to understand how family members communicated with one another, what influenced their decisions, and educational experiences of their children in relation to their communication choices. Research questions included: 1) What were the experiences of parents navigating communication and education for their children and 2) What did inclusion mean for their children?

To better understand the experiences of parents who had Deaf-Plus children and the influences on their choices for communication for their child, the research team recruited six families for the study. Participant criteria included having a school-aged Deaf-Disabled child who used ASL[3] to communicate. Participant recruitment consisted of social media advertisements and snowball techniques. The team collected data in four forms: 1) 18 hours of semi-structured interviews, 2) 20 hours of participant observation, 3) Over 150 pages of reflexive journals and field notes, and 4) A two-hour focus group.

The team approached data analysis using open inductive coding for qualitative research (Bogdan & Biklin, 2014) and constant comparison (Kolb, 2012; Smulowitz, 2017) to existing Deaf studies and disability studies scholarship about language acquisition, cultural identity development, and educational placements. The four researchers each read the data several times in order to chunk it into broad categories about communication and social influences. The team then compared the various categories they developed, selecting ones that were consistent among researchers and redefining other categories that differed. Continuing to use open inductive coding, the research team refined and reduced the categories until they were able to develop distinct themes.

### *Theoretical Framework*

In this work, the researchers utilized a combination of disability studies and Deaf studies frameworks to examine the data. These lenses of analysis complement one another, though are distinct fields of study. Disability studies challenges the socially constructed notion of normalcy and "recognizes that disability is a key aspect of human experience, and that disability has important political, social, [cultural] and economic implications for society as a whole, including both disabled and nondisabled people" (Ferguson & Nusbaum 2012, p. 71). Ferguson

Table 1. *Participant demographic information*

| Participants | Khan Family | Padilla Family | Hill Family | Foss Family | Allen Family | Simmons Family |
|---|---|---|---|---|---|---|
| Household Income and Employment (mother, father) | >$100K Doctor, Doctor | >$100K Store worker, Truck driver | $30K-$100K Social services, Electrician | $30K-$100K Occupational therapist, NA* | >$100,000 Unemployed, Investments | >$100,000 Unemployed, N/A* |
| Ethnicity | Middle Eastern | South American | American | Eastern European | American | Latino |
| Parents' ASL (mother, father) | Learner, Learner | Learner, Learner | Proficient, Learner | Learner, N/A* | Proficient, Learner | Learner, N/A* |
| Languages Used at Home | English, Urdu, ASL | Spanish, English, ASL | English, ASL | English, ASL | English, ASL | English, ASL, Spanish |
| Deaf Child's Disabilities | CHARGE Syndrome Autism Spectrum Disorder | CHARGE Syndrome, Autism Spectrum Disorder | CHARGE Syndrome | Cerebral Palsy, Polymicrogyria, Global Developmental Delay | Autism Spectrum Disorder | Microcephaly, ADHD |
| Child Gender, Age | Male, young teen | Male, young teen | Female, grade school | Female, young teen | Male, young teen | Female, preschool |

Table 2. *Participant biographical information*

| | |
|---|---|
| Khan Family | Dr. & Dr. Khan had three children and the youngest one who was Deaf-Plus, was the only male child. The parents immigrated to the US for better opportunities for their family. They are committed to their Muslim faith and community. Meeting with this close-knit family was always a pleasure, because they were welcoming, thoughtful and loving. They were strong supporters of their son, always scaffolding activities to support his learning and understanding. Their son was bright, inquisitive, and sarcastic. |
| Padilla Family | This family consisted of a mother, father, grandmother, and the younger of two sons was Deaf-Plus. They immigrated to the US for better opportunities for their family. After losing a due process hearing about their son, the family continued their commitment to improving their son's education. This objective was the focus of our interactions. The Padillas were systematic, often taking notes and political. At the same time, they were soft and affectionate. When they looked at their son, their love shone on their faces. Their son was affectionate, curious, and technologically savvy. |
| Hill Family | This family consisted of a mother, father, two grown sons, and one daughter, who was Deaf-Plus. The family was a strong supporter of the Deaf community. It was casual and enjoyable to work with this all-American family. They were generous and joked often. Their daughter was charismatic, energetic, and had a strong imagination |
| Foss Family | This family consisted of a mother and her adopted Deaf-Plus daughter. They were very close and loving. Ms. Foss was an enormous advocate for her daughter, knowledgeable, and uncompromising. Her daughter had a strong presence in Special Olympics and other sporting activities. She was affectionate, playful, and good-humored. |
| Allen Family | This family consisted of a mother, father, and their Deaf-Plus son. They were strong advocates for their son and it was clear that they valued family loyalty. The Allens acted as teachers in their community when they provided ASL resources to important people in their son's life. Their son was involved with many extracurricular activities, including swimming and art. |
| Simmons Family | This family consisted of a mother and her Deaf-Plus daughter. In order to provide her daughter the best learning environment, the mother made numerous sacrifices, including moving her daughter in with the grandmother in order to be closer to a school for the Deaf. The mother and her family were determined to give the Deaf-Plus child an ASL-rich environment, making choices such as hiring a Deaf nanny. |

& Nusbaum (2012) outline that disability studies work must be: social in nature, the study of disability as a foundational human characteristic, interdisciplinary, participatory, and values-based. Therefore, it is inherently political in nature (Annamma et al., 2013). Deaf studies is an interdisciplinary approach to "the study of Deaf individuals, communities, and cultures as they have evolved in a larger context of power and ideology" (Bauman, 2017, p. 210). Like disability studies, Deaf studies doesn't focus on bodily impairment, but on socio-cultural positioning and equity. It also examines the linguistic component of this community. While Deaf studies scholars often distance Deaf people from labels of disability, because Deaf people identify as a cultural-linguistic minority (Lane, 2002), this study centralizes the synchronicity of Deaf and disabled experiences.

**Results**

*External Influences on Parent's Decision-Making Regarding Language and Communication*

For all parents in this study, finding the appropriate resources to support their children's language and communication development presented a challenge, especially when parents did not have the experience to make these critical decisions on their own. Consequently, external influences played a significant role in parents' selection of a language and communication mode for their children. For most families, the influence from medical professionals about communication was scant while they focused on their children's early acute medical needs and later presumptive about carrying out cochlear implant surgeries. However, parents explored technology and communication options for their children outside of

the medical field, including family, social media, and the Deaf community sources.

*"Doom and gloom" medical discourse*

For four of the families, the children's early complex medical needs took priority over their hearing status. The Hills stated: "The deafness at that point was the last thing we were concerned about. We were more concerned with keeping her alive." Doctors told the Hills that their daughter was born with a heart murmur, a single kidney, colobomas, and a missing vestibular system. They felt that everything they heard from medical practitioners was "doom and gloom," which was not only depressing, but prevented them from enjoying their daughter. This type of rhetoric suffused the early years of their children's lives for the Hills, Ms. Simmons, the Padillas and the Khans. Ms. Simmons countered, "We were just glad to have her," which was also how the Khans felt. The Khans described how the doctors had very low expectations for their child: "The doctor told us after surgery, 'He will not be a part of your life and you will be going to the doctor so often for something or other.'" The Hills shared a similar experience when they were told by a doctor that their daughter would never be able to walk. In an early appointment, the doctor said "you need to prepare yourself" and left the room, leaving the parents both overwhelmed and scared for their daughter's future. As the Padilla's son was rushed out of the delivery room to a different hospital for care, doctors "prepared" an exhausted mom and dad for the difficult life upon which they were about to embark--if their son survived.

Parents felt that because their children required substantial medical attention during their early lives, language and communication development were not important topics of discussion among medical and service professionals. The Padillas expressed their frustration in the beginning of their son's life: "Nobody, including early intervention, was concerned about communication and nobody advised me to try a way to communicate with [my son] at all." All the professionals with whom they interacted, focused on what was wrong with their child, paying little attention to what the child could do or might be able to do in the future. The families were not provided the professional support they needed to give their child an effective way to communicate. The Hills also described their frustration with an absence of support from hearing service professionals. They described how at home they "were doing simple signs but felt lost." The Allens felt this way when they had initially selected ASL for their son, but soon realized that professionals did not provide them with the resources to support this decision. They explained: "You wish there was more information presented with less bias. Because you're in a medical situation...it's immediately a medical problem." When audiologists presented information to parents, it was mostly through a lens that defined Deaf as a problem that needed to be fixed--more doom and gloom. When parents were only given information that identified their children's hearing loss as a medical condition, it left little opportunity for dialog about various language and communication options.

For the Allens and the Khans some of the doom and gloom they experienced was in the form of coercion from medical professionals to have their child undergo cochlear implantation. The Khans described their interaction with an ENT surgeon: "So basically, the ENT surgeon was the one who actually forced us. He called and said if it were my child, I would go with the cochlear implant." As parents who had no prior experience with Deaf people, the Khans described that following the doctor's advice seemed like the only option at the time. However, while the doctors had given them the impression that their son would be able to listen and speak with the cochlear implant, it turned out not to be true, which was difficult. The Allens described a similar experience: "The cochlear implant surgeon said to us, 'I'm sorry that I ever told you that [your son] would hear just like everybody else because it may not be possible.'" After being pressured to choose the auditory/oral route for their son, the Allens soon realized that the cochlear implant was not going to serve in the way the doctors had initially believed.

*Constructing communication fluency with the support of family, social media, and the Deaf community*

Realizing that medical practitioners were not providing them with the tools they desired, several parents turned to resources outside the medical field to support their children's language and communication development. Three families discussed input from their relatives. For Ms. Simmons, extended family played a central role in her daughter's caretaking. She explained, "I think my parents were trying to believe the technology-forward thinking...they kind of dove right in to helping me with her therapies at the time." The Allens, on the other hand, explained that their extended family was not particularly involved or invested in the decision-making process: "They didn't know anything about it." The Hills described that their family were mostly concerned for their daughter's health: "My mom got a little scared 'cause [my daughter] had so many surgeries. Why were we gonna do an elective surgery and do the cochlear implants?" The Hills and Ms. Foss found it more beneficial to connect with other parents of Deaf-Plus

children rather than their family members for support. The Hills stated: "It was so freeing to be able to say 'my mother is not getting this' and for her to go 'I understand, I get it.'" Common experience turned out to be a strong bond.

With the accessibility of social media, parents of Deaf-Plus children have found ways to meet and connect with other parents who share experiences similar to their own. Three families mentioned that they used social media for connecting with other parents, sharing resources, and accessing information about learning ASL. Ms. Foss explained, "I will say Facebook...being on a lot of the Facebook pages and...talking to those parents and being able to say this is what my child does, does your child do this? I find that very helpful." She explained that joining Facebook pages not only for parents of Deaf children but for parents of children with the same disabilities as her daughter was helpful in finding answers to many of her questions. The Khans shared this sentiment: "Even just to get advice, go on the Facebook page and find out." The Hills explained that the use of Internet resources as a way to keep up-to-date on their ASL skills: "I still get Youtube from Bill Vickers. I subscribed to his channel so if something new comes up, I review the video."

Parents rarely discussed seeking advice from the Deaf community. The Hills were the exception. They stated, "So before we even thought about cochlear implants, we got involved in the school for the Deaf. That is where we really started learning to sign." When conversations about cochlear implants began to arise, the Hills valued the opinions of Deaf adults in making their final decision to implant their daughter: "I remember talking to Deaf adults going: 'What would you do? Should I do this? Is she going to be denied her Deaf identity because I am doing this?'" Through their dialog about the medical advice to implant their daughter and their newfound relationship with the Deaf community, the Hills determined they would implant their daughter, but continue to teach their daughter ASL regardless the outcome of cochlear implant surgery.

*Language and Communication Varies Among Deaf-Plus Children and Their Family Members*

Raising a child with disabilities presented parents with a unique set of challenges. One of these unique experiences was when parents discovered their child was also Deaf and they decided that the family would learn ASL. As expected, learning a new language proved to be a difficult and time-consuming task for all families, but one that had a positive impact on their lives. As the Deaf-Plus children developed ASL skills independent of their families and in some cases, surpassed their parents' ASL skills, the typical role of parent-as-expert started to become blurred. The parent became a learner and the child transformed into a communication expert. At times, the parents and children struggled to use ASL as an effective mode of communication but were successful in managing the wants and needs of their Deaf-Plus child.

*Family Members Developing Communication Strategies*

ASL quickly became a part of parents' language repertoire. For three of the families, ASL was the third language they used at home. The approach to learning this new and complex language varied among the families. Four of the six families attended classes at ASL-using schools and one family completed multiple online courses from a Deaf university. All families also heavily relied on YouTube.com videos and online resources to enhance their ASL skills, with one family exclusively using these electronic sources. Specifically, most parents cited Bill Vickar's online ASL resource, lifeprint.com, as integral to their learning. Even with several years of practice, few parents reported feeling confident in their ASL skills. Parents often felt that their Deaf-Plus child's skills were more advanced than their own or developing in a different way. Ms. Foss explained that her daughter's ASL skills have surpassed her own so much so that her child was the one teaching her: "A lot of my skills have come from my daughter. I pick things up from her." This is not a concept unique to the Foss family. The Padillas experienced this too: "After a while, [my son] was signing and teaching us!" Ms. Simmons described the difficulty she often experiences when attempting to make sense of what her daughter is communicating to her:

> *I've been trying to match her the best I can, but it's not like you can really look up a sign. You can look up a word and find it in ASL, but I can't describe the sign to Google and figure out what she's saying.*

Ms. Foss described feeling a similar way when she was required to turn to professionals in order to determine what her daughter was signing: "There are times when I will record her and send the video to someone at school because I don't know what she's saying." She further remarked, "I was always fascinated by sign language, but when I had to learn it myself I found out how not easy it was. I was like, wait, it's not just words!" Learning another language in a short amount of time is no easy feat, but parents felt it was imperative. The Allens' encapsulated this necessity, "No one wants to not be able to understand what their child is asking or saying."

An added complexity arose with communication between the Deaf-Plus children and their relatives. While most families attempted to learn some signs, only Ms. Simmons' family expressed that their child could fully communicate with his or her extended family: "My mother, who my daughter lives with during the school year, is actually fluent in sign language. She learned sign language because of my daughter." Immediate family members in the Khan family sign to communicate, but their extended family and cultural-religious family at their mosque did not yet sign. Other parents felt frustrated about the ASL skill levels of members of their families. For example, the Allens stated:

> *Communication with our son is difficult because no one has really taken the time to learn to communicate with him well. We live very close to a few of our family members and they include us in everything; but he always has to have to go between me or my husband for him to interact with other family members, which makes it kind of challenging and frustrating.*

> *The Allens were not the only parents whose roles shifted from caretakers to interpreters when interacting with family: "My parents' and families' signing skills are not good...No one really signs with her. I do a lot of interpreting" (Ms. Foss).*

The Allens were not the only parents whose roles shifted from caretakers to interpreters when interacting with family: "My parents' and families' signing skills are not good...No one really signs with her. I do a lot of interpreting" (Ms. Foss).

With various levels of ASL fluency between the Deaf-Plus children and their family members, each family has had to devise a communication method that works best for them. For some, this meant writing messages back and forth (Padillas, Khans), texting one another (Khans), and fingerspelling to their child (Khans, Foss) when their ASL skills were insufficient. In addition to utilizing external sources to support communication clarity among the family members, most of the families reported using Simultaneous Communication (SimCom) rather than consistently using ASL: "Since ASL isn't our first language, we typically speak when we sign, which isn't grammatically correct" (Simmons family). The Fosses, Khans, and Hills explained that communication in their household mirrored that of the Simmons' where SimCom was the primary mode of communication.

Regardless of struggles with communication, all families reported that they knew enough sign language and have developed sufficient strategies to be able to communicate effectively with their Deaf-Plus children. The Padillas stated, "We feel that we know enough sign to make him understand what he has to do or what he cannot do." Still, this foundational level of ASL was sometimes inadequate as their children began to require more advanced communication interactions. Ms. Simmons explained:

> *I don't know sign language enough to be able to teach her how to communicate her emotions or complex sentences and stuff like that. It's not my language or a language I'm very good at. I don't know how to teach her those everyday things like: 'Tell me how you're feeling.'*

Some parents' novice ASL skills became a barrier to assisting their child with schoolwork. Ms. Foss explained, "I'm starting not to be able to help her with homework. I only have the sign to talk about nouns and verbs. I have words. I don't have the signs for this skill level. This isn't my skill level." However, other parents felt this inability to fluently communicate in the language of their Deaf-Plus child had not yet become a significant obstacle to overcome. One family reported that their level of ASL proficiency had complicated their personal relationships with their child. The Khans described:

,

> *Sometimes [my son] can tell if I'm not understanding. I try my best, but sometimes I just don't understand. If I take too much time, he gets a little frustrated, so I try not to. He understands our capacity. He doesn't go beyond what we don't understand. So, if he thinks we don't know a sign, he will spell it for us, he will write it down.*

### *Negotiating an effective communication system for Deaf-Plus children*

ASL was the preferred language of Deaf-Plus children in this study. For the Hills and Khans, ASL was introduced into the home almost immediately after birth. However, the other four families began with an auditory/oral approach due to various influences, with some children not acquiring language until much later in life: "For the first five years, we didn't give him a language" (Padillas family). Ms. Simmons quickly realized that prohibiting the use of ASL, which was a requirement of her daughter's early intervention program at school, did not yield positive results:

> *I started teaching her sign language because I thought she was frustrated. She seemed frustrated all the time. I just wanted some way for her to be able to communicate with me. I taught her about 200 words that way. She picked it up immediately!*

Communication resolving behavior issues became a common theme throughout the interviews with parents. The Allens described, "Over the last few years, [my son] has improved a lot. With the improvements in communication came improvements in behavior."

The Hills' and Khans' children's behavior also improved as frustration about communication diminished.

The Deaf-Plus children's their complex disabilities made using ASL even more difficult. For example, the Padillas explained:

> *Our son communicates in sign language. That's the language he prefers; but at the same time, considering our son is Autistic, it has been difficult for him to learn that language. In sign language, it's more than just moving your hands...it's facial expressions, body language, etc.*

Ms. Simmons explained that ASL skill level and environment was only one consideration in creating effective communication: "[My daughter] tends to get very frustrated and has tantrums. Even though we have her in such a high ASL environment, her other developmental delays keep her from wanting to communicate." For other children, the fine motor skills used while signing proved challenging. For the Allens, Augmentative and Alternative Communication (AAC) was beneficial for easing their child's frustration with communication:

> *[My son] doesn't use the AAC app as much now because he has more language using ASL, but he did benefit from the app. It reduced his anxiety about us not understanding what he was saying because he had difficulty signing clearly. He has differently formed fingers, so sometimes his signs might not be as distinct or clear as you might want.*

It was often the case that, although helpful, AAC was not consistently used by the children because they preferred to sign.

The distinct variations of ASL skills between the Deaf-Plus child and their family members resulted in a shift in the typical familial roles for some of the participants; the child became the expert and the parent became the learner. In some instances, this created a divide between the family and the Deaf-Plus child. The Khans recalled a time when this language barrier was evident:

> *Sometimes if I don't know how to talk to him in ASL I just do it my English way. He understands. So, one time he was supposed to present to me for his ASL class and he didn't do it. We were at a school picnic and I told the teacher, 'I don't know why he didn't want to present to me.' And when the teacher asked him, he said, 'Mom does English sign language and my presentation is supposed to be in ASL.'*

The Allens discussed struggling with ASL grammar themselves, which was not a similar issue for their Deaf-Plus child: "It's interesting because [my son] naturally uses appropriate ASL grammatical structure. That's how he sees things, whereas I really have to think about it, but that's just how he thinks."

*Struggling to Determine and Secure an Inclusive and Productive Learning Environment for Their Deaf-Plus Children*

It was an ongoing and often difficult process for parents in this study to broker an educational placement for their Deaf-Plus children which served all their children's communication, social, and disability support needs. Parents found that selecting one placement typically meant sacrificing academic goals or their notion of the least restrictive environment (LRE) for their child. Furthermore, parents often found school personnel to be barriers to having agency over the education of their children and that the individuals influencing the education of their children were seemingly unqualified to hold those positions. Some parents successfully negotiated the educational placement they desired for their child, while others did not or are still searching for an appropriate placement.

Early in their children's lives, parents had to make decisions about educational placements for their children. Aside from Ms. Foss, who grew up with a disabled sibling, worked as an occupation therapist, and chose to adopt a Deaf-Plus child, none of the parents had much experience with disabled or Deaf people. They worked hard to learn from friends, educators, and the Internet about special education services so they could make informed decisions. The focus on the children's physical disabilities discussed earlier continued during the school years for the Padillas, Fosses, and Simmons. For these families, the children's need to communicate seemed to be an afterthought, so parents had to become advocates. Ms. Foss recounted:

> *The child study team showed me special schools for children with multiple disabilities...I had to request seeing a Deaf school, because the special schools said they would learn ASL with her and I was like 'but you're supposed to be teaching her!'*

The Padillas also wanted an ASL rich environment for their child, but the head of special education for their district told them "No one on the street signs, so he isn't ever going to have anyone to communicate with." This was a common narrative about how using sign language would cause the children to be isolated from the world. The Khans initially followed this advice and placed their son in a neighborhood school where he floundered, but after he moved to an ASL-using Deaf school they lamented: "I wish he had been there since the beginning. He might have been so much better and he might have learned a lot before." The Simmons shared this sentiment: "No matter how hard I try, I will never be as good [using ASL] as somebody whose spoken it their whole life and had the Deaf experience." Like the Simmons, the Hills quickly resolved that their daughter would

attend a Deaf school because they knew a general education placement with an ASL interpreter wouldn't provide the intensive communication support that she needed. The Allens tried multiple placements for their son: An oral school for the Deaf, an ASL using Deaf school, and finally a segregated special education classroom. It was perplexing for the family, because regardless of where he went, the schools were unable to simultaneously provide the needed communicative, disability related, and social supports for their son. In the end, they selected the segregated classroom with the most intensive supports (e.g. Applied Behavior Analysis: ABA) in hopes that a more restrictive environment would eventually help their son blossom and have access to a richer life. Still early in their evolution as experts about disability, Deafhood, and their own children, the path toward choosing an educational placement was convoluted, but these six families universally chose to prioritize communication in their choices, even when medical and educational professionals did not. They were certain that any conversation about inclusion that did not begin with access to interacting with peers and teachers was not a conversation about inclusion at all.

Struggles with schools complicated parents' resolutions about the best placement for their children. The Allens summed up the constraints they faced: "It's all resource and financially motivated," which the other families echoed. The Padillas faced significant struggles in their attempts to move their son to an ASL using Deaf school. They showed the research team their son's IEP goals. Few of these goals were learning oriented, but instead they were function-based. Furthermore, the school reported for three quarters in a row that their son was not making adequate progress toward his social, emotional, and behavioral goals, but in the fourth quarter, he seemingly magically did for six of seven goals, which his parents knew was untrue. When Mrs. Padilla asked what the percentages of the success were in the earlier quarters, the IEP team could not answer. The documents were invalid and written to support the placement decisions the school made. The Padillas entered due process to fight for his right to be educated in a way that was "more than babysitting him." However, not a single professional who knew anything about hearing loss or language acquisition of Deaf people was involved in the hearing. Ultimately, the Padillas lost the case and due to expense and fatigue had to give up:

> *Our battle was so hard, so stressful, and so depressing and at the end it was weird because they were the ones to decide that they would help my son and then they all just talked so badly about his deficits or how everything was his own fault. We became too tired of fighting.*

This was not the only family who felt that IEPs were flawed, including supposed progress documented on them. The documents became subjective institutional weapons that schools used to wield their power. The Khans described that in the neighborhood school, one teacher documented in the IEP how signed language was an ineffective communication tool for their son, while another teacher showed the Khans just how much potential their son had to use this modality. They didn't fully understand the IEP as a legal document that could work for or against their wishes: "Honestly, I would say I did not understand it [the IEP] and about levels of what he's supposed to be or our rights, but I felt he was treated like a baby by the entire school [hearing school]." Errors in IEPs were not limited to hearing status. Ms. Foss explained that her daughter's IEP referred to her as having Autism and a social communication disorder, when Cerebral Palsy was a neurological disorder. "Other schools refused to teach the Deaf-Plus children ASL, because "it is a crutch that they won't ever get rid of [Ms. Simmons]." Aligning with this statement, parents reported how educators assigned to their children acted as experts but knew so little about Deaf or signed language. The Hills had early intervention to instruct their daughter ASL: "Her IE who was a TOD didn't know how to sign.. once I started to get more fluent, she would always ask me for signs. I am like 'You gotta be kidding me!'" The Padillas experienced this too when they began to receive some communication-based services. A teacher of the Deaf (TOD), who only knew rudimentary sign language, served as their son's interpreter.

Not all families struggled to negotiate the educational placement of their child. The Hills, Ms. Foss, and the Allens reported little resistance from schools when they wished for their child to attend an ASL using school, because it was clear that the home district did not have a remotely appropriate placement for their children. However, once in school, educators equipped to instruct Deaf students were not always prepared to instruct Deaf-Plus students. Ms. Foss' school contacted her claiming that her daughter didn't communicate or only signed single words to which she responded: "I'm like I don't know what child you are talking about because I can't get her to stop." To her, the school simply didn't understand Deaf-Plus children: "The problem is they are expecting output when she doesn't always have output, but the input is absolutely necessary." The Hills faced similar misunderstandings from TODs when their daughter was labeled as stubborn and easily distracted when she began responding to sounds using her cochlear implant and expressing her opinions, which her parents celebrated as successes. For the Allens, it was a struggle to access services. Consistency was important for their son, but

the school was unable to retain paraprofessionals, because they were under-payed. Whether parents struggled to get the placement they wished for their child or struggled having all their children's needs understood and addressed, their relationships with schools were difficult and parents felt they paid too little attention to what the children learned socially and academically.

As parents became experts about their children and their support needs, they became more confident in their visions of what inclusion for their child meant. All parents emphatically agreed that they wished for TODs who had a strong understanding of how to teach Deaf students who have multiple support needs. Parents generally felt ASL using schools were the most inclusive and permitted a better chance for their children to reach their academic potential. For example, the Khans stated: "Since he's been in a Deaf environment, his learning has multiplied 10 or 15-fold... It's where he can interact naturally and his language is a benefit rather than a service." The Padillas also communicated the importance of collectivity to achieve true inclusion for their son: "I don't like that everything is individual like an Individual Educational Plan [sic]. Why not have a plan for the whole class to be inclusive and learn?" Ms. Foss, the Hills, and the Allens had different ideas. The Hills wondered if there ever could be a truly inclusive class for their daughter simply because of her relative uniqueness. Ms. Foss qualified this idea in relation to inclusion meaning where her child was educated: "If you want my daughter to feel like she is really 'in' the community, she has to sometimes be in the middle, to have skills others do not and not always the lowest kid in the classroom." Parents in the focus group nodded in agreement. To them, an important component of being a citizen of the classroom is not only to have something to contribute, but to also feeling efficacious and respected.

**Discussion**

Consistent with McCracken and Turner (2012), the families talked at length about their feelings of not being supported by medical practitioners and educators to make decisions about communication for their child. Moreover, even when parents chose how their child would communicate, only the child received communication-based services rather than the entire family. Consequently, they had to facilitate their own acquisition of ASL. Instead of receiving support for communication, families felt their lives became full of medical appointments and incessant deficit discourse about their children. For most parents, this did not change when their children went to school. The "doom and gloom" or what the children could not do took center stage, aligning with previous findings (Sunderland, Catalano, & Kendall, 2009; Wiley et al., 2019). These findings also support previous finding about the burden of medical appointments for families with disabled children (George,Vickers, & Barton, 2008). For able-bodied children, access to language is a priority from the first day of their lives (Mayberry, Lock, & Kazmi, 2002), but communication for children with complex support needs is not viewed as integral to brokering a fulfilling life (Hustad & Miles, 2010), because they are seen as incomplete humans (Hazlam, 2006). The parents and researchers alike wondered why it was so difficult for educators to view these Deaf-Plus children as communicators and as valuable humans.

In this research, parents responded to the deprioritization of language and doom and gloom with action. Parents who learn about hearing loss and communication options first from medical practitioners tend not to seek out additional information from other types of sources (Kluwin & Stewart, 2000). This did not hold true with the parents in this study. When unsatisfied with the lack of dialog about communication for their children, they unequivocally demanded that medical practitioners and schools do more to support their families. Whether or not those demands were met, parents looked to their extended families and Internet support groups not only about language, but also to resist the overwhelmingly negative narratives about their children. They formed learning communities around ideas of ASL language and its marginalization, ableism, and parenting as power. This finding adds to the growing body of evidence that online support groups for disabled people and the "wise," Goffman's (1963) notion of those who are sufficiently close enough to a stigmatized individual to truly "get it," are an important component of disability culture (Ellis & Goggin, 2013; Kerr & McIntosh, 2000). That the parents in this study sought out these groups shows them as resourceful and purposeful advocates for their children. While research shows the positive impact of parent involvement in children's education (Lee & Bowen, 2006), it fails to emphasize just how crucial it was for these Deaf-Plus children. Parents described the many errors misinformed educators made about their children, some of them reprehensible and dangerous. Had parents permitted the schools to make educational and communication choices for their children without their input and oversight, the consequences might have been disastrous. Interestingly, only one family discussed connecting with Deaf adults to help them become informed decision-makers. The Deaf community feels that parents of Deaf children need this exposure in

order to counterbalance the overwhelming medical/oral advice parents receive from the moment a Deaf child is born (Young, 1999). Nevertheless, all families ultimately chose ASL as a language for their children and families, which may be partially attributed to the increased visibility of ASL using people in the media. While parents did not discuss why they did not seek the expertise of Deaf adults, it is likely that access to these individuals proved difficult and that parents felt intimidated by Deaf people.

Instead of seeking out Deaf people directly, parents and family members continued to learn about Deaf identity from the Internet, which proved to be an important resource not only for support but also language learning. Learning ASL is difficult and may be especially so for parents who work, have limited incomes, or their child is the only Deaf person they know. Parents in this research talked about lifeprint.com (Vickars, 2019), a longstanding ASL and Deaf cultural resource. Vickars released this free online resource because he recognized the need for access to quality ASL instruction for families of Deaf children. Despite access to this website, other Internet resources, and community ASL classes, the families of the Deaf-Plus children have developed widely varying ASL skills. It was not the researchers' intent to evaluate participants' ASL skill levels, but they often talked about this topic, sometimes bemoaning their stalled learning or comparing the skill levels of various people in the family. Other times, they felt proud of the work they had done. Consistent with research about hearing parents of Deaf children, most of the parents struggled to become fluent in ASL (Vacarri & Marschark, 1997), but felt their skill levels adequately met the needs of their children (Wood, 1991). Much of this scholarship casts parents' communication skills in a negative way without highlighting the innovative ways they find to communicate. Instead of using only ASL, these families used a wide range of communication techniques including, but not limited to: Signing, texting, gesturing, drawing, noises, speech, and some type of inexplicable parent-child thought transference. To diminish the triumph of parents and children creating effective communication systems seems to reinforce the subtheme of persistent "doom and gloom."

Communication between parents and children was complicated by more than hearing status. The Deaf-Plus children experienced motor, information processing, and learning delays as well as difficulties with maintaining attention. Nevertheless, it was clear in the research that all parents and their children constructed a unique communication system, which communicated their love and respect of one another. Here lies a theoretically sticky area. Deaf studies scholarship shows that access and exposure to grammatically correct and conceptually accurate ASL (or full access to spoken language) is critical for appropriate linguistic development (Paul, Wang, & Williams, 2013; Strong & Prince, 2000). Some of the children in this study had no friends, sat segregated in special education classrooms without access to language, and lived a life in and out of hospitals. Most of the time, these Deaf-Plus children primarily interacted with only their families. Given the relative social isolation of their children that the parents discussed, the expeditious development of a system of personally meaningful communication that worked for the family may have trumped ideas of "optimal." Parents and children must first establish basic needs of safety and health, which includes the development of a strong parent-child relationship, before working toward the achievement of the child's potential or self-efficacy (McLoed, 2007). Without securing these, the future linguistic outcomes, which the Deaf studies scholarship references may not come into fruition anyway. Rather than viewing multimodal communication systems and formal ASL use as philosophically opposed, it may be that at least for the time being, the parents wisely chose to meet the immediate needs of their families. However, if families become ambivalent about improving family-wide ASL skills, it may have negative impacts on their child's social and intellectual development (Hall, 2017).

Recognizing and acknowledging the limitations of individual educator's, administrator's, child's, medical practitioner's and parent's knowledge or experience was an overarching barrier to developing inclusive, rigorous, and productive educational placements for these Deaf-Plus children. It is problematic that school personnel were unable to adequately consult parents about Deaf-Plus children's educational placements and yet still represented themselves as experts about the education of these children. This follows a scant amount of literature produced about this hard to access topic (Crawford, 2008, Hansuvadha, 2009). The problem lies not just that personnel are underqualified, but in our expectations and casting of who special educators must be. To illustrate this point, as a culture, we don't expect physicians to be experts about every bodily system, even though they attend postsecondary education for numerous years, but we do expect specialized understanding about communication and learning from special education teachers about all disabilities. The Deaf-Plus children in this study had complex support needs, each complicating the other. Parents explained that special educators seemed to select one or a few of those needs to support based on their own knowledge while neglecting the others. They generally saw the children as multiply disabled and focused on this rather

than a holistic and self-affirming Deaf-Plus identity. Consequently, communication and the development of children's Deaf identity was often under-prioritized. This notion of appropriate "casting" may be applied to parents, medical practitioners, and the Deaf-Plus children as well. It is important for educational teams to understand the nature of all constituents' expertise and consider the contributions that each makes to providing a Deaf-Plus child a quality education.

Finally, these findings raise new ideas about the meaning of inclusion for Deaf-Plus children. Consistent with previous literature regarding inclusion for Deaf students (Kent, 2003; Leigh, 1999; Singer & Vroman, 2019), the parents in this study felt that the most inclusive educational environment for their children was a school that met both their linguistic and social needs. In other words, an ASL using school was more inclusive for their children than a mainstream setting. However, inclusion goes beyond access to language and communication. For these children and their families, inclusion meant not always being the lowest student in the class. Instead, their children should be able to contribute academically to the class and other students should be able to learn from their children. Furthermore, inclusion meant that their Deaf-Plus children were valued members of the school community, rather than treated as lesser than their peers. This encompasses but is not limited to: Having their opinions matter, a right to pursue academics, sports, and life skills, and acting in non-normative ways without consequence. These findings build on previous findings by Singer (2019) in that not only should parents consider educational placements that are most supportive, most liberating, and most culturally-sustaining, but also the most academically empowering for their children. Furthermore, IEP teams should value children's opinions about their own education, which may not always occur, especially if the child is considered "severely disabled." Therefore, for these Deaf-Plus children, true inclusion occurs not only when these students are learning and communicating effectively with their teachers, Deaf peers, and Deaf-Plus peers, but also when they are contributors to their school community at-large.

**Conclusions**

Being a parent of a Deaf-Plus child comes with innumerable challenges including, but not limited to: Negotiating an effective communication method between and among family members, constantly attempting to be optimistic and hopeful in spite of the negative advice often received from medical practitioners, and navigating the various educational placements in order to find the most appropriate setting for the child. One approach to combat the seemingly endless vat of negativity surrounding parenting a Deaf-Plus child is to communicate with other parents about the joys of parenting their Deaf-Plus children. This type of positive interchange of personal anecdotes and advice could be extremely beneficial for all parties involved. Through communicating with other parents of Deaf-Plus children, whether in person or via an online support group, parents can receive guidance and encouragement from people who have a similar set of experiences rather than from an isolated party such as medical practitioners or biased websites.

While some educators have professional training in teaching Deaf or disabled students, it is the parents who are experts in their individual child and his or her needs. Teachers of the Deaf and special educators should aspire to view the parents as an integral component of the educational team. Parents should be included in any and all discussions regarding the Deaf-Plus child's education, because they know their own child's personality, disabilities, peculiarities, competencies, and potential. In doing so, parents are more likely to feel as though they are part of the team rather than adversaries like they did in this study. This could not only strengthen the relationships between educators and parents, but it can also lead to the Deaf-Plus child receiving more appropriate educational supports. In addition, every member of the IEP team, including parents and children, should recognize their individual strengths and weaknesses. In other words, all IEP team members should have a basic understanding of how they can enhance conversations and where their understandings might be limited. Another implication for school districts and social services that arose from this research is language and communication training provided for families of Deaf-Plus children. Parents desperately want to learn the language their child uses, but often found it hard to attend night classes or effectively engage in online resources. If school districts or social services provide training programs for the parents, more effective communication could occur not only between the parents and their Deaf-Plus child but between the parents and the school district as well.

Medical practitioners should strive to ensure there is a positive and humane dialogue regarding Deaf-Plus children. It is critical that parents receive support and encouragement from their doctors and other medical professionals since they are a significant source of information when parents begin the journey of raising a Deaf-Plus child. Parents often automatically trust the advice given from medical practitioners because they are perceived as the experts, especially early in a Deaf-

Plus child's life. When conversations between doctors and parents tend to be pessimistic. It is difficult to change the nature of this discourse once it has begun. It is imperative that medical professionals transform the apathetic, detached rhetoric surrounding Deaf-Plus children to more humane and encouraging discourse. Another implication of this research for medical practitioners is the inclusion of psychological health of the family and child in the treatment plan. Discovering one's child is Deaf and has additional disabilities can be incredibly challenging for a parent both mentally and emotionally. While this primarily affects the parents in the beginning, the Deaf-Plus child is likely to undergo emotional struggles as he or she develops. Identity development and family acclimation should be a part of a total psychological wellness program that accompanies a Deaf-Plus child's treatment plan. The emotional well-being of the families in this study were generally ignored and their stories suggest that they would have benefitted from embedded services.

Future research could include examining how raising a Deaf-Plus child affects roles in parenting. This study represented parents as a unit, but in reality, parents experienced raising their Deaf-Plus children in different ways. Furthermore, the voices of the Deaf-Plus children were not a central component of this research. Heideggerian hermeneutics posits that various realities occur simultaneously, each contributing to an overarching, multifaceted reality. Using this approach to interviews with each member of the family could unearth unique perspectives, which contribute to a whole and complicated understanding of this complex phenomenon. Beyond the roles of parents in families, the roles of Deaf-Plus people in Deaf culture is an under-investigated topic. Broadening research questions to explore the roles of Deaf-Plus people in various contexts would help us further understand how disability is viewed within the Deaf community.

This research provided parents of Deaf-Plus children an opportunity to share their stories and experiences. Through observations, interviews, and analysis, the researchers were able to determine the extent to which external influences affect parents' decision-making regarding language and communication, various strategies families use to ensure effective communication can ensue regardless of varying levels of fluency in a signed language, and the difficulty of determining and attaining an appropriate, inclusive, and productive learning environment for the Deaf-Plus children. The research has provided data to support improving inclusive educational environments for Deaf-Plus children based on their individual characteristics and experiences.

**Footnotes**

[1] The authors chose to capitalize Deaf when it referred to any person despite cultural affiliation or language use. The term "deaf" is only used when referring to hearing status or medical conditions. In the United States, culturally Deaf people view themselves as a sociolinguistic minority rather than a category of disability.

[2] Parents in the study referred to their children in various ways, but during the focus group, they collectively decided to use the term Deaf-Plus as the identification we employed in the study.

[3] ASL is a complete language with its own set of grammatical rules. Though the criteria specifically stated "ASL," families and children used a broad range of manually-coded English.

**References**

Aiken-Forderer, M. (1988). Home and school support for physically handicapped Deaf children. in H. T. Pricket & E. Duncan (Eds.), *Coping with the multi-handicapped hearing impaired* (29-36). Springfield, IL: Charles C. Thomas.

Allen, S., DeLuca, D., & Napoli, D. J. (2007). Societal responsibility and linguistic rights: The case of Deaf children. *Journal of Research in Education, 17*, 41-53

Antia, S., Jones, P., Reed, S., and Kreimeyer, K. (2009). Academic status and progress of Deaf and Hard of Hearing students in general education courses. *Journal of Deaf Studies and Deaf Education, 14*, 293-311. https://doi.org/10.1093/deafed/enp009

Bailes, C. N., Erting, L. C., Thumann-Prezioso, C., & Erting, C. J. (2009). Language and literacy acquisition through parental mediation in American Sign Language. *Sign Language Studies, 9*(4), 417–456. https://doi.org/10.1353/sls.0.0022

Bauman, H. D. L., & Murray, J. J. (2010). 14 Deaf Studies in the 21st Century:"Deaf-gain" and the Future of. *The Oxford handbook of deaf studies, language, and education, 2*, 210.

Borders, C. M., Bock, S. J., Giese, K., Gardiner-Walsh, S., & Probst, K. M. (2018). Interventions for students who are Deaf/Hard of Hearing. In *Viewpoints on interventions for learners with disabilities* (75-105). England: Emerald Publishing Limited.

Burke, T. B., Kushalnagar, P., Mathur, G., Napoli, D. J., Rathmann, C., & Vangilder, K. (2011). Language needs of Deaf and Hard-of-Hearing infants and children: Information for spiritual leaders and communities. *Journal of Religion, Disability & Health, 15*, 272–295. https://doi.org/:10.1080/15228967.2011.590644

Calderon, R., & Naidu, S. (1999). Further support for the benefits of early identification and intervention for children with hearing loss. *Volta Review, 100*(5), 53-84.

Calderon, R., Bargones, J., & Sidman, S. (1998). Characteristics of hearing families and their young Deaf and Hard of Hearing children: Early intervention follow-up. *American Annals of the Deaf, 143*, 347-362. https://doi.org/10.1353/aad.2012.0100

Calderon, R., & Greenberg, M. T. (2000). Challenges to parents and professionals in promoting socioemotional development in deaf children. *The deaf child in the family and at school: Essays in honor of Kathryn P. Meadow-Orlans,* 167-185.

Cawthon, S. W., & Online Research Lab. (2007). Accommodations use for statewide standardized assessments: Prevalence and recommendations for students who are Deaf or Hard of Hearing. *Journal of Deaf Studies and Deaf Education, 13*(1), 55-96. https://doi.org/10.1093/deafed/enm029

Chapman, D. A., Stampfe, C. C., Bodurtha, J. N., Dodson, M., Pandya, A., Lynch, K. B., & Kirby, R. S. (2011). Impact of co-occurring birth defects on the timing of newborn hearing screening and diagnosis. *American Journal of Audiology, 132*(20), 132-139. https://doi.org/10.1044/1059-0889(2011/10-0049)

Crawford, F. (2008). Underprepared" Veteran" Special Education Teachers' Reliance on Racist and Classist Ideologies. *Counterpoints, 319*, 49-72.

Das, V. K. (1996). Aetiology of bilateral sensorineural hearing impairment in children: A 10 year study. *Archives of the Diseases of Children, 74*, 8-12. http://dx.doi.org/10.1136/adc.74.1.8

Decker, K. B., Vallotton, C. D., & Johnson, H. A. (2012). Parents' communication decision for children with hearing loss: Sources of information and influence. *American Annals of the Deaf, 157*(4), 326-339.

DesGeorges, J. (2003). Family perceptions of early hearing, detection, and intervention systems: Listening to and learning from families. *Mental Retardation and Developmental Disabilities Research Reviews, 9*, 89–93. https://doi.org/10.1002/mrdd.10064

Ellis, K., & Goggin, G. (2013). Disability and social media. In *The social media handbook* (pp. 134-151). Routledge.

Foss, K. A. (2014). Constructing hearing loss or "Deaf gain?": Voice, agency, and identity in television's representations of d/Deafness. *Critical Studies in Media Communication, 31*(5), 426-447. https://doi.org/10.1080/15295036.2014.968603

Gascon-Ramos, M., Campbell, M., Bamford, J., & Young, A. (2010). Influences on parental evaluation of the content of early intervention following early identification of Deafness: A study about parents' preferences and satisfaction. *Child: Care, Health and Development, 36*, 868–877. doi:10.1111/ j.1365–2214.2010.01092.x

George, A., Vickers, M. H., Wilkes, L., & Barton, B. (2008). Working and caring for a child with chronic illness: Challenges in maintaining employment. *Employee Responsibilities and Rights Journal, 20*(3), 165-176.

Hall, W. C. (2017). What you don't know can hurt you: The risk of language deprivation by impairing sign language development in deaf children. *Maternal and Child Health Journal, 21*(5), 961-965.

Hansuvadha, N. (2009). Compromise in collaborating with families: Perspectives of beginning special education teachers. *Journal of Early Childhood Teacher Education, 30*(4), 346-362.

Haslam, N. (2006). Dehumanization: An integrative review. *Personality and Social Psychology Review, 10*(3), 252-264.

Helfand M., Thompson D., Davis R., McPhillips H., Homer C., & Lieu T. (2001). *Newborn hearing screening: Systematic evidence review, 5* (AHRQ Publication No. 02-S001).

Higgins, P. C. (1980). *Outsiders in a hearing world.* Beverly Hills, CA: Sage.

Holcomb, T. K. (2012). *Introduction to American deaf culture*. Oxford University Press.

Hustad, K.C. & Miles, L.K. (2010). Alignment between augmentative and alternative communication needs and school-based speech-language services provided to young children with cerebral palsy. *Early Child Serv (San Diego), 4*(3), 129-140.

Hyde, M., & Power, D. (2000). Informed parental consent for cochlea implantation of young Deaf children: Social and other considerations in the use of the "bionic ear." *Australian Journal of Social Issues, 35*(2), 117–127. https://doi.org/10.1002/j.1839-4655.2000.tb01089.x

Individuals with Disabilities Education Improvement Act, PL108-446, 20 U.S.C. §§1400 et seq. (2004).

Jure, R., Rapin, I., & Tuchman, R. F. (1991). Hearing impaired autistic children. Developmental *Medicine and Child Neurology, 33*(12), 1062-1072. https://doi.org/10.1111/j.1469-8749.1991.tb14828.x

Kent, A (2003). Identity issues for Hard-of-Hearing adolescents aged 11, 12, and 15 in mainstream settings. *Journal of Deaf Studies and Deaf Education. 8*(3). 315-324. https://doi.org/10.1093/deafed/eng017.

Kerr, S. M., & McIntosh, J. B. (2000). Coping when a child has a disability: exploring the impact of parent-to-parent support. *Child: Care, Health and Development, 26*(4), 309-322.

Kirk, S., Glendinning, C., & Callery, P. (2005). Parent or nurse? the experience of being the parent of a technology-dependent child. *Journal of Advanced Nursing, 51*(5), 456-464. https://doi.org/10.1111/j.1365-2648.2005.03522.x

Kluwin, T. N., & Stewart, D. A. (2000). Cochlear implants for younger children: A preliminary description of the parental decision process and outcomes. *American Annals of the Deaf, 145*(1), 26–32. https://doi.org/10.1353/aad.2012.0247

Knoors, H., & Marschark, M. (2012). Language planning for the 21st century: Revisiting bilingual language policy for Deaf children. *The Journal of Deaf Studies and Deaf Education, 17*(3), 291-305. https://doi.org/10.1093/deafed/ens018

Knoors, H., & Vervloed, M. P. (2011). Educational programming for Deaf children with multiple disabilities: Accommodating special needs. In M. Marschark & P. E. Spencer (Eds.), *Oxford handbook of Deaf studies, language, and education* (82-94). New York, NY: Oxford University Press, Inc.

Kurtzer-White, E., & Luterman, D. (2003). Families and children with hearing loss: Grief and coping. *Mental Retardation and Developmental Disabilities Research Reviews, 9*(4), 232–235. https://doi.org/10.1002/mrdd.10085

Kushalnagar, P., Mathur, G., Moreland, C. J., Napoli, D. J., Osterling, W., Padden, C., & Rathmann, C. (2010). Infants and children with hearing loss need early language access. *The Journal of Clinical Ethics, 21*(2), 143.

Lane, H. (1999). *The mask of benevolence: Disabling the Deaf community* (2nd ed.). New York, NY: Vintage Books.

Lane, H. (2002). Do deaf people have a disability?. *Sign language studies, 2*(4), 356-379.

Lederberg, A. R., Schick, B., & Spencer, P. E. (2013). Language and literacy development of Deaf and Hard-of-Hearing children: Successes and challenges. *Developmental Psychology, 49*(1), 15. http://dx.doi.org/10.1037/a0029558

Lee, J. S., & Bowen, N. K. (2006). Parent involvement, cultural capital, and the achievement gap among elementary school children. *American Educational Research Journal, 43*(2), 193-218.

Lee, Y., Jeong, S. W., & Kim, L. S. (2013). AAC intervention using a VOCA for Deaf children with multiple disabilities who received cochlear implantation. *International Journal of Pediatric Otorhinolaryngology, 77*(12), 2008-2013. https://doi.org/10.1016/j.ijporl.2013.09.023

Leigh, I. W. (1999). Inclusive education and personal development. *Journal of Deaf Studies and Deaf Education, 4*(3), 236–245. https://doi.org/10.1093/deafed/4.3.236

Luetke-Stahlman, B., & Nielsen, D. C. (2003). The contribution of phonological awareness and receptive and expressive English to the reading ability of Deaf students with varying degrees of exposure to accurate English. *Journal of Deaf Studies and Deaf Education, 8*(4), 464-484. https://doi.org/10.1093/deafed/eng028

MacSweeney, M., Campbell, R., Woll, B., Giampietro, V., David, A. S., McGuire, P. K., ... & Brammer, M. J. (2004). Dissociating linguistic and nonlinguistic gestural communication in the brain. *Neuroimage, 22*(4), 1605-1618. https://doi.org/10.1016/j.neuroimage.2004.03.015

Marschark, M., Sapare, P., Convertino, C., Seewagen, R., & Maltzen, H. (2004). Comprehension of sign language interpreting: Deciphering a complex task situation. *Sign Language Studies, 4*(4), 345–367. https://doi.org/10.1353/sls.2004.0018

Marschark, M., Shaver, D. M., Nagle, K. M., & Newman, L. A. (2015). Predicting the academic achievement of Deaf and Hard-of-Hearing students from individual, household, communication, and educational factors. *Exceptional Children, 81*(3), 350-369.

Marschark, M., & Spencer, P. E. (2010). *The Oxford handbook of Deaf studies, language, and education* (Vol. 2). Oxford University Press.

Mason, K., Rowley, K., Marshall, C. R., Atkinson, J. R., Herman, R., Woll, B., & Morgan, G. (2010). Identifying specific language impairment in Deaf children acquiring British Sign Language: Implications for theory and practice. *British Journal of Developmental Psychology, 28*(1), 33-49. https://doi.org/10.1348/026151009X484190

Mauldin, L. (2016). *Made to hear: Cochlear implants and raising Deaf children.* Minneapolis: University of Minnesota Press.

Mayberry, R. I., Lock, E., & Kazmi, H. (2002). Development: Linguistic ability and early language exposure. *Nature, 417*(6884), 38.

McCracken, W., & Turner, O. (2012). Deaf children with complex needs: Parental experience of access to cochlear implants and ongoing support. *Deafness & Education International, 14*(1), 22-35. https://doi.org/10.1179/1557069X12Y.0000000005

McLeod, S. (2007). Maslow's hierarchy of needs. *Simply psychology, 1.*

Meyers, J. E. & Bartee, J. W. (1992). Improvements in the signing skills of hearing parents of Deaf children. *American Annals of the Deaf, 137*(3), 257-260. https://doi.org/10.1353/aad.2012.0462

Miles, B. (1999). Talking the language of the hands. DB-Link, 1-11.

Mitchell R. E. Karchmer M. A. (2004).Demographics of deaf education: More students in more places. *American Annals of the Deaf, 151*(2),95–104. doi:10.1353/aad.2006.0029

Moog, J. S. (2000). Auditory-oral education: Teaching deaf children to talk. *Audiology Online.*

Moores, D. F. (2011). *Partners in education: Issues and trends from the 21st International Congress on the Education of the Deaf.* Gallaudet University Press.

Most, T., Wiesel, A., & Blitzer, T. (2007). Identity and attitudes towards cochlear implant among Deaf and Hard of Hearing adolescents. *Deafness and Education International, 9*, 68–82. https://doi.org/10.1002/dei.207

Musselman, C., & Kircaali-Iftar, G. (1996). The Development of Spoken Language in Deaf Children: Explaining the Unexplained Variance. *Journal of Deaf Studies and Deaf Education, 1*(2), 108-121. Retrieved from http://www.jstor.org/stable/23805397

Napoli, D. J., Mellon, N. K., Niparko, J. K., Rathmann, C., Mathur, G., Humphries, T., ... & Lantos, J. D. (2015). Should all Deaf children learn sign language?. *Pediatrics, 136*(1), 170-176. https://doi.org/10.1542/peds.2014-1632

National Association of State Directors of Special Education (NASDSE), (2018). *Optimizing Outcomes for Students who are Deaf or Hard of Hearing: Educational Service Guidelines*, Alexandria, Virginia: NASDSE.

Nielsen, D. C., & Luetke-Stahlman, B. (2002). Phonological awareness: One key to the reading proficiency of Deaf children. *American Annals of the Deaf, 147*(3), 11-19. https://doi.org/10.1353/aad.2012.0213

Pitts-Taylor, V. (2010). The plastic brain: Neoliberalism and the neuronal self. *Health, 14*(6), 635-652. https://doi.org/10.1177%2F1363459309360796

Padden, C., Humphries, T., & Padden, C. (2009). *Inside deaf culture.* Harvard University Press.

Paul, P. V., Wang, Y., & Williams, C. (2013). *Deaf students and the qualitative similarity hypothesis: Understanding language and literacy development.* Gallaudet University Press.

Qi, S., & Mitchell, R. E. (2011). Large-scale academic achievement testing of Deaf and Hard-of-Hearing students: Past, present, and future. *Journal of Deaf Studies and Deaf Education, 17*(1), 1-18. https://doi.org/10.1093/deafed/enr028

Ritter-Brinton, K., & Stewart, D. (1992). Hearing parents and Deaf children: Some perspectives on sign communication and service delivery. *American Annals of the Deaf, 137*(2), 85–91. https://doi.org/10.1353/aad.2012.1357

Russo, T. J. & Fallon, M. A. (2001). Helping military families who have a child with disability cope with stress. *Early Childhood Education Journal, 29*(1), 3-8. https://doi.org/10.1023/A:1011348620920

Sass-Lehrer, M., Moeller, M. P., & Stredler-Brown, A. (2016). What every early intervention professional should know. In M. Sass-Lehrer (Ed.), *Early intervention for deaf and hard-of-hearing infants, toddlers, and their families* (3-35). New York: Oxford Press.

Sauer, J.M. & Jorgensen, C. M. (2016). Still caught in the continuum: A critical analysis of least restrictive environment and its effect on placement of students with intellectual disability. *Inclusion, 4*(2),56-74. https://doi.org/10.1352/2326-6988-4.2.56

Schick, B., Marschark, M., & Spencer, P. (2006). *Advances in the sign language development of Deaf children.* New York: Oxford University Press.

Singer, S. (2019). "It's like growing an identity in a barren field:" Continuing the conversation about 21st century Deaf identities. *SOJO Journal, 4*(1). 1-16.

Singer, S. & Vroman, K. (2019). A new model of educating Deaf students. In D. Ford (Ed.), *Keywords in Radical Education* (90-105). Amsterdam: Koninklijke Brill Publishers.

Sipal, R. & Sayin, U. (2013). Impact of perceived social support and depression on the parental attitudes of mothers of children who are Deaf. *Journal of Child & Family Studies, 22*(8), 1103–1111. https://doi.org/10.1007/s10826-012-9672-3

Strieker, T., Salisbury, C., & Roach, V. (2001). *Determining policy support for inclusive schools.* Alexandria, VA: Consortium on Inclusive Schooling Practices.

Strong, M., & Prinz, P. (2000). Is American Sign language skill related to English literacy. *Language acquisition by eye*, 131-141.

Sunderland, N., Catalano, T., & Kendall, E. (2009). Missing discourses: concepts of joy and happiness in disability. *Disability & Society, 24*(6), 703-714.

Svirsky, M. A., Robbins, A. M., Kirk, K. I., Pisoni, D. B., & Miyamoto, R. T. (2000). Language development in profoundly deaf children with cochlear implants. *Psychological Science, 11*(2), 153-158.

Szymanski, C., & Brice, P. J. (2008). When Autism and Deafness coexist in children: What we know now. *Odyssey: New Directions in Deaf Education, 9*(1), 10-15.

Szymanski, C., Lutz, L., Shahan, C., & Gala, N. (2013). *Critical needs of students who are Deaf or Hard of Hearing: A public input summary.* Washington, D.C.: Laurent Clerc National Deaf Education Center.

Thierfelder, P. & Stapleton, P. (2016). Errors in the written English of native users of sign language: An exploratory case study of Hong Kong Deaf students. *System, 58*, 12-24. https://doi.org/10.1016/j.system.2016.03.001

Traxler, C. (2000). Measuring up to performance standards in reading and mathematics: Achievement of selected Deaf and Hard-of-Hearing students in the national norming of the 9th edition stanford achievement test. *Journal of Deaf Studies and Deaf Education, 5*(4):337-348. https://doi.org/10.1093/deafed/5.4.337

Turan, Z. (2016). Cochlear implanted Deaf children with additional disabilities: The mother's perspective. *International Journal of Medicine and Medical Sciences, 8*(7): 66–74. https://doi.org/10.5897/IJMMS2016.1240

van Dijk, R., Nelson, C., Postma, A., & van Dijk, J. (2010). Deaf children with severe multiple disabilities: Etiologies, intervention, and assessment. In M. Marschark, P. E. Spencer, & P. E. Nathan (Eds.), *Oxford Handbook of Deaf Studies, Language, and Education* (172-191). New York, NY: Oxford University Press, Inc.

Vickars, W. (2019). *ASL University.* Retrieved from: www.lifeprint.com

Walsh T.M. & Volsko T.A. (2008). Readability assessment of internet-based consumer health information. *Respir Care, 53*, 1310–1315.

Weaver, K. A. & Starner, T. (2011). We need to communicate!: Helping hearing parents of Deaf children learn American Sign Language. *The Proceedings of the 13th International ACM SIGACCESS Conference on Computers and Accessibility,* 91-98. https://doi.org/10.1145/2049536.2049554

Whicker, J. J., Muñoz, K., & Nelson, L. H. (2019). Parent challenges, perspectives and experiences caring for children who are Deaf or Hard-of-Hearing with other disabilities: A comprehensive review. *International Journal of Audiology, 58*(1), 5-11. https://doi.org/10.1080/14992027.2018.1534011

Wood, D. (1991). Communication and cognition: How the communication styles of hearing adults may hinder—rather than help—deaf learners. *American Annals of the Deaf,* 247-251.

Young, A. M. (1999). Hearing parents' adjustment to a deaf child-the impact of a cultural-linguistic model of deafness. *Journal of Social Work Practice, 13*(2), 157-176.

Young, A. (2018). Deaf children and their families: Sustainability, sign language, and equality. *American Annals of the Deaf, 163*(1), 61–69 https://doi.org/10.1353/aad.2018.0011

Young, A. (2003). Parenting and Deaf children: A psycho-social literature based framework. Retrieved from http://www.ndcs.org.uk/family_support/how_ndcs_can_ help/parenting/resources_for_professionals/a_psychosocial.html.

Young, A. & Tattersall, H. (2007). Universal newborn hearing screening and early identification of Deafness: Parents' responses to knowing early and their expectations of child communication development. *The Journal of Deaf Studies and Deaf Education, 12*(2), 209–220. https://doi.org/10.1093/deafed/enl033

Young, A., Jones, D., Starmer C. & Sutherland, H. (2005). Issues and Dilemmas in the Production of Standard Information for Parents of Young Deaf Children — Parents' Views, *Deafness & Education International, 7*(2), 63-76. DOI: 10.1179/146431505790560400